



Team approach in DEIC management
**PRIMER ON ASSESSMENT
& MANAGEMENT OF
NEURODEVELOPMENTAL
DISORDERS (<10 yrs)**



Child Development Centre
Medical College,
Thiruvananthapuram, Kerala

Editors | Prof (Dr) MKC Nair DSc
Dr Deepa Bhaskaran MD
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Child Development Centre Medical College Campus
Thiruvananthapuram
2024

VEENA GEORGE
MINISTER FOR HEALTH
WOMAN AND CHILD DEVELOPMENT
GOVERNMENT OF KERALA



Date 17.10.2024

Message

The Department of Health and Family Welfare, Government of Kerala, is committed to improve the survival outcome through early identification and management of Defects at Birth, Deficiencies, Diseases, Developmental delays including disabilities- '4 Ds', and assured link to care, support, and treatment to meet these challenges. For effective implementation of the programme, confirmation of screening findings, management, follow up of screened children for which early intervention and offer referral support for the needy, District Early Intervention Centres (DEICs) are established at District Hospital level in all 14 districts of Kerala and functioning since 2013 onwards. DEICs are the hub of all activities and act as a clearing house and also provide referral linkages. Capacity building for DEIC functionaries is very important for the effective functioning of this dream initiative. I consider the new book entitled the 'Primer on Assessment and Management of Neurodevelopmental Disorders among children below 10 years' as an important contribution of Child Development Centre (CDC), Kerala for the effective assessment and management of children attending DEICs.

Government of Kerala has considered early detection and early intervention for developmental disorders among children seriously and undertaken many initiatives for strengthening it. In order to ensure early detection of developmental delay, Women and Child Development Department, Government of Kerala has initiated a program in collaboration with Child Development Centre, Kerala for capacity building of Anganwadi Workers. This will facilitate early identification developmental delays among children below 6 years and those children with suspected developmental delay will be referred to DEICs. In this regard, I consider this book as a very important step in helping DEIC functionaries in confirmation of developmental issues among children and offering management services for them.

I believe that the meticulous effort and unwavering commitment of CDC have resulted in the development of this book that will have a transformative impact on the early detection and early intervention services provided through DEICs. I would like to extend my heartfelt congratulations to the entire team involved in the development of this book. This book will provide a guidance for interventions for Autism Spectrum Disorders and Attention Deficit Hyperactivity Disorder in group therapy mode which has been proved to be useful in providing intervention to children. CDC has developed these interventions based on years of practical experience and I am confident that this will serve as a model for providing interventions in DEICs.

Veena George

Office : Secretariat Annexe-2, 7th Floor, Room No. 701
Government Secretariat, Thiruvananthapuram-695 001
Phone-Office : 0471-2327876, 2327976 Fax : 0471-2327016 Mobile : 9400066111
E-mail : min.hlth@kerala.gov.in



KERALA.HEALTH

Dr. Rajan Khobragade IAS
Addl. Chief Secretary

Message

15th October 2024

I am delighted to note that Child Development Centre (CDC), Kerala is bringing out a Primer on Assessment and Management of Neurodevelopmental Disorders among children below 10 years for functionaries of District Early Intervention Centre (DEIC). The District Early Intervention Centers are established under Rashtriya Bal Swasthya Karyakram (RBSK) for managing children identified with developmental delays and also link children identified with specific diseases, deficiencies and defects at birth with tertiary level health services. DEIC provides the much needed early interventions services, which are easily approachable, adaptable, user friendly and cost effective.

DEIC functionaries have a crucial role in the early detection and early intervention on childhood neurodevelopmental disorders (NDDs). Their expertise and dedication will have a profound impact on the lives of children with NDDs. This book covers a range of topics related to assessment and intervention on different NDDs, including Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Cerebral Palsy, Epilepsy, Cortical Vision Impairment, etc. I believe that this book will further empower them with knowledge, tools and strategies to provide optimal care and support of children with NDDs.

I wish warmest greetings to all contributors involved in the development of this book. I hope and believe that this book will definitely guide the health care providers to serve the neuro-diverse children to have an early diagnosis and facilitate in providing early intervention. I encourage all DEIC functionaries to use this book as a reference manual for early detection and providing early intervention for children with neurodevelopmental disorders.


Rajan Khobragade

EDITORIAL

The CDC Kerala– The Untold Story describes our life time experience in conceptualizing and systematically developing Child Development Centre (CDC) Kerala in the last 37 years, (1987-2024). CDC project was started as a Ph.D. research project on 1st of August, 1987, supported by KHRWS and then Royal Family of Travancore. In 1995, the Government of Kerala, took the initiative to establish the first CDC in India, with the introduction of Diploma in Clinical Child Development (DCCD) course under Director of Medical Education and later upgraded to Post-graduate Diploma in Clinical Child Development (PG-DCCD). It has become a national training centre with introduction of different courses under University of Kerala like PG Diploma in; Developmental Neurology, Adolescent Pediatrics, Child Adolescent Family Counselling, Health Science Research, etc.

CDC Kerala's major contribution was in creating and validating a 'conceptual framework' of a valid link between childhood disability, low birth weight, adolescent girls' nutrition and fetal onset adult lifestyle diseases. Starting with a randomized controlled trial (RCT) proving beyond doubt that early stimulation is effective in improving the neurodevelopmental status of at-risk babies at one and two years of age, the same cohort was followed-up in detail at 5, 13, 16, 19 and 24 completed years, substantiating the 'conceptual framework' and leading on to the award of Doctor of Science (D.Sc.) for a medical person for the first time in the history of University of Kerala (1).

Developmental therapy, focusing on habilitation (prevention of impairment going on to disability) is dedicated to millions of high risk newborns or NICU/SNCU graduates in India and LMIC countries, who would get an opportunity to get neurodevelopmental follow-up and early stimulation in the first 1000 days of life and early detection-intervention for neurodevelopmental disorders till 6 years of age by trained Developmental Therapists. The moment a disability is confirmed by a Developmental Pediatrician/Pediatrician/Pediatric Neurologist, etc. rehabilitation (prevention of disability going on to handicap) at CDCs/DEICs/rehab centres must be initiated by professional therapists working as a team (team approach).

On the occasion of the 50th anniversary of ICDS to be celebrated in 2025, there has to be a comprehensive nationwide program for early detection and intervention for all types of developmental delay through the ICDS network in India.

MKC Nair, Deepa Bhaskaran, Leena ML.

Editors

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PRIMER ON ASSESSMENT & MANAGEMENT OF NEURODEVELOPMENTAL DISORDERS (<10 yrs)

Contributors

Chapter	Topic	Author
	Part 1: Assessment of NDDs	
Chapter1	Neurodevelopment Follow-up & Early Intervention – Research Base	MKC Nair, D.Sc. Formerly Vice Chancellor, KUHS & Founder Director, CDC
	Early Detection of Neurodevelopmental Disabilities using NDST	Ms Sunitha RM Developmental Therapist, CDC
Chapter3	Diagnosis of ASD using INDT-ASD & Certification using ISAA	Dr Deepa Bhaskaran, Associate Professor & Director (I/C), CDC
Chapter4	Diagnosis of ADHD using INDT-ADHD	Dr Indu Viswanathan, IAP Fellow - Developmental & Behavioral Pediatrics, CDC, TVM
Chapter5	Diagnosis of Epilepsy using INDT – Epilepsy	Dr Meera R, , Developmental Pediatrician, Travancore Medicity, Kollam
Chapter6	Diagnosis of NMI using INDT -NMI	Dr Meera R, , Developmental Pediatrician, Travancore Medicity, Kollam
	Part 2: Management of Epilepsy, CP & CVI	
Chapter7	Management of Epilepsy	Dr P A Mohammed Kunju, Prof of Pediatric Neurology & Consultant Pediatric Neurologist, CDC & Dr Hashma Mohammed P, IAP Fellow, CDC
Chapter8	Management of Cerebral Palsy	Dr P A Mohammed Kunju, Prof of Pediatric Neurology & Consultant Pediatric Neurologist, CDC&Dr Hashma Mohammed P, IAP Fellow, CDC
Chapter9	Diagnosis and Management of Cerebral visual impairment.	Dr Anitha Balachandran, Additional Professor at Regional Institute of Ophthalmology, Thiruvananthapuram
	Part 3: CDC Model Group Therapy in ASD	
Chapter10	CDC Model Group Therapy in ASD	Ms Prasanna GS, Developmental Therapist, CDC
	Sensory integration therapy in ASD	Ms Bismi David, Occupational Therapist, CDC
	Communication Intervention in NDDs	Ms Sharaon Susan Sam, Speech Pathologist and Audiologist, CDC
	Part 4: CDC Model Group Therapy in ADHD	
Chapter11	CDC Model Group therapy in ADHD & Academic intervention in ADHD	Dr Mini AO, Developmental Therapist, CDC
	Occupational Therapy in ADHD	Ms Bismi David, Occupational Therapist, CDC
	Parent Training on Behavior Management in ADHD	Ms Jasmine George, Clinical Psychologist, CDC
	Physical Activity Intervention in ADHD	Dr Juby Raj AR, Project Associate, CDC

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P A R T

Assessment of NDDs

Neurodevelopment Follow-up & Early stimulation – Research Base

MKC Nair, D.Sc.

Formerly Vice Chancellor, KUHS, Founder Director & Emeritus Professor in Developmental Behavioural & Adolescent Paediatrics, CDC Kerala, & Director, NIM-Spectrum-CDRC, NIMS Medicity Campus, Neyyattinkara, Thiruvananthapuram-695123. Email: cdcmkc@gmail.com

Preamble: My child guidance experience along with Ms. Indira from January 1980 at SAT hospital Medical College Trivandrum has taught me three lessons; (i) there is an element of mental sub-normality in most cases of behavioural problems in children; (ii) there is invariably a family adjustment problem behind it and (iii) if there is a problem, there is a solution. First, I started a developmental clinic along with Dr. Asok Kumar, where every child reminded me that it is already late. I need to put on record three names, Late Dr. Elsie Philip, then HOD Pediatrics, who entrusted Child Guidance Clinic to me, Dr. KA Kumar then HOD Psychiatry and Dr. S. Hariharan, then HOD Physical Medicine, who insisted that young children be seen in Child Guidance Clinic first, and refer only the needed ones. The popular practice then was to use pyritinol in all birth asphyxia cases. The first question, to be answered was if Pyritinol is effective among term babies with post asphyxial encephalopathy. Hence, a placebo controlled RCT among term post asphyxial encephalopathy babies using pyritinol (Vit. B6 derivative) was done, which showed that pyritinol is not effective in improving the neurodevelopmental status (Bayley scales – mental development index, psychomotor development index) of post asphyxia encephalopathy babies(1).

It was in this context that the Child Development Centre Project was started on 1st of August, 1987, with the help of KHRWS, later Royal Family of Travancore and Government of Kerala. The experience of following-up lakhs of at-risk babies and specifically following-up 1000 babies till 25 years of age has been a long journey of learning many new concepts;

1. Life cycle Approach to child and adolescent development: This involves the following stages(2);

- 0-1 yr – Infant: Follow-up and early stimulation of premature & LBW babies
- 0-3 yrs – Toddler: Developmental screening & assessment
- 3-6 yrs – Preschool child: Preparing for school entry
- 6-12 yrs – Primary school child: Early markers of learning disorder
- 12-18 yrs – Adolescents: Preparing for future parenthood

The American Academy of Paediatrics (AAP) has recommended 70 Indicators to be taken care-off in follow-up program under 5 post discharge follow-up areas, namely; (i) Developmental assessment, (ii) Behavioural – Psychosocial assessment, (iii) General care and physical health, (iv) Speech & Language assessment, and (v) Vision & Hearing assessment(3).

2. Neurodevelopmental follow-up of LBW and very LBW babies involve yearly appraisal and a cycle of management that include; Risk stratification → Early intervention → assessing outcomes → Change in NICU Practices

3. Risk stratification of preterm /LBW babies as per National Neonatology Forum (NNF) guidelines.

4. Ultrasound examination of the head, looking for periventricular pathology predicting cerebral diplegia, OAE examination for hearing and looking for retinopathy of prematurity (ROP) in high-risk babies.

5. CDC Model Early stimulation for at-risk babies

The four major sensory modalities recommended for neonatal developmental intervention include(4);

Visual stimulation (decoration of surroundings, with mobiles and brightly coloured objects)

Auditory stimulation (talking, singing, music boxes, recorded mother's voice, recorded heartbeat).

Tactile stimulation (non nutritive sucking, stroking, flexing, massaging, rubbing, handling, positioning).

Vestibular-Kinesthetic stimulation (rocking, oscillating beds, eg. water beds).

6. Effectiveness of CDC model early developmental stimulation: CDC model early stimulation was administered to 900 babies with monthly visit to CDC and continued stimulation at home by mother and at the end of two years using Bayley scales Mean Bayley index (average of mental development index and psychomotor development index) was calculated. The summary of the results showed that; (i) as compared to 84.2 Bayley index for babies above 2500 grams, the babies below 1500 grams had 75.3 only, and (ii) those babies below 1500 grams, who received stimulation had 83.8 Bayley index, which is almost same as 84.2 for normal birth weight babies, proving beyond doubt that early stimulation is effective. Multiple Regression Analysis for Bayley Score at 2 years showed that, apart from birth weight, presence of neonatal seizures, intra-uterine infections, poor socio-economic status suggested by residence and occupation of father, the most significant factor that decided better outcomes was provision of early stimulation(5).

7. Developmental prediction: Illingworth, the father of developmental medicine had opined years ago that developmental assessment cannot be used for prediction of later outcomes(6). Instead, it is useful to assess the present status in relation to average performance of other babies of same age, particularly; (i) Growth & Development in relation to age, (ii) Comparison with others, (iii) Assess muscle tone – hyper or hypotonia, (iv) Vision & hearing status and (v) Emotional development. In almost all disability surveys, what get reported are the obvious disabilities needing rehabilitation services, but those that can give near cent percent results with early intervention are the delays before six years, namely, developmental delay, motor delay, cognitive delay, communication delay, speech and language delay and finally personal social delay needing Habilitation (preventing impairment going on to disability).

8. Developmental follow up and early stimulation for all babies: Though high-risk babies may have more chances of delay; even normal babies can also have delay and hence the need for universal developmental follow up. The mother could be the therapist and the role of developmental therapist is to train mothers to continue to do the same at home. In spite of having different developmental tools. Developmental surveillance or developmental screening is not universally practiced in most countries. Here is the relevance of "DOC", a simple tool that can be used by mothers and health workers to do developmental monitoring. The baby need formal developmental assessment, if the following mile stones are not achieved by corrected and completed months; (i) Social Smile – 2 months, (ii) Head Holding – 4 months, (iii) Sitting – 8 months, (iv) Standing – 12 months, (v) Communication – 18 months (have reasonable communication skills, socialization skills, and not in his/her own world), and (vi) Make sure that the baby See, Hear & Listen at all visits. The same can be made more useful by following the CDC grading for three important motor

milestones in which grade-0,I,II are abnormal and grade-III, IV, V are normal. Grade I & V has no confusion, hence focus on II, III, & IV(7).

Head Holding:

- Grade II: Dorsal suspension - lifts head along with body.
- Grade III: Prone position - elevates on arms, lifting chest.
- Grade IV: Holds head steady while mother moves around.

Sitting

- Grade II: Sits 30 seconds or more leaning forward.
- Grade III: Sit with the child's back straight.
- Grade IV: While sitting, can turn around and manipulate a toy.

Standing

- Grade II: Takes few steps with both hands supported.
- Grade III: Can stand alone with legs apart.
- Grade IV: Comes to standing position by throwing weight on arms.

9. Outcome of using developmental intervention package: 821 babies <1800 grams were provided the intervention and assessment was done at 6 months using DASII. The results showed that at 6 months assessment on DASII, motor DQ abnormalities for 600–900 grams birth weight group was 80%, as against only 17.1% for 1500–1800 grams birth weight group(8).

10. Use of Different Developmental Screening Tools: Prevalence of developmental delay among 604 babies at 12 months using the diagnostic tool DASII was 13.3% and using the following screening tools was(9);

- CDC grading for standing : 24.8%
- DDST (Denver II) gross motor : 24.3%
- Amiel Tison passive angles : 24.0%
- Together had high Specificity, NPV & accuracy against DASII motor DQ

11. Neurological Evaluation

a) Amiel Tison passive angles: When it comes to neurodevelopmental follow-up, rather than trying to give a diagnosis of cerebral palsy, Amiel Tison has suggested to look for tone abnormalities which are persistent or abnormal if not disappearing by 12 months and measured by passive angles of adductor angle, popliteal angle, heel to ear angle, dorsiflexion angle of foot and scarf sign. For example, using the adductor angle by separating the thighs of the baby, even the mother can understand restriction of angles suggesting hypertonia that could be managed by carrying the baby astride the hip of the mother and doing passive exercises in a playful manner, so that the baby enjoys the therapy. Physiotherapy on the other hand, involve stretching of muscles making the baby cry even before therapy is initiated and hence not suitable in infancy, unless absolutely indicated. The developmental therapists (DT) are specially trained to look after the first 1000 days (270+365+365) of the baby(10), assisting; (i) Obstetrician (270 days inside womb), (ii) Neonatologist (first month), and (III) Developmental Pediatrician/Pediatrician (first 2 years).

b) Use of Infant Motor Screen (IMS): Early intervention program for high-risk babies

Early intervention for 52 high-risk babies was given and assessed at 12 months of age, which showed that 36.5% were abnormal using IMS alone, 40.4% abnormal on DDST (motor) alone, 42.3% abnormal using both IMS and DDST, as against 40.4% abnormality using the gold standard Bayley Scales of Infant Development(11).

12. Development and validation of Trivandrum Developmental Screening Chart (TDSC: 0-6 years):

The 51-items of Trivandrum Development Screening Chart (TDSC) for children of 0-6 years, were carefully prepared from the norms in various existing developmental charts/scales, by experts keeping in mind the

face validity and content validity. The criterion validity assessed in a community sample of 1,183 children of 0-6 y with a mean age of 35.4 months against Denver Developmental Screening Test (DDST) as the 'Reference Standard', showed that; (i) when one item delay in TDSC (0-6 y) was considered as 'TDSC delay', the sensitivity and specificity of TDSC (0-6 y) was found to be 84.6% and 90.8% respectively with a Negative Predictive Value of 99.2% and LR (negative) of 0.17. The test-retest ICC of 0.77 and inter-rater ICC of 0.97 observed were good and acceptable(12).

TDSC items based developmental therapy package among LBW babies: Developmental Assessment Scale for Indian Infants (DASII) results at 18 months among 240 LBW babies, who received developmental therapy and 260 normal birth weight babies not receiving showed no statistically significant difference, suggesting that developmental therapy is effective(13).

Groups	Mental age	Mental DQ	Motor age	Motor DQ
LBW: Intervention(N:240)	18.3	101.8	18.7	139.4
NBW: No Intervention(N:260)	18.2	98.7	18.5	135.4
Statistical Significance	Nil	Nil	Nil	Nil

13. Development and Validation of Language Evaluation Scale Trivandrum (LEST: 0-3 & 3-6 years)

The normal range for the 33 items of Language Evaluation Scale Trivandrum for 0-3 years LEST (0-3) were carefully selected from various existing language development charts and scales, by experts keeping in mind the face validity and content validity. The criterion validity was assessed using a community sample of 643 children of 0 to 3 years of age. LEST (0-3) was validated against Receptive Expressive Emergent Language Scale (REELS) and when one item delay was taken as LEST delay, the sensitivity and specificity of LEST(0-3), was found to be 95.9% and 77.5%, respectively with a negative predictive value of 99.8% and LR (negative) of 0.05. Similarly, when two item delay was taken as LEST delay (test positive), the sensitivity and specificity of LEST (0-3), was found to be 66.7% and 94.8% respectively with a negative predictive value of 98.7% and LR (negative) of 0.35. The test-retest ICC of 0.69 and inter-rater ICC of 0.94 were good and acceptable(14).

Similarly, using a community sample of 606 children 3-6 years of age, LEST: 3-6 years with 31-items, was validated against extended REELS. One item and two item delay as LEST delay showed a sensitivity of (81%, 47%); specificity (68%, 94%); PPV (12%, 31%); NPV (98%, 97%) and accuracy (68.5%, 92%), respectively, suggesting that LEST:3-6years is a simple, valid, community screening tool(15).

14. Effect of Early Language Intervention (ELI):

The effect of systematic clinic and home based early language intervention program in children reporting to the early language intervention (ELI) clinic with full partnership of specially trained developmental therapist and the parents was studied. ELI was given to 455 children 0–3 years with Speech and Language Delay for a period of 6 months and the results showed a mean pre intervention language quotient (LQ) 60.8 and a mean post intervention LQ of 70.6, using REELS with a statistically significant improvement of nearly 10 language quotient (LQ) points(16).

Kerala scenario

A state wide survey of less than 3 years babies covering one Anganwadi area per panchayath/ municipal ward showed that out of 32,664 babies screened by Anganwadi workers, there was 2.5% developmental delay using TDSC and 2.8% language delay using LEST and 3.4% using TDSC and/or LEST positive. Out of the total 1,110 children clinically evaluated by a trained pediatrician, 69.3% children had developmental delay, 14.3% speech delay, 5.7% global delay, 5.3% gross motor delay and 3.6% suspected of hearing impairment(17).

Similarly, a community survey carried out among 1,01,438 children below 6 years of age in Thiruvananthapuram district by ASHA workers showed 2.5% prevalence of developmental delay on TDSC

(2 or more item delay). Out of 1,329 children who reached the evaluation camps in PHC 43.1% were normal. 25% children had speech and language delay and 23% children had multiple disabilities(18).

15. Trivandrum Autism Behavioural Checklist (TABC): 65 children with suspected Autism Spectrum Disorder (ASD) features who were referred to NIMS-Spectrum-Child Development Research Centre (CDRC) were evaluated with Trivandrum Autism Behaviour Checklist (TABC) as a screening test and Childhood Autism Rating Scale-2-Standard Version (CARS-2-ST) as a gold standard diagnostic test by two independent observers blind to the results of each other. The results showed 96.3% sensitivity, 81.6% specificity, 78.8% positive predictive value, 96.8% negative predictive value, 87.7% accuracy, 5.2 positive likelihood ratio, and 0.045 negative likelihood ratio, all suggesting that TABC with 20 simple questions under four major domains of social interaction, communication, behavioural characteristics, and sensory integration is a useful screening tool for detecting ASD(19).

In a study of risk factors of ASD, on multivariate analysis the following factors were found to be significant; Not playing with same age children (OR:19.7) (meaning 20 times more chance of developing ASD), No outings for the child (OR:3.4), Do not tell stories/sing songs to child (OR:3.2), Breast feeding duration nil/less than 6 months (OR=3.4)(20).

16. Nursery Evaluation Scale Trivandrum (NEST: 4 – 6 years):

NEST is used for functional assessment of pre-school children, as a guide line to pre-school teachers to note the individual child's development and as a screening tool to identify preschool children who needs one to one instruction. NEST does not assess the intelligence of the child; instead, it assesses the skill development of pre-school children.

Originally NEST had 181 items and after Item reduction done by factor analysis, the item number was brought down to 69 under 6 domains; (i) gross motor development: 13 items; (ii) fine motor development: 14 items; (iii) cognitive development: 12 items; (iv) personal social development: 11 items; (v) expressive language development: 7 items; (vi) receptive language development: 12 items. NEST abridged has evolved from our clinic and community experience of using NEST, now it has 26 items under six domains and the 3rd and 97th percentile age placement in months are also given(7,21).

National Scenario

To date, global health policy makers have relied on national census disability data, even though such an approach grossly underestimates disability prevalence in children. Hence, to better understand the spectrum of childhood neurodevelopmental disorders (NDDs), there was a need to utilize valid and practical screening methodologies based on globally accepted disease definitions.

17. The INCLEN study: assessed 3,964 children 0 – 9 years identified from five geographically diverse populations in India using probability proportionate to population size, cluster sampling technique using diagnostic tools for all ten NDDs and for the whole sample. The results showed that, overall 12% children between the ages of 2 and 9 years had at least one NDD. There was site-specific variation in the prevalence: Dhenkanal had the lowest and Palwal the highest prevalence of NDDs. Hearing impairment, intellectual disability, speech and language disorders, epilepsy, and learning disabilities were among the most common NDDs across the sites(22).

18. This INCLEN: NDD Project has also lead to development of four INCLEN Diagnostic Tools namely;

- i. INCLEN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD)(23).
- ii. INCLEN Diagnostic Tool for Epilepsy (INDT-EPI)(24).
- iii. INCLEN Diagnostic Tool for Attention Deficit Hyperactivity Disorder (INDT-ADHD)(25).
- iv. INCLEN Diagnostic Tool for Neuro-Motor Impairment (INDT-NMI)(26).

International Scenario

Millennium Development Goal 4 mobilised countries to reduce child mortality by two thirds, and though India did not reach the target, it considerably reduced child mortality in the MDG-era. In this context, the

Indian Council of Medical Research and The INCLEN Trust International had conducted a national research priority setting exercise which showed that research priorities varied geographically, according to the stage of development of the area and mostly pertained to implementation sciences, which was expected given diversity in epidemiological profiles(27).

There is global consensus that current child health policy must include considerations for all survivors keeping in mind that children with disabilities have a greater risk of not realising their developmental potential than children without disabilities. Also, mortality risks associated with disabilities in older children, particularly those from low-income and middle-income countries (LMICs), have not been duly recognised, mainly because of the dearth of population-based data(28).

Available data show that globally the likelihood of a child having a disability before their fifth birthday was ten times higher than the likelihood of dying (377.2 vs 38.2 per 1000 livebirths) in 2019. However, disability funding declined by 11.4% between 2007 and 2016, and only 2% of the estimated US\$79.1 billion invested in early childhood development during this period was spent on disabilities(29).

Global investment in promoting inclusive education without complementary investment in early detection and intervention services for school readiness from birth is unlikely to yield optimal enrolment of children with disabilities. The health systems in LMICs will need to be adapted and strengthened to be functional and disability-friendly as it is currently the case in high income countries(30).

Policy Practice Statement: Consensus Statement of the IAP - Neurodevelopmental Chapter on Neurodevelopmental Disorders Habilitation Process(31)

The objective of this guidelines is to provide practical clinical guidelines for pediatricians on the prevention, early diagnosis and management of neurodevelopmental disorders (NDDs) in the Indian settings. It also defines the roles of developmental pediatricians and developmental therapist/development nurse counsellor. Recommendations are;

1. Preconception counselling as part of focusing on first 1000 days; promoting efforts to organize systematic training programs in newborn resuscitation program (NRP), lactation management, developmental follow-up and early stimulation for SNCU/ NICU graduates.
2. There is a need for nationwide studies with representative sampling on epidemiology of babies with early NDD in the first 1000 days in India.
3. There is a need to distinguish the process of habilitation (prevention of impairment going on to disability) and rehabilitation (prevention of disability going on to handicap), especially in a developing country like India, and define the roles of all stakeholders to reduce the burden of neurodevelopmental disorders.
4. Risk stratification of NICU graduates, newborn screening, counselling parents, screening for developmental delay by trained professionals, using simple validated Indian screening tools at 4, 8, 12, 18 and 24 months.
5. As per DSM-V, Neurodevelopmental disorders are described as a group of conditions with onset in the development period of childhood.
6. Specific learning disability (SLD) has been documented as the most common NDD after 6 years in India, and special efforts should be made to establish the epidemiology of infants and toddlers at risk for SLD, where ever measures are available. Holistic assessment of 10 NDDs at child developmental Centres (CDCs) / district early intervention centre (DEICs) by multidisciplinary team members;
7. Confirmation of diagnosis by Developmental Pediatrician/ Developmental Neurologist/ Child Psychiatrist using clinical/ diagnostic tools.
8. Providing parent guided low intensity multimodal therapies before 3 years age as a center-based or home-based or community-based rehabilitation;
9. Developmental pediatrician to seek guidance of pediatric neurologist, geneticist, child psychiatrist,

physiatrist, and other specialists, when necessary;

10. Need to promote ongoing academic programs in clinical child development for capacity building of community-based therapies, are the chief recommendations.

Policy Implications

It is gratifying to note that Government of India has utilized the CDC pioneering research on early stimulation and concept of Child Development Referral Unit (now DEIC) in the Rashtriya Bal Swasthya Karyakaram (RBSK). As we are celebrating 50th anniversary of ICDS on 2025, there is a definite opportunity to use Trivandrum Developmental Screening Chart (TDSC) and Language Evaluation Scale Trivandrum (LEST) as simple community screening tools for 0 – 6 years by Anganwadi and ASHA workers, under supervision of Developmental Therapist in the Mobile Units/proposed Block Early Intervention Centre (BEIC), as has been successfully piloted in Kerala.

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Further Reading

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Neuro Developmental Screening Tool (NDST)

Ms Sunitha RM

Developmental Therapist, CDC

Key points: NDST is a screening tool developed and validated by INCLEN – NDD research team to screen 10 neurodevelopmental disorders among children 2-9 years old.

NDDs that can be screened using this tool include: Attention Deficit/Hyperactivity Disorder (ADHD), Cerebral Palsy (CP) and other Neuromuscular Impairments (NMIs), Epilepsy, Hearing Impairment, Learning Disorders, Intellectual Disability (ID), Pervasive Developmental Disorders (PDD)/Autism Spectrum Disorders (ASD), Speech and Language Disorders and Vision Impairment.

There are two versions of NDST available – Long version and short version. Long version consists of 39 items and the short version 12 items.

2.1 Introduction

Neurodevelopmental disorders (NDDs) have always been an important concern but yet to be considered as a significant public health problem for children of low and middle income countries including India. Neurodevelopmental Disabilities are a diverse group of severe chronic conditions that begin at any point in development up to 22 years of age, usually lasting throughout a person's life time and include the following specific conditions: Attention Deficit/Hyperactivity Disorder (ADHD), Cerebral Palsy (CP) and other Neuromuscular Impairments (NMIs), Epilepsy, Hearing Impairment, Learning Disorders, Intellectual Disability (ID), Pervasive Developmental Disorders (PDD)/Autism Spectrum Disorders (ASD), Speech and Language Disorders and Vision Impairment. Many children have multiple disabilities and currently NDDs represent a large proportion of childhood morbidity.

2.2 TOOL DEVELOPMENT

When this study was first proposed many years ago, almost no data was available for India or for neighbouring countries. After successfully obtaining funding from the U.S. National Institutes of Health (NIH), the voluntary health organization Autism Speaks and The National Trust- Government of India, the NDD team was formed with NKArora, Executive Director, INCLEN as Team Leader, MKC Nair, then Director, Child Development Center, Medical College Thiruvananthapuram, Kerala as Principal investigator, Dr

Shefali Gulati and many experts as key resource persons. Dr Arora involved the National Trust, part of the Ministry of Social Justice and Empowerment, Government of India, a choice that undoubtedly contributed to success in helping to develop public policy.



2.3 Development of NDST:

The 39 questions NDST was developed in English based on the concept of Ten Questions questionnaire (TQQ) to screen for a larger number of NDDs. It was translated to vernacular language and piloted on 593 subjects (325 children with confirmed diagnosis of NDD and 268 with no NDD, aged 2-9 years) identified from outpatient/specialty clinics of nine participating medical institutions located in different parts of India. Piloting revealed that the content validity of individual item and item-clusters, contextual meaning and relevance of examples were not always clear in every region.

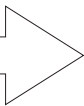
The NDST was subjected to reliability tests (test re-test and inter-rater) at two sites (New Delhi and Thiruvananthapuram). The test-retest reliability was measured by Spearman-Brown split-half reliability coefficient and the inter-rater reliability through intra-class correlation coefficient. Test re-test reliability coefficient was above 0.8 for 35 (89.7%) on questions for both doctors and research assistants. Inter-rater reliability correlation co-efficient was above 0.8 for 21 (53.8%) questions; no item had a reliability coefficient less than 0.5. No item during test-retest reliability assessment and three items in the inter-rater reliability test were in the 0.5-0.6 range at both sites. Overall, the NDST was performing similarly in New Delhi and Thiruvananthapuram and between doctors and research assistants. Subsequently, NDST has been applied in the field on 4000 children (2-9 years age) selected from five regions using population proportionate to size cluster sampling technique (200 clusters of 20 children – five boys and five girls in each of 24-71 and 72-107 months age group), separately by a field assistant and a doctor, on the same child and validated against the consensus clinical criteria diagnoses.

High negative predictive value (95%) make it an ideal screening tool to rule out NDDs among 2-9 year old children in the community. After doing criterion validation, it was concluded that NDST can be used reliably to screen different types of NDD, with high sensitivity and specificity. The tool could reduce the cost of identifying children requiring management for NDD in similar settings in Asia or elsewhere.

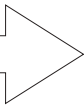
NDST Long Version (39 questions)


<p>1. Does your child make common age appropriate gestures to greet familiar people? For Example: - Namaste/ Namaskara/ Vanakkam/ Salaam/ Bye-Bye/ Tata.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	
<p>2. Did /does your child ever seek your attention by pointing to things? For Example: - Fan/ birds/ animals/ aero-plane/ kite.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	

<p>3. Does your child look at your face and maintain eye contact when you are talking to him /her?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 309 1346 453" type="text"/>
<p>4. Did/does your child ever engage in pretend plays or games which involve role play? For Example: - Ghar-Ghar/ father-mother/ marriage of dolls/ Doctor-Patient/ Teacher-Student / Thief-Police.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 692 1346 836" type="text"/>
<p>5. Like other children of his /her age, is your child able to do his /her activities of daily living by himself/ herself? For Example: - self-feeding/self-dressing.</p> <p>0. No 1. To some extent 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1059 1346 1203" type="text"/>
<p>6. Does your child have difficulty in seeing clearly from a distance? (without spectacles) For Example: - Recognizing somebody from a distance of 10-15 steps or Reading written material on blackboard</p> <p>0. No 1. To some extent / Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1461 1346 1605" type="text"/>
<p>7. Does your child have difficulty in seeing, either during day or night? (without spectacles)</p> <p>0. No 1. To some extent/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1861 1346 2005" type="text"/>

<p>8. Does your child have difficulty in seeing small objects? For Example: - grains/ peas/ beads/ pebbles/ ants/ coins.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input type="checkbox"/>
<p>9. Does your child bring objects very close to the eyes to see them? For Example: - toys/ pictures/ books.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input type="checkbox"/>
<p>10. Compared with other children of his /her age, did your child have any delay in walking?</p> <p>0. No 1. Delayed walking 2. Not yet walking 8. Refused to answer 9. Do not know/ Not sure</p>	<input type="checkbox"/>
<p>P A T T</p> <p>SKIP</p> <p>IF THE RESPONSE TO QUESTION No. 10 is "2" GO TO QUESTION No.12</p>	
<p>11. Does your child collides with objects while walking independently or has frequent falls while walking?</p> <p>0. No 1. Sometimes/ Infrequently 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input type="checkbox"/>
<p>JOIN AFTER SKIP 12 </p> <p>12. Does your child have difficulty in moving his /her limbs?</p> <p>0. No 1. To some extent 2. Yes/ Very much 8. Refused to answer 9. Do not know/ Not sure</p>	<input type="checkbox"/>

<p>13. Does your child have difficulty in getting up from squatting position or has progressive worsening difficulty in walking, running or climbing stairs?</p> <p>0. No 1. To some extent 2. Yes/ Increasing difficulty 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 285 1346 432" type="text"/>
<p>14. Does your child have stiffness or floppiness and/or reduced strength in his /her arms or legs?</p> <p>0. No 1. To some extent 2. Yes 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 571 1346 718" type="text"/>
<p>15. From birth till date, has your child ever had fits, or became rigid, or had sudden jerks or spasms of arms, legs or whole body?</p> <p>0. No 1. Yes/ Only once 2. Yes/ Twice or more 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 857 1346 1003" type="text"/>
<p>16. From birth till date, has your child ever lost consciousness?</p> <p>0. No 1. Yes/ Only once 2. Yes/ Twice or more 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1141 1346 1287" type="text"/>
<p>P A T T</p> <p>SKIP</p> <p>If child never attended school SKIP question No. 55a,56a, 57a and 58a. 17, 18, 19, and 20 Go to Question No.59a 21</p>	
<p>17. Did your child need change of school, or dropped out of school due to very poor performance?</p> <p>0. No/ Other Reasons (e.g. - Transfer, Family or Economic Reasons) 1. Required change of school 2. Dropped out of school 8. Refused to answer. 9. Do not know/ Not sure</p>	<input data-bbox="1235 1629 1346 1775" type="text"/>
<p>18. Do the teachers complain about your child's very poor performance in studies?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the times 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1908 1346 2054" type="text"/>

<p>19. Compared to his/ her classmates, does your child have significant difficulty in any of the subjects?</p> <p>0. No</p> <ol style="list-style-type: none"> 1. Only one subject 2. Yes/ Two or more subjects 8. Refused to answer 9. Do not know/ Not sure 	<input type="text"/>
<p>20. Compared to his/ her classmates, does your child find it difficult to read or write or to do simple calculations?</p> <p>0. No</p> <ol style="list-style-type: none"> 1. To some extent/ Sometimes 2. Yes/Continuous difficulty in one or more of these abilities 8. Refused to answer 9. Do not know/ Not sure 	<input type="text"/>
<div style="border: 1px solid black; padding: 5px; display: inline-block; margin-bottom: 10px;">JOIN AFTER SKIP 12</div>  <p>21. Can your child speak?</p> <p>0. No/ does not speak</p> <ol style="list-style-type: none"> 1. Makes sounds only 2. Yes/Says recognizable words 8. Refused to answer 9. Do not know/ Not sure 	<input type="text"/>
<p>22. After attaining initial speech has your child now stopped speaking or has he/she stopped learning new words and sentences?</p> <p>0. No</p> <ol style="list-style-type: none"> 1. Somewhat reduced 2. Yes/Stopped Speaking /lost speech 8. Refused to answer 9. Do not know/ Not sure 	<input type="text"/>
<p>P SKIP</p> <p>A</p> <p>T IF THE RESPONSE TO</p> <p>T <u>QUESTION No. 21 is "0" AND QUESTION No. 22 is "2"</u> GO TO QUESTION No. 23</p>	
<p>23. Is your child's speech in any way different from other children of his/ her age? For Example: - stammering/ lisping/ unclear speech.</p> <p>0. No</p> <ol style="list-style-type: none"> 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure 	<input type="text"/>
<p>24. Can your child speak words or sentences which can also be understood by non-family members?</p> <p>0. No</p> <ol style="list-style-type: none"> 1. To some extent/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure 	<input type="text"/>

<p>25. Does your child often repeat the same word or phrase over and over again in the same manner? For Example: - On being asked his/her name, your child repeats the phrase 'tell me your name' instead of actually telling his/her name.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 323 1346 467" type="checkbox"/>
<p>26. Can your child name familiar objects (if less than 3 years old) or is able to describe an object /event or an action (if more than 3 years old)? For Example: - dog/bird/ water/ cup/ spoon. (for children less than 3years) or narrate a story / poem. (for children more than 3years)</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 697 1346 841" type="checkbox"/>
<p style="text-align: center;">JOIN AFTER SKIP 27 </p> <p>27. Does your child have difficulty in hearing? (without hearing aid)</p> <p>0. No 1. To some extent / Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1071 1346 1215" type="checkbox"/>
<p>28. Does your child pay attention when you address him/her by name?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1373 1346 1517" type="checkbox"/>
<p>29. Does your child give attention to common sounds? For Example: - sound of clapping/ radio/ telephone bell/ falling utensils/ motor vehicle horn /cycle bell.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ not sure</p>	<input data-bbox="1235 1645 1346 1789" type="checkbox"/>
<p>30. Do you always need to speak loudly to get the attention of your child?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1917 1346 2061" type="checkbox"/>

<p>31. Does your child seem to have difficulty in comprehending what you are saying?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ not sure</p>	<input data-bbox="1260 288 1369 432" type="text"/>
<p>32. Does your child insist on sameness and actively resist any change in his/ her routines? For Example: - Insisting on the same dress/ asking for the same place to sit while eating / insisting on no change in the arrangement of the toys or household items.</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1260 629 1369 773" type="text"/>
<p>33. Does your child appear to be lost in his/her own world, no matter what he/she is doing?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1260 969 1369 1113" type="text"/>
<p>34. Does your child do activities that are purposeless, repetitive and excessive? For Example: - head banging/ finger tapping/ circling and spinning/ object banging.</p> <p>0. No 1. Sometimes/Less than half the time 2. Yes/Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1260 1285 1369 1429" type="text"/>
<p>35. Compared with other children of his /her age, does the mental development of your child appear to be slow?</p> <p>0. No 1. To some extent 2. Yes/ Very much 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1260 1596 1369 1740" type="text"/>
<p>36. Compared with other children of his /her age, does your child have difficulty in learning new things?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1260 1884 1369 2028" type="text"/>

<p>37. As compared to other children of his/ her age is your child excessively active and he/she appears to be “on the go”?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not t know/ Not sure</p>	<input data-bbox="1235 281 1346 425" type="text"/>
<p>38. As compared to children of his/ her age, does your child appear to act, speak or behave without thinking? For Example: -</p> <ul style="list-style-type: none"> • without awaiting his turn interrupts others in the middle of conversation, and/or • answers questions before they have been completed, and/ or • is unable to wait for his /her turn in play. <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not t know/ Not sure</p>	<input data-bbox="1235 653 1346 797" type="text"/>
<p>39. As compared to children of his/ her age, does your child have difficulty in sustaining attention on activities at school, home or play?</p> <p>0. No 1. Sometimes/ Less than half the time 2. Yes/ Most of the time 8. Refused to answer 9. Do not know/ Not sure</p>	<input data-bbox="1235 1036 1346 1180" type="text"/>

2.4 NDST Short version items

1. Does your child have difficulty in seeing either during day or night? (without spectacles)
2. Compared with other children of his/ her age, did your child have any delay in talking?
3. Does your child have stiffness or floppiness and/ or reduced strength in his/her arms or legs?
4. From birth till date, has your child ever had fits or become rigid or had sudden jerks or spasms of arms, legs or whole body?
5. From birth till date, has your child ever lost consciousness?
6. Compared to his/ her classmates, does your child find it difficult to read/write or do simple calculations?
7. Can your child speak?
8. Is your child's speech in any way different from other children of his/ her age?
Stammering, lisping, unclear speech.
9. Does your child often repeat the same word or phrase over and over again in the same manner?
10. Does your child have difficulty in hearing (without hearing aid) ?
11. Compared with other children, of his/her age, does your child have difficulty in learning new things?
12. As compared to children of his/ her age, does your child have difficulty in sustaining attention on activities at school, home or play?

NDST Instructions for Interpretation

Even one-item positive (Yes/ Most of the time) may be taken as an indication for doing confirmatory test. Although NDST was validated for screening of children two to nine years, in the case of children with delay it can be applied upto 12 years.

No	NDDs	Corresponding Item no in screening tool
1	Visual Impairment	6,7,8,9
2	Hearing Impairment	27,28,29,30
3	Intellectual Disability	5,31,35,36
4	Speech & Delay	21,22,23,24,25,26
5	Autism Spectrum Disorder	1,2,3,4,5,28,29,30,32,33,34
6	Neuro Muscular Disorders	10,11,13
7	Cerebral Palsy	12, ,14
8	Epilepsy	15,16
9	Attention Deficit Hyperactive Disorder	37,38,39
10	Learning Disability	17,18, 19,20

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Diagnosis of ASD using INDT-ASD & Certification using ISAA

Dr Deepa Bhaskaran
Director (I/C), CDC

Key points: Autism Spectrum Disorder (ASD) is a clinically heterogenous condition with a wide range of etiological factors and causing significant public health burden and it causes a serious developmental disadvantage to the child in the form of poor schooling, social function and adult productivity.

About 1 in 36 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

ASD is nearly 4 times more common among boys than among girls.

The INCLEN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD), has been developed by INCLEN- NDD team in India. It depends on both history from primary caregivers and direct observation of a child between 2 and 9 years.

ISAA is an objective tool to assess persons with autism. The tool uses observation, clinical evaluation of behaviour, testing by interaction with the subject and also information supplemented by parents or caretakers so as to make a diagnosis of autism.

All children should be screened by a standardized autism screening tool at 18 and 24 months of age.

If screening results are positive or concerning then: (a) continue parental education, (b) refer the child for comprehensive ASD evaluation, (c) initiate an early intervention program, (d) evaluate hearing status, and (e) schedule next follow-up visit after a month.

The IAP expert group recommends that ASD should be diagnosed using the DSM-5 and INCLEN tool INDT ASD and certified using the ISAA.

The Diagnostic and Statistical Manual for Mental Disorders, Version IV Text Revision (DSM-IV-TR), was published by the American Psychiatric Association in 1994 (revised in 2000). In this Autism Spectrum Disorder (ASD) is defined as a disorder featured by qualitative impairments in social interaction, with variable degrees of difficulties in communication and marked repetitive behaviors or restricted interests. Version 5 (DSM-5) was published in 2013. There have been significant changes in the proposed criteria for autism diagnosis and classification, but all the core features from the DSM-IV TR are still included [1]

Worldwide estimates indicate that the prevalence of ASD has been increasing. The US Centre for Disease Control and Prevention (CDC) reports it to be around 1%. There are no authentic figures for the Indian population, but it is estimated that there are around 2.3 million affected children in India [2]

Autism Disorder: A total of 6 or more items from Areas 1, 2, and 3, as specified below

Area 1: Impairments in Social Interaction (at least two of the following)			
Impairment in the use of nonverbal behaviors	Failure to develop peer relationships appropriate to developmental level	A lack of spontaneous seeking to share enjoyment, interests, or achievements with others	Lack of social or emotional reciprocity
Area 2: Impairments in Communication (at least one of the following)			
Delay or total lack of development of spoken language	In individuals with adequate speech, marked impairment of ability to initiate or sustain conversation with others	Stereotyped and repetitive use of language or idiosyncratic language	Lack of varied, spontaneous make-believe play appropriate to developmental level
Area 3: Restricted Repetitive Patterns of Behavior, Interests, and Activities (at least one of the following)			
Preoccupation with one or more patterns of interest that is abnormal in intensity or focus	Inflexible adherence to specific routines or rituals	Stereotyped and repetitive motor mannerisms	Persistent preoccupation with parts of objects

DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision.

3.1 The INCLIN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD), has been developed in India. It can be used by people trained in the administration and depends on both history from primary caregivers and direct observation of a child between 2 and 9 years. The tool has been standardized and validated using the CARS. The advantages of INDT-ASD are that it takes into account various ethnic and religious variables with particular reference to peer interaction and play skills. In situations where the history obtained is inconsistent with observations of the child, information is given as to what should be given significance. It is a useful tool in a resource-constrained setting, since it can be completed in a short time. The tool is better equipped to diagnose children with severe autism, but it needs to be further evaluated to see if it can also reliably diagnose those with high-functioning autism or Asperger Syndrome (3)

3.3 Clinical features of ASD:

Deficits in Social Interaction:

- Impairment in the non-verbal behaviours used for social interaction:
 - Eye-to-eye contact
 - Facial expressions
 - Body postures and gestures
- Child may appear to be “in his/her own world”
- Lack of spontaneous sharing of enjoyment and interests with other people
- Social interaction is rarely initiated spontaneously
- Signs of attachment with familiar people or even clinginess to a specific caregiver, or
- Excessive familiarity with strangers due to the absence of social inhibitions and stranger anxiety
- Failure to develop peer relationships appropriate to developmental level
- Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
- Lack of showing objects of interest to others
- Lack of bringing objects of interest to others
- Lack of pointing out objects of interest

Lack of social or emotional reciprocity

- Not actively participating in simple social play or games
- Preferring solitary activities
- Involving others in activities only as tools or “mechanical” aids

Deficits in Communication

- Deficits in verbal and non-verbal communication
- Delay in or total lack of the development of spoken language (verbal) in absence of attempt to compensate by gestures (nonverbal)
- 50% never develop speech
- In the remaining 50%, language acquisition is delayed and/or deviant
- Impairment in the ability to initiate or sustain a conversation
- Stereotyped, repetitive use of language
- Repetition of words or phrases regardless of meaning or relevance (echolalia)
- Pronominal reversal (substituting 'I' for "you" or vice-versa)
- May not be able to understand gestures or use them during communication
- Lack of social imitative play
- Delayed / absent protodeclarative pointing

Restricted and Repetitive Behavior

- Stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- Inflexible adherence to specific, non-functional routines or rituals
- Stereotyped and repetitive motor mannerisms
 - Hand or finger flapping
 - Body twisting
 - Complex whole-body movements
- Preoccupation with parts of objects

Other Features in Autism

- Sensory symptoms: Visual, auditory, olfactory, perceptual, and increased sensitivity to touch
- Play: Atypical or deviant, mechanical and repetitive, Lining things up
- Abnormalities of mood or affect
- Inappropriate to the situation or circumstances
- Inappropriate fear
- Oblivious to hazards or may have excessive fear of harmless objects

Co-morbidity

- Psychiatric Disorders
- Intellectual Disabilities
- Epilepsy / Seizures
- Feeding Disturbances and Gastrointestinal problems
- Sleep Disturbances

Natural History

- Infancy: Delayed language development.
- Clinical spectrum changes with age and level of developmental maturity.
- Deficits continue into and through adult life
- Social behavior remains deviant
- Hyperactivity tends to improve and ritualistic behaviors start decreasing during adolescence
- Depression may develop in some high functioning autistic individuals.

3.4 INDT-ASD Diagnostic Tool:

The tool has two sections:

- Section A has 29 symptoms/items
- Section B contains 12 questions corresponding to B and C domains of DSM-IV-TR, time of onset, duration of symptoms, score and diagnostic algorithm.

- It takes approximately 45-60 minutes to administer the instrument and score.
- A trichotomous endorsement choice ('yes', 'no', 'unsure/not applicable') is given to the assessor/interviewer.
- Clinician/psychologist has to make behavioral observations on the child and score the item as well.
- For any discrepancy in parental response and interviewer's assessment, it is indicated for each question whether parental response or assessor's observation should take precedence.
- Each symptom/item is given a score
 - ‘1’ for ‘Yes’
 - ‘0’ for ‘No’ or ‘unsure/not applicable’.
- Presence of ≥ 6 symptoms/item (or score of ≥ 6), with at least two symptom/item each from impaired communication and restricted repetitive pattern of behavior, is used to diagnose ASD.

Instructions for Evaluation

Primary caregiver must be present with the child

These behaviors are to be assessed in the context of children of same age

Explain to parents that the answers should be based on the child's behavior most of the time

Follow the age directions given along with the question. For questions where no age cut-off is given, they should be asked for all children i.e. all ages (2-9 years)

Ask the questions verbatim

Question can be repeated if the respondent cannot understand

Still, if the respondent cannot understand, give example for the particular behavior; No further elaboration is allowed

The questionnaire should be supplemented by observations for the suggestive behavior in the child throughout the assessment.

Observe the behavior of the child during the entire interview to confirm the presence or absence of a particular behavior (First ask, then observe if observation is discrepant, then re-ask the question and recheck the observation also).

When there is discrepancy between parental response and your observation, * indicates whether parent report or observation should take precedence, and marked accordingly.

When parent's response is "Unsure", your observation of the particular behaviour will be given weightage even when asterisk (*) is on parental response. In case you are also unable to observe the behavior, then only mark the response as "Unsure"

Some criteria have multiple questions. While scoring, consider the criteria fulfilled even if response to any one of the questions is abnormal. For example, the criterion A1a is considered fulfilled if any one of i, ii, iii, or iv is abnormal in the child.

3.5 Indian scale for assessment of autism (ISSA)

ISAA is an objective tool to assess persons with autism (both children and adults). The tool uses observation, clinical evaluation of behaviour, testing by interaction with the subject and also information supplemented by parents or caretakers so as to make a diagnosis of autism. ISAA consists of 40 items rated on a 5-point scale ranging from 1 (never) to 5 (always). The 40 items of ISAA are divided under six domains. Training in ISAA from a certified person is needed before a pediatrician can start certifying ASD.

They are

Domain-I Social Relationship and Reciprocity

Individuals with autism do not relate with other people. They remain socially unresponsive, aloof and may struggle to understand the feelings of another person. They have considerable difficulties in use of body language and nonverbal communication like eye contact, facial expressions, and gestures and establishing friendships with children of the same age.

Domain-II Emotional Responsiveness

Individuals with autism do not show the anticipated feelings in a social situation. Emotional reactions are unrelated to the situation and may show anxiety or fear which is excessive in nature without apparent reason. They may engage in self-talk that is inappropriate for their age and may lack fear of danger.

Domain-III Speech - Language and Communication

Individuals with Autism will have difficulties in the development of speech. They find it difficult to make their needs known verbally and nonverbally and may also have difficulty in comprehending the nonverbal language of others. People with autism often, have echolalia and may repeat a word, phrase or sentence which is not appropriate to the context.

Domain-IV Behaviour Patterns

Individuals with autism may involve in self–stimulatory behaviour like flapping of hands or use an object for this purpose. They insist on following routines, sameness and may resist change. Some autistic children may be restless and show aggressive behaviour.

Domain-V Sensory Aspects

A good number of autistic people are either hyper or hypo sensitive to light, sound, smell and other external stimuli. They may ignore objects or become preoccupied by them. Some autistic children explore their environment by smelling, touching or tasting objects.

Domain-VI Cognitive Component

Individuals with autism may lack attention and concentration. They either do not respond to instructions promptly or respond after a significant delay. On the other hand, individuals with autism may possess special or unusual ability known as, savant ability in some areas like reading, music, memory and art.

Guidelines for Test Administration

The examiner should be thorough with the test items, test materials, recording and scoring. He should adhere to the guidelines for rating ISAA. Each item of ISAA is to be assessed and rating is to be done based on the intensity, duration and frequency of the characteristics.

a) Testing Conditions

ISAA must be administered under standard testing conditions and testing methods as mentioned below.

- Ø Person's physiological condition (fatigue, sleep and state changes)
- Ø Comfort level of the person being tested
- Ø Periods of fear or oppositionality in the person being tested
- Ø Quality of informant's verbalizations
- Ø Consideration of environmental and cultural influences
- Ø Congenial environment and rapport while interviewing informants
- Ø Understanding individual differences
- Ø Thorough familiarity with the test content and procedures
- Ø Flexibility of the examiner.

b) Methods of Assessment

- i) Observation

- ii) Informant interview
- iii) Testing

c) Testing Time

Assessment may take 20-30 minutes

d) Materials

The assessment kit should comprise the following items.

- | | |
|-------------------------------|----------------------------|
| 1. Watch | 2. Hand bell |
| 3. Paper and crayons | 4. Blocks |
| 5. Squeezer – Cat / Dog | 6. Fruits/Vegetable toys |
| 7. Box | 8. Bottle and pellets |
| 9. Mirror | 10. Shape sorter |
| 11. Slide with a rolling ball | 12. Musical toys |
| 13. Car | 14. Ball (different sizes) |
| 15. Doll (different types) | 16. Rattle |
| 17. Picture book | 18. Peg board with rings |
| 19. Sorting board | 20. Cup |
| 21. Spoon | 22. Beads with a string |
| 23. Colour card/Board | 24. Key. |

Scoring System

ISAA should be scored as per the scoring system given below.

Each of the 40 test items is to be rated on a Likert scale of 5 categories, out of which one is to be checked. These are further measured by providing percentages to specify the frequency, degree and intensity of behavioural characteristics that are observed. The categories along with the percentages assigned are as follows:

Rarely (Up to 20%) indicates that the person exhibits this behaviour pattern for up to 20% of the time. This score is normal for their age and socio-educational background - Score 1.

Sometimes (21 – 40 %) indicates that the person exhibits this behaviour pattern for 21%-40 % of the time. Some of these behaviours may be a cause for attention and concern, but by and large they may be considered within normal limits for their age and socio-educational background.

Person is completely independent in activities of daily life - Score 2.

Frequently (41 – 60%) indicates that the person exhibits this behaviour pattern for 41% - 60% of the time. These behaviours occur with such frequency and regularity that they interfere with the persons' functioning in daily life. Behaviour at this level will be definitely disabling.

Person may be able to perform activities of daily life with minimum assistance - Score 3.

Mostly (61– 80 %) indicates that the person exhibits this behaviour pattern for 61% - 80 % of the time. The given behaviour may occur without any obvious stimulus. The behaviour under contemplation occurs so regularly that it significantly interferes with the person in performing daily activities.

Person needs assistance in activities of daily life - Score 4.

Always (81% - 100 %) indicates that the person shows this behaviour pattern almost all the time and it is a major handicap. The behaviour shown is not appropriate to the given situation.

Person is completely dependent on activities of daily life - Score 5.

The minimum score that can be obtained is 40.

The maximum score that can be obtained is 200.

Norms of ISAA for Diagnosis of Autism

ISAA Scores	Degree of Autism
< 70	Normal
70 to 106	Mild Autism
107 to 153	Moderate Autism
>153	Severe Autism

Percentage of Disability as per the score

Score	Percentage%
70	40
71-88	50
89-105	60
106-123	70
124-140	80
141-158	90
Above 158	100

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INCLIN Diagnostic Tool for Attention Deficit Hyperactivity Disorder (INDT - ADHD)

Dr. Indu S Viswanathan

IAP Fellow - Developmental & Behavioral Pediatrics, CDC, TVM.

Key points: ADHD, characterized by inattention, hyperactivity and impulsivity is one of the most prevalent neurodevelopmental disorders affecting school aged children. Indian studies show a pooled prevalence of 6/100 children. Boys are affected 2-10 times more than girls.

ADHD can track into adulthood also. At 25 years of age, 15% of previously diagnosed individuals meet full diagnostic criteria for ADHD, while 65% show partial remission of symptoms.

INDT-ADHD, developed by the NDD team, is a validated diagnostic tool for ADHD that is freely available, and has been developed for resource limited settings, through expert consensus based on established DSM-IV-TR criteria

INDT-ADHD is useful in diagnosing ADHD in Indian children between 6 - 9 years. It is available in English, Hindi, Malayalam, Odia, Konkani, Urdu, Khasi, Gujarati & Telugu.

Section A comprises of 18 items related to 'inattention' and 'hyperactivity/impulsiveness' symptoms (9 each). Section B has 8 items pertaining to onset, duration, functional impairment & a diagnostic algorithm.

Diagnostic accuracy of INDT - ADHD was high irrespective of age and gender with acceptable sensitivity, specificity, positive predictive value & negative predictive value as well as high internal consistency (0.91); Inattention: good (0.84); Hyperactivity-Impulsivity: good (0.87). INDT ADHD can well differentiate ADHD from normal children but cannot effectively differentiate ADHD from other NDD's, especially ASD.

Introduction

Attention deficit hyperactivity disorder (ADHD) is one of the most prevalent, most extensively studied neurobehavioral disorder affecting school-aged children. It is characterized by inattention, hyperactivity and impulsivity. There is a worldwide prevalence of 7-10% among school going children¹. Indian studies give a pooled prevalence of 6/100 children². It is 2-10 times more common among boys³.

The developmental impacts of ADHD lie in the fact that it is not just a disorder of childhood. It is a lifelong condition, manifesting as early as preschool age, where the high activity level and poor inhibitory control

result in behavioral disturbances, unintentional injuries and feelings of parental incompetence. Across school age and adolescence, there is often academic impairment and very often, reduced tolerance by peers. Further down the lane, these factors can be compounded by occupational difficulties, low self-esteem leading to antisocial behavior, substance abuse, relationship problems, mood instability etc⁴. It has been reported that, at 25 years of age, 15% of previously diagnosed individuals meet full diagnostic criteria for ADHD, while 65% show partial remission of symptoms⁶.

ADHD Diagnosis - the Indian scenario⁵:

ADHD is purely a clinical diagnosis, using diagnostic criteria such as DSM 5, ICD -11 etc. It depends on the developmental level of the child along any co-morbid disorders, if present. There is often a vast subjectivity in symptom recognition and the degree of functional impairment. In India there exists different levels of awareness & expertise about ADHD among community clinicians along the length and breadth of the country.

American Academy of Pediatrics (AAP) recommends DSM - 5 (previously DSM - IV - TR), evaluation for co-morbid conditions and neurological examination for diagnosis of ADHD. Several other rating scales used for diagnosis of ADHD are limited by bias, cost, requirement for extensive training, decreased availability and poor applicability. INDT - ADHD, developed by the NDD team is thus useful in that it is a validated, freely available tool useful for diagnosing ADHD in Indian children (6-9 years).

Psychometric properties of INDT - ADHD⁵:

INDT-ADHD has a sensitivity of 87.7 % (81.1-89.4), specificity of 97.2 % (86.7-99.9), positive predictive value (PPV) of 98.0 (90.6-99.9) and negative predictive value (NPV) of 83.3 (74.3-85.6) for distinguishing between ADHD versus typically developing children. The diagnostic accuracy of INDT- ADHD was high irrespective of age and gender. It can well differentiate ADHD from normal children, but cannot effectively differentiate ADHD from other NDD's, especially ASD. The inter-rater reliability & test-retest reliability were confirmed, and the tool demonstrated high internal consistency (0.91); Inattention: good (0.84); Hyperactivity-Impulsivity: good (0.87).

1. Tool administration⁵:

- The primary caregiver must be present at the time of assessment for obtaining the history. They must have been staying with the child for at least the last 6 months.
- The behavior in question must be present at the time of evaluation and had been a usual feature in the child at least for the previous 6 months.
- The behaviors should be compared with other children of similar age and similar background before answering.
- The questions should be asked *verbatim*. If they are not able to understand, the question may be repeated. Still if they are unable to understand, examples can be provided for the behavior, appropriate for the child's background. No further elaboration is allowed.

Section A:

Comprises of section A1 and Section A2.

- **A1** has 9 questions regarding inattention and **A2** has 6 questions regarding hyperactivity and 3 questions for impulsivity.
- All 18 questions need to be asked.
- Answers are given using a 2 - point scale - Yes/No. E.g.: Does your child often avoid activities that require sustained mental efforts (e.g.: homework/classwork, looking at picture book, listening to story)? - Yes/No.

1. Number of 'Yes' responses in A1 of Section A (Inattention): **0**: less than 6, **1**: six or more

2. Number of 'Yes' responses in A2 of Section A (Hyperactivity-Impulsivity): **0:** less than 6, **1:** six or more
3. Did these symptoms start before the age of 7 years in your child? **0:** No, **1:** Yes
4. Does your child have/had any of these problems such as: frequent fights with other children, No/few friends, very frequent injuries, frequent scolding by parents, frequent complaints from teachers, poor school performance. **0:** No (*None* of the above problems), **1:** Yes (*One or more* of the above problems)
5. Can these symptoms be explained by 'Autism' and/or 'Intellectual disability'?
6. Brief comments about the child's condition: Here additional notes and observations made during the interview can be recorded.
- 7. Diagnosis:** Overall, the number of 'Yes' responses in either or both A1 and A2 of Section A should be more than or equal to 6.
 - o Diagnosis of ADHD - if the response to 1 or 2 is '1', 3&4 is '1' and 5 is '0'.
 - o No ADHD: If the response to 1-4 is '0' and/or response to 5 is '0' or '1'.
 - o Other NDD: If the response to 1-4 is '0' and 5 is '1'.
 - o 'Indeterminate': any other responses.

8. Conclusion:

The INDT-ADHD diagnostic tool for ADHD is a freely available tool, developed for the resource limited settings through expert consensus based on established DSM-IV-TR criteria.

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Diagnosis of Epilepsy using INDT – Epilepsy

Dr Meera R

Developmental Pediatrician, Travancore Medicity, Kollam

Key points : INDT-EPI, developed by INCLEN- NDD team is a useful tool for diagnosis of childhood epilepsy by non-expert medical professionals (with adequate training) in different clinical settings.

The INDT-EPI has high validity to identify children with epilepsy when used by primary care physicians.

The candidate test for epilepsy had sensitivity and specificity of 85.8% and 95.3%; positive and negative predictive values of 94.0% and 88.5%; and positive and negative likelihood ratios of 18.25 and 0.15, respectively.

This instrument can be used in day-to-day clinical practice for diagnosing epilepsy by the primary health care physicians thereby expanding the care for epilepsy patients and reducing diagnosis management gap in resource-limited settings.

Introduction

Epilepsy contributes to significant morbidity with reported prevalence of 2.4-5.6 per 1000 in

India. However, nearly 75% of these do not receive appropriate treatment, many due to a lack of proper diagnosis. The diagnosis of epilepsy is mostly based on clinical history supported by neuroimaging and electroencephalography. The INCLEN Diagnostic Tool for

Epilepsy (INDT-EPI) has been developed with the major aim of increasing the access to care for seizure disorders. The INDT-EPI was developed as consensus clinical criteria (CCC) for diagnosing epilepsy by the Technical Advisory Group (TAG) consisting of pediatricians, developmental pediatricians, child psychiatrists, pediatric neurologists, pediatric otorhinolaryngology, community physicians, clinical psychologists, special educators, specialist nurses, speech therapists, occupational therapists, and social scientists through a series of discussions and meetings using Delphi method and over three rounds of 2-day workshops. In the absence of an objective “gold standard” diagnostic test, the decision of a team of experienced pediatric neurologists with access to all investigations was considered as nearest to the “gold standard” for diagnosis of childhood epilepsy.

5.1 DEFINITION OF EPILEPSY

Epilepsy is a disease of the brain defined by any of the following condition;

- At least two unprovoked (or reflex) seizures occurring >24 hours apart

- 2 One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years

Diagnosis of an epilepsy syndrome

The overall prevalence of epilepsy is 3.0-11.9 / 1,000 population in India

- Seizure – transient occurrence of signs and/or symptoms results from abnormal excessive or synchronous neuronal activity in the brain.
- Epilepsy – disorder characterized by 2 or more unprovoked seizures occurring more than 24 hours apart beyond neonatal period in India

DIFFERENTIAL DIAGNOSIS OF EPILEPSY

● **Non-epileptic event**

- Breath holding spells
- Syncope.1res

● **Provoked seizures**

- Febrile seizures
- Following head trauma (within 7 days)
- During acute phase of CNS infections
- Metabolic disturbances –hypoglycemia, hypocalcemia, hyponatremia, hypoxia

Co-morbidities

- Intellectual disability
- Behavioural disturbances
- Cerebral palsy
- Autism
- Vision impairment
- Hearing impairment
- Attention-Deficit/Hyperactivity Disorder
- Feeding difficulties

Misdiagnosis of Epilepsy

- Not an uncommon phenomenon
- Majority studies of first events were retrospective and have shown that syncopal attacks outnumber true seizures
- Art of asking questions and eliciting better semiology of events has been shown to have very good specificity of correctly identifying seizure and non-epileptic events (NEE).

Paroxysmal Non-epileptic events (PNEE)

- Misdiagnosis may lead to inappropriate and potentially harmful treatments
- Distinguishing between epileptic and non-epileptic events simulating seizures is essential
- Frequently encountered in day to day practice and large number of discrete entities
- Taking a thorough history is the most crucial part of any evaluation in addition to a careful observation

5.2 What is the need of a diagnostic tool?

A validated and culturally adapted Indian tool is necessary to diagnose epilepsy in resource limited settings

- Early diagnosis and prompt treatment/referral can be made by primary health care provider
- Training of primary health care provider is essential to reduce the burden on tertiary health care systems and allow appropriate, judicious and cost-effective use of available resources

Epilepsy-Consensus clinical criteria

A child will be diagnosed as having epilepsy

Only if

He/she have history of 2 or more unprovoked seizures beyond 28 days of life.

Overview of INDT-EPI tool

- INDT-EPI included questions in simple language: the tool has a total of 13 questions
- Elicit the history of common seizure types
 - Generalized and partial motor seizures
 - Absence seizures
 - Myoclonic seizures (questions 1,2,10,11)
- Number of seizures (question 3)
- Duration between first and last seizures (Question 4)
- Provoked seizures such as febrile seizures (Question 5)
- Seizures occurring during neuro-infections (Question 6), head trauma or during systemic illnesses
- Neonatal seizures (Question 7)
- Seizure mimics such as breath holding spells (question 8) and syncopal attacks (question 9).
- Question 12 and 13 are final diagnosis.

INDT-EPI tool:

Question 1: Has your child ever had fits / daurae / mirgee / chamki?

- **Mark YES:** If Parents say that the child has had fits / daurae / mirgee / chamki
- **Mark NO:** If child never had seizure

Question 2: Did your child ever have episodes of loss of consciousness associated with any of the following?

- Up rolling of eyes
- Deviation of eyes to one side
- Tongue bite
- Frothing from mouth
- Passing urine / stool in clothes
- Shaking of limbs
- Limbs becoming stiff
- **Mark YES:** If the child had loss of consciousness with at least one of the associated features
- **Mark NO:** If the child never had loss of consciousness OR child had loss of consciousness, but not associated with any of the seven listed features

If the answer to Question 2 is 'Yes', then complete questions 3-9; otherwise go to question 10

Question 3: How many such episodes has the child had?

- Mark "0": If the child has had only ONE episode/seizure.
- Mark "1": If the child has had MORE THAN ONE episode/seizure.

1. Has your child ever had fits / daurae / mirgee / chamki?
 क्या आपके बच्चे को कभी दौरा/मिरगी/चमकी आया है?

0: No नहीं 1: Yes हाँ

2. Did your child ever have episodes of loss of consciousness associated with any of the following-
 क्या आपके बच्चे के साथ कभी निम्नलिखित में से किसी से भी जुड़ी बेहوشा की कभी भी घटना हुई है-

0: No नहीं 1: Yes हाँ

- Up rolling of eyes	आँसों को ऊपर की ओर घटना
- Deviation of eyes to one side	एक ओर आँसों का विचलन
- Tongue bite	दाँती में जीभ का घटना
- Frothing from mouth	मुँह में झाग आना
- Passing urine / stool in clothes	बापटों में stool/पेशाब होना
- Shaking of limbs	अंगों में कंपन
- Limbs becoming stiff	अंगों का बड़ोर होना

☛ If response to question 2 is "1", proceed to complete questions 3-9
 यदि प्रश्न 2 का उत्तर "1" है तो प्रश्न 3 से 9 तक के प्रश्नों के उत्तर दें

☛ If response to question 2 is "0", proceed to complete 10 and 11 (skip questions 3-9)
 यदि प्रश्न 2 का उत्तर "0" है तो प्रश्न 10 और 11 के उत्तर दें (3 से 9 तक के प्रश्नों को छोड़ दें)

Question 4: What was the duration between first and last episode/seizure?

- Mark "0": If the child has had two or more seizures but LESS THAN 24 hours apart.
- Mark "1": If the child has had two or more seizures MORE THAN 24 hours apart.
- Remember, according to the CCC for epilepsy, "2 or more unprovoked seizures at least 24 hours apart" will be classified as Epilepsy. Questions 3 and 4 elicit this information.

Question 5: Did your child have these episodes ALWAYS accompanied by fever? (Ask only if the seizure occurred when the child was 6 months - 6 years of age)

- **How to ask:** Emphasise "ALWAYS"
- **Mark YES:** If child has/had seizures ALWAYS accompanied by fever
- **Mark NO:** If child's seizures were NOT accompanied by fever
- Child has/had seizures accompanied by fever AND ALSO seizures not accompanied by fever (Febrile and a febrile seizures occurring together)

Question 6: Did your child have these episodes only during a brain infection (meningitis or encephalitis): during active CNS infection/ during hospitalisation / head trauma (within 7 days) or other infections such as diarrhoea/pneumonia or any other cause as told to you by your doctor?

- **Mark YES:** If child had seizures due to some identifiable cause and within the 7 days of that insult/ event as listed in the description
- **Mark NO:** If seizures were not related to any identifiable cause

Question 7: Did your child have these episodes ONLY during 1st month of life?

- **Mark YES:** If child had seizures ONLY during the neonatal period
- **Mark NO:** If child did not have seizures during the neonatal period OR
- If the child had seizures during AND beyond the neonatal period also OR
- If the child had seizures only after the neonatal period

Question 8: Did your child have all these episodes associated with change in colour or loss of consciousness in the settings of anger, pain, frustration and prolonged crying with breath holding? (May add colloquial terms for Breath holding spells)

- **How to ask:** Emphasise "PROLONGED CRYING", "BREATH HOLDING" and turning blue.

- **Mark YES:** If the child had episodes of breath holding as described above
- **Mark NO:** If the child never had breath holding spells

Question 9:

- **Did your child have all these episodes after prolonged standing?**
- **How to ask:** Emphasis should be on “**prolonged standing**”
- **Mark YES:** If child had episodes of fainting or unconsciousness after prolonged standing
- **Mark NO:** If child has never had such episodes

Question 10: Does your child have/had frequent episodes of “going blank” or lose awareness of his/her surroundings?

- **YES:** Child had frequent episodes of “going blank” OR Child had frequent episodes of “losing awareness of surroundings”
- **NO:** Child never had episodes of “going blank”/“losing awareness of surroundings”

Presence of absence seizures can be often confirmed by asking the child to hyperventilate. However, failing to elicit absence seizures by hyperventilation does not rule out it.

Question 11: Did your child ever have ANY of the following without loss of consciousness? (Excluding occasional jerks occurring ONLY during sleep)

- Sudden and unexplained episodes of falling to the ground
- Sudden head drop
- Sudden jerking movement with bending of body
- **Mark YES:** If child had or continues to have any form of myoclonic jerks as described above without loss of consciousness
- **Mark NO:** If child never had abnormal jerky movements / head drop / sudden unexplained fall to ground OR
- Occasional jerks occurring only during sleep

10. Does your child has had frequent episodes of “going blank” or lose awareness of his/her surroundings?
 क्या अचानक बड़का बार-बार झुलता है या बार-बार अपने आसपास के परिवेश से अनभिज्ञ हो जाता है

0: No नहीं 1: Yes हाँ

11. Did your child ever have ANY of the following?
 क्या आपके बच्चे को निम्नलिखित में से कुछ हुआ है?

- Sudden and unexplained episodes of falling to the ground
अचानक पड़ने की अचानक एवं **unexplained** घटनाएँ
- Sudden head drop अचानक सिर में गहिरा अवनत
- Sudden jerking movement with bending of body
अचानक झुकने की अचानक से घटनाएँ

0: No नहीं 1: Yes हाँ

12. Diagnosis निदान Anti Epileptic drug intake* (0:No 1:Yes)
 0: No Epilepsy कोई एपिलेप्सी नहीं
 1: Epilepsy एपिलेप्सी
 2: Single seizure ** एकल अतिवृत्त
 9: Indeterminate*

*AED: summary assessment record of CAB (see 10)
 **To be rechecked for other associated NDDs from Summary assessment record of CAB and enter final diagnosis in point 13

13 Final Diagnosis
 0: No Epilepsy
 1: Epilepsy
 9: Indeterminate

Interpretation and Diagnosis

EPILEPSY

- Response to **ALL questions 2, 3 and 4 is "1" AND response to ALL of the questions 5-9 is "0"**
- **AND/OR**
- Response to **either/both of the questions 10 or 11 is 1**

SINGLE SEIZURE

Response to question 2 is "1" AND question 3 is "0" AND response to all of the question 5-9 is "0"

- If any associated NDD classify as Epilepsy
- If no associated NDD check for Anti-epileptic drug intake: If anti-epileptic drug being used classified as indeterminate and if no anti-epileptic drug being used classify as no epilepsy

Interpretation and Diagnosis

- **Indeterminate**
- Response to **questions 1 OR 2 is "1" AND ANY of 5-9 is "1" and child is on Anti Epileptic Drug** he is indeterminate

In case of single seizures as detailed above

AIIMS Modified INDT Tool for Epilepsy

Why Modified tool has been made?

- To broaden the age group 0-18 years
- Based on practical definition of epilepsy by ILAE in 2014
- Include description of neonatal seizures

The INDT-EPI has high validity to identify children with epilepsy when used by primary care physicians. The candidate test for epilepsy had sensitivity and specificity of 85.8% and 95.3%; positive and negative predictive values of 94.0% and 88.5%; and positive and negative likelihood ratios of 18.25 and 0.15, respectively. INDT-EPI is a useful tool for diagnosis of childhood epilepsy by non-expert medical professionals (with adequate training) in different clinical settings, and for future epidemiological studies. This instrument can also be used in day-to-day clinical practice for diagnosing epilepsy by the primary healthcare physicians thereby expanding the care for epilepsy patients and reducing diagnosis management gap in resource-limited settings.

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Diagnosis of Motor Impairment using INDT – NMI

Dr Meera R

Developmental Pediatrician, Travancore Medicity, Kollam

Key points: NMDs are disorders resulting from pathology of the anterior horn cell, nerve roots, peripheral nerve, neuromuscular junction and/or the muscle.

They manifest at different ages with a broad spectrum of symptoms, signs & variable severity.

INDT-NMI consists of three sections:

Section-I (Triage questions) consists of four questions to elicit information from the parents/ primary caregiver of the child regarding attainment of selected motor developmental milestones.

Section-II (Observations): Physician makes three observations for assessing hand function, gait and muscle weakness.

Section-III consists of six questions, and the operator (graduate physician) does the neurological examination necessary for confirmation of NMI.

Using expert evaluation as gold standard, overall sensitivity of the INDT-NMI was 75.4% and specificity was 86.8%. INDT-NMI helped graduate physicians to correctly classify 86.6% (112/129) children with NMI into different types (cerebral palsy, neuromotor diseases and other NMI).

Graduate primary care physicians with a structured short training can administer the new tool and diagnose NMI in 2-9 year old children with high validity.

Neuromotor Impairments are static or progressive difficulty in performing daily activities or coordinated movements

Two pathology: NMI can be UMN or LMN

There are three broad groups of NMI:

- o Cerebral palsy
- o Neuromuscular disease
- o Other neuromotor impairment

6.1 CEREBRAL PALSY (CP)

Cerebral palsy is a disorder of **tone, movement & posture**, due to static or **non-progressive** disturbances that have occurred in the **developing brain** (e.g. birth asphyxia, kernicterus)

- Associated conditions
 - Disturbances of sensation
 - Disturbance of cognition
 - Disturbance of communication
 - Seizures
 - Feeding problems

All developmental delays are not Cerebral Palsy... so what is not Cerebral Palsy?

- Progressive neurological disorder
- Developmental regression
- Global developmental delay without any tone or movement abnormalities
- Transient tone and postural abnormalities which resolve by 1-2 years of age (e.g. preterm children)

EARLY MARKERS OF CP

EARLY INFANCY

- Delayed attainment of milestones
- Excessive stiffness of limbs and/or trunk
- Abnormal twisting postures
- Persistence or asymmetry of Moro's & the ATNR beyond 6 months of age
- Early hand preference
- Cortical thumb

LATER INFANCY & CHILDHOOD

- Persistence of asymmetry in posture, movement & reflexes
- Excessive stiffness or abnormal twisting
- Persistent ATNR
- Delay in achieving milestones

6.2 NEUROMUSCULAR DISORDERS

NMDs are disorders resulting from pathology of the anterior horn cell, nerve roots, peripheral nerve, neuromuscular junction and/or the muscle. These present with lower motor neuron (LMN) type of weakness. There can be static or progressive or fluctuating course. They manifest at different ages with a broad spectrum of symptoms, signs & variable severity.

COMMON NMDs

- Muscular dystrophies
- Spinal muscular atrophy (SMA)
- Hereditary neuropathies
- Myasthenia gravis
- Acute flaccid paralysis (AFP)
 - Paralytic poliomyelitis
 - Guillain-Barre' syndrome (GBS)
 - Transverse myelitis
 - Traumatic neuritis
 - Inflammatory myopathies

EARLY MARKERS OF NMDs

- Decreased fetal movement during antenatal period
- Floppy baby/infant
- Delay in attaining motor milestones
- Abnormal mode of walking (high stepping gait, toe walking or waddling gait)
- Difficulty in running, climbing stairs, getting up from the floor & frequent falls
- Enlargement/wasting of muscles
- Overt muscle weakness of recent origin

Other NMDs

- All conditions other than CP and NMD that cause weakness and/or problems in activity of daily living
- It includes:
 - Sequelae of CNS infections
 - Neural tube defects (NTDs) with sequelae
 - Stroke and its sequelae
 - Neurodegenerative disorders
 - Acquired CNS demyelinating disorders

6.3 WHY DIAGNOSTIC TOOL IS NECESSARY?

- Benefit from early diagnosis
 - Early stimulation therapy
 - Improved neurodevelopmental outcome
 - Implication in prognosis especially in infants with NMI of genetic etiology (eg SMA/DMD)

PRINCIPLES OF INDNT - NMI TOOL

- For any child presented with CNS complains thorough history taking and detailed CNS examination have pivotal role in diagnosis
- INDNT-NMI tool is based on principles of focused history and CNS examination.
- A complete CNS examination is time taking and at times becomes a challenge in pediatric age group.
- Focused CNS examination tailored to child's complaint can obtain essential information for diagnosis while maintaining child's maximum cooperation.

OVERVIEW OF INDNT-NMI

- It consists of three sections:
 - Section-I (Triage questions) consists of four questions to elicit information from the parents/primary caregiver of the child regarding attainment of selected motor developmental milestones.
 - Section-II (Observations): Physician makes three observations for assessing hand function, gait and muscle weakness.
 - Section-III consists of six questions, and the operator (graduate physician) does the neurological examination necessary for confirmation of NMI.
- Thus final diagnosis of NMI is derived through an algorithm based on interpretation of three sections (*i.e.* 13 questions/items)
- The final diagnosis informs whether the case has:
 - Cerebral palsy (CP)
 - Neuromuscular disorders (NMD)

- o Other NMI (that does not fit in to either CP or NMD)
 - o No NMI
 - o Indeterminate clinical condition
- This tool requires approximately 20-25 minutes for assessing each child

Triage Question: Question 1: Does your child have difficulty in ANY of the following: Sitting/ getting up from sitting position/ Standing / Walking/ Running?

- **How to ask:** Ask each component of the question separately and wait for parent's response. After getting clear response, then move on to next component
- **Mark YES:** If the child has difficulty in ANY of the above listed activities or **If** the child has NOT ATTAINED that milestone
- **Mark NO:** If the child has no difficulty in the above activities

Triage Question: Question 2: Did your child start performing the following activities later than children of his/her age (Sitting without support beyond his/her first birthday/ Walking without support beyond 2nd birthday)

- **How to ask:** Ask each component of the question separately and wait for parent's response. After getting clear response, then move on to next component.
- **Mark YES:** If the child had DELAY in attainment of these motor milestones
- If the child had NOT ATTAINED these milestones yet
- **Mark NO:** If the child had NO DELAY in attainment of these motor milestones

Triage Question: Question 3: Does your child have ANY of the following?

- **Excessive tightness or limpness of the body/ Toe-walking/ abnormal posture of any limb/ decreased or unequal use of any limb/ Frequent falls**
- **Mark YES:** If the child has abnormality mentioned
- **Mark NO:** If the child has no abnormality as listed in the question
- **Mark Not Applicable:** for components “frequent falls” and toe walking” if the child is unable to walk or not yet attained walking

Triage Question: Question 4: Does your child have difficulty in performing ANY of the following activities? (For children above 4 years age only)

- **Bathing or cleaning self/ Toileting/ Dressing/ Feeding self**
- **How to ask:** Ask each component of the question separately and wait for parent's response. After getting clear response, then move on to next component.
- **Mark YES:** If there is difficulty in any of above listed activities
- **NO:** If the child has NO difficulty in any of the above activities
- **Mark Not Applicable:** For children between 2-4 years of age
- If parents say that “we have never allowed the child to do these tasks; we do this ourselves”

Observation based question: Question 5: Observe for the following when the child is walking:

- o Limping
- o Unsteadiness of gait (Ataxia)
- o Toe walking
- o Waddling gait
- o Scissoring gait

- o High stepping gait
- o Unable to walk
- **How to test:** Ask the child to walk across the room (at least 10 meters) comfortably and observe the gait. If you are attentive, you can also observe the gait when the child enters examination room.
- **Mark as YES:** If the child has any of the abnormal gait described above
- If the child is unable to walk
- **Mark as NO:** If the child's gait is normal
- **Mark as Not Applicable:** If the child has not attained walking yet

Observation Based Question: Question 6: Observe for the following when the child is standing up from floor:

- Requires assistance for standing up from floor or unable to stand/ Gowers' sign
- **How to test:** Make the child sit down on the floor completely and then ask him/her to get up to standing position without holding the furniture.
- **Mark as YES:** If the child has difficulty in getting up from sitting on floor
- If the child requires assistance to stand from sitting position
- If the child has not learned standing yet
- If Gower's sign is positive
- **Mark as NO:** If the child has NO difficulty in getting up from sitting on floor
- If the child DOES NOT require assistance to stand from sitting

Observation Based Question: Question 7: Observe hands and look for the following:

- o Tremors
- o Unequal power of hand grip
- o Fisting of one or both hands
- **Tremors** - Ask the child to stretch his/her arms and spread out the fingers
- **Unequal power of hand grip** - Ask the child to grasp your two fingers as forcefully as he/she can, while you try to separate your fingers
- **Fisting of one or both hands** - Observe during the course of examination
- Mark as **YES:** If the child has any of the above listed abnormalities in hands
- Mark as **NO:** If the child has none of the abnormalities in hands

Motor examination: Question 8

- **Muscle Power**
 - o **0: Normal**
 - o **1: Decreased**
- **How to test:** Test at least two muscles in each limb and note down the power whether normal or decreased. In upper limbs, shoulder abductors and wrist extensors are to be tested; and in lower limbs hip extensors and ankle dorsiflexors are to be tested.

Motor examination: Question 9: Muscle Tone

- 0: Normal
- 1: Hypotonia
- 2: Hypertonia

• **How to test:**

- See the posture of limbs: frog-like posture or scissoring
- Feel the muscle
- Do: Passive movements of the joints and range of motion at the joints.

• **Interpretation:**

- Flappability
- Spasticity:
 - UL → pronation and supination; pronator catch
 - LL → hip extensors, knee extensors & plantar flexors of foot

Motor examination: Question 10: Deep tendon reflexes (biceps, triceps, knee and ankle jerks)

- 0: Normal
- 1: Diminished or absent
- 2: Exaggerated

- You should elicit DTRs at biceps and triceps in UL, and knee & ankle in LL.
- DTRs are grades as follows
 - 0: absent
 - 1+: Sluggish or reduced
 - 2+: normal
 - 3+: Exaggerated
 - 4+: Brisk with presence of clonus

Motor Examination: Question 11: Plantar Response

- **How to test:** Gently draw a blunt stimulus along the lateral border of the sole. Watch the big toe and remainder of the toes. Possible responses are as follows:
- **Interpretation**
- All toes flex - Flexor response
- Extension of great toe and fanning of other toes - Extensor plantar response
- No movement - Not elicitable
- Big toe extends, other toes extend, ankle dorsiflexion - Withdrawal response

Motor Examination: Question 12: Balance and Coordination

- **0:** Normal
- **1:** Poor balance of trunk or limbs (Ataxia)

- **How to test:** Truncal ataxia is seen as swaying/unsteadiness while sitting
- Ataxic gait can be identified by asking the child to walk

Motor examination: Question 13:

• **Abnormal Movements**

- **0:** No abnormal movements
- **1:** Abnormal movements

- Abnormal movements observed in children with dyskinetic cerebral palsy includes:
 - Choreoathetoid movements
 - Dystonia
 - Tremor
 - Ballismus

Motor System Examination (Question 8-13) Interpretation:

A: NEUROMOTOR IMPAIRMENT

- **0:** No neuromotor dysfunction (Responses to **ALL** of 8-13 is “0”)
- **1:** UMN dysfunction (At least TWO out of 9-11 is “2”)
- **2:** LMN dysfunction (Response to 8 is “1”, AND response to 9 or 10 is 1 AND 11 is not 2)
- **3:** In coordination/ Abnormal movements (Response to 12 OR 13 is “1”)
- **9:** Indeterminate (If the findings are abnormal but not fitting in any of the above)

14: Interpretation

- **B. Onset of symptoms (Only for UMN dysfunction)**
 - **0:** At or before 2 years of age
 - **1:** After 2 years of age or cannot be ascertained
 - **8:** Not applicable
- **C. Course of the child's illness**
 - **0:** Static or improving
 - **1:** Progressive
 - **8:** Not applicable
- **D. Is there a clear** Spinal cord pathology resulting in impairment

Modified INDT- NMI Tool

- What is the need for a modified tool?
 - Age group broaden to **0-18 years** children
 - Detailed description of symptoms and signs of cerebellum and extrapyramidal involvement

Using expert evaluation as gold standard, overall sensitivity of the INDT-NMI was 75.4% and specificity was 86.8%. INDT-NMI helped graduate physicians to correctly classify 86.6% (112/129) children with NMI into different types (cerebral palsy, neuromotor diseases and other NMI). In conclusion, graduate primary care physicians with a structured short training can administer the new tool and diagnose NMI in 2-9 year old children with high validity. The tool will help early diagnosis of NMI in primary care and institution of physiotherapy and assignment to a specialist for detailed evaluation and management.

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2

P A R T

Management of Epilepsy, CP & CVI

Management of Epilepsy

Dr P A Mohammed kunju

Prof of Pediatric Neurology & Consultant Pediatric Neurologist, CDC & Dr Hashma Mohammed P, IAP Fellow, CDC

Key points: Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, usually practically applied as having two unprovoked seizures >24 h apart.

Epileptic syndromes are “a group of clinical entities that are reliably identified by a cluster of electro-clinical characteristics”.

The choice of the antiepileptic drug (AED) depends on the type of seizure, the age of the child, sex and economic factors. Monotherapy should be preferred over polytherapy.

Knowledge of adverse reaction is important as the compliance is very important.

In patients who had been seizure-free for at least two years a trial of AED therapy withdrawal can be tried.

For children whose seizures took long time for control may have to wait for 3-5 yrs of seizure freedom before stoppage. Patient with juvenile myoclonic epilepsy (JME) may require lifelong treatment. Stoppage should not be abrupt.

Depending on the previous seizure status and duration of treatment, reduction can be attempted gradually in 3-6 months. If at any juncture seizure recurs, initial dose must be restarted.

FEBRILE SEIZURES

Febrile seizures are fever precipitated seizures without evidence of intracranial infection or other cause and are typically seen in the age group of 6 months to 60 months. These are of two types- simple and complex. Features of *simple febrile seizure* is one in which the seizures are generalized, lasting less than 15 minutes, occurring one per febrile episode and without any postictal focal neurological deficit. The seizures which are focal, lasting more than 15 minutes, more than one per episode and associated with focal deficits are termed *complex febrile seizure*. A lumbar puncture can be done in case of clinical suspicion of CNS infection (persistent drowsiness/irritability, meningeal signs etc). Neuroimaging and EEG are not indicated in a case of typical febrile seizures. In cases of atypical febrile seizures EEG can be done on an individual basis to exclude conditions like herpes encephalitis. Treatment is mainly acute control of seizures. Intermittent

prophylaxis with diazepam (2-5mg) or clobazam (5mg BD) for 3days with fever is given in simple febrile seizure to allay parental anxiety. Continuous prophylaxis with phenobarbitone or valproate can prevent complex febrile seizures. However it is better to restrict long term drugs only when there are afebrile seizures. The risk of subsequent epilepsy for a child with typical febrile seizures is 1% and that of atypical febrile seizures is 6%. As such there is no contraindication for giving vaccination. Advise intermittent prophylaxis before giving vaccine.

7.2 CLASSIFICATION OF EPILEPSY

The ILAE (International League Against Epilepsy) classifies the epilepsies based on the seizure type. They are broadly classified as –

- A. *Generalized* – seizures which are arising within and are rapidly engaging bilaterally distributed networks
- B. *Focal* – seizures which are originating within networks limited in one hemisphere
- X. *Unknown* – seizures which cannot be classified as either focal or generalised like epileptic spasms.

A. Generalized seizures are further classified into –

1. Tonic clonic seizures (GTCS) – Tonic phase is characterised by bilaterally symmetric tonic contractions which last for 10-20 sec. This is followed by the clonic phase. Urinary or fecal incontinence, autonomic abnormalities like tachycardia, mydriasis, cardiac arrhythmias and tachypnoea occurring in the recovery phase that follows this phase.
2. Tonic seizures (GTS)- Here there are only tonic contractions of the muscles, no clonic phase is seen. It can last from 10-20 sec to a few minutes and can occur multiple times in a day. These are the most commonly seen in Lennox- Gastaut syndrome.
3. Clonic seizures (GCS) – These are characterised by rhythmic bilateral clonic convulsions. These are different from the clonic phase of GTCS as the latter are due to phasing in of seizure suppressing mechanisms.
4. Absence – in its typical form it manifests as an impairment of consciousness without loss of postural tone or any motor activity. The child stops doing what he was previously doing and develops a blank facial expression along with a flickering of eyelids which is usually short lasting less than 30 sec, characterised by a typical EEG pattern of 3 per sec generalised spike and wave abnormalities.
5. Myoclonic – These are sudden shock like, irregular contractions of the muscles lasting less than 100ms. They may occur singly or as irregular clusters.
6. Atonic – These are characterised by sudden loss or diminution of muscular tone.

B. Focal seizures (formerly partial seizures) –

- a. With retained awareness (simple partial seizure)– The child develops an abnormal tonic or clonic movement restricted only to a part of the body like the head, neck, face or extremities.
- b. With impairment of consciousness (complex partial seizure CPS) – Apart from the abnormal movements these children may also develop an “aura “ which is an unpleasant feeling or epigastric discomfort or fear prior to the onset of the seizures. Automatism may also be seen, which are abnormal activities like lip smacking, chewing, swallowing , picking or pulling at clothes etc.

7.3 EPILEPTIC SYNDROMES

ILAE define epileptic syndromes as – “a group of clinical entities that are reliably identified by a cluster of electro-clinical characteristics”. This will identify epilepsies with good prognosis (benign syndromes) from

worse prognosis (catastrophic epileptic syndromes). Epileptic encephalopathies are severe epilepsies where the epileptic electrical discharges lead to progressive psychomotor dysfunction.

- a. *Infantile spasms or West syndrome* – occurs between 3 and 12 months of age. It is a triad of Infantile spasms, deterioration of psychomotor development and hypsarrythmia. The spasms come as clusters, each cluster having few to even 100 spasms., EEG is known as hypsarrythmia (fig1). Most common causes are perinatal hypoxic injury, idiopathic and tuberous sclerosis.
- b. *Childhood absence epilepsy (CAE)* – It is a syndrome characterized by recurrent absence seizures occurring per day. It usually has its onset between 4 and 10 years. The EEG shows typical 3 HZ generalized spike and wave discharges. (fig2) The prognosis is excellent with most of the children going in remission by the age of 12 years.
- c. *Lennox Gastaut syndrome (LGS)* – This syndrome is characterised by multiple seizure types - tonic, atonic and atypical absence type and cognitive and behavioural abnormalities. The age of onset is below 11 years with a peak between 3-5 years of age. The condition is difficult to control requiring poly-therapy and has a poor prognosis.
- d. *Benign childhood Epilepsy with centro-temporal spikes (BCECTS)*- This is an epileptic syndrome with an onset typically in late childhood. The seizures are simple partial seizures of one half of the face with associated tingling of the buccal area and the throat. These usually occur in the night and the child makes gurgling sounds and wakes up from sleep with the seizures and is unable to respond for a few minutes though he is conscious and can comprehend everything. The EEG shows characteristic frontotemporal or parietotemporal sharp waves activated by sleep. The disease has a good outcome with about 99% going into remission by the age of 18 years.

7.4 TREATMENT

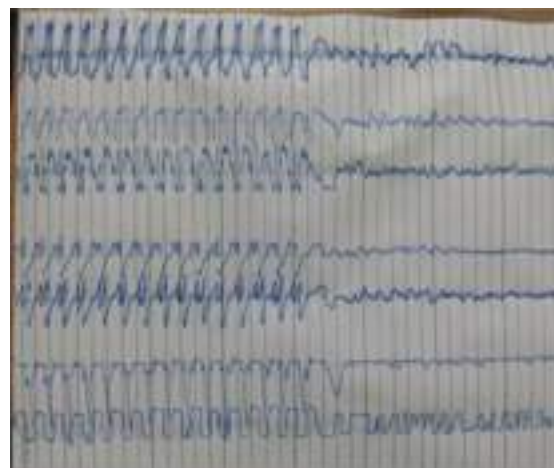
The choice of the antiepileptic drug (AED) depends on the type of seizure, the age of the child, sex and economic factors. Monotherapy should be preferred over polytherapy. The following are the preferred drugs for a particular type of seizure –

- a. Generalized Tonic Clonic Seizures (GTCS) – **Sodium Valproate**, Levetiracetam, phenobarbitone, phenytoin, lamotrigine
- b. Focal seizures – **Carbamazepine**, Levetiracetam, Oxcarbazepine, phenytoin, phenobarbitone and clobazam.
- c. Myoclonic seizures – Clonazepam, valproate, phenobarbitone, Levetiracetam
- d. Absence – **Sodium Valproate, ethosuximide**, Lamotrigine, clonazepam (uncontrolled absence a combination of Valproate and Lamotrigine can be used)
- e. Tonic seizures – Valproate, phenytoin, phenobarbitone, topiramate, lamotrigine

Preferred drug for common epileptic syndromes-

- a. Benign childhood epilepsy with centrotemporal spikes – Carbamazepine, valproate, levetiracetam, oxcarbazepine.
- b. Childhood absence epilepsy – Ethosuximide, valproate, lamotrigine
- c. Infantile spasms – ACTH, Valproate, vigabatrin. (for tuberous sclerosis)
- d. Lennox gestaut syndrome – Valproate, Lamotrigine, levetiracetam
- e. Juvenile myoclonic epilepsy- Valproate, Levetiracetam, lamotrigine

Start with one drug slowly, go to the maximum dose. If seizures are persisting reduce the first and start another drug simultaneously. If still no control either a 3rd drug can be tried similarly or can be used as 2nd add-on.



7.5 SIDE EFFECTS SEEN OF ANTIEPILEPTIC DRUGS(AED)

Knowledge of adverse reaction is important as the compliance is very important. Some may be even life threatening - system wise adverse reaction can be remembered.

CNS- Phenytoin- ataxia; Phenobarbitone- hyperkinetic behaviour in children; Levetiracetam – Irritability, behavioural and psychotic changes

GIT- Valproate- weight gain, hepatic failure, and pancreatitis

Hematology – Carbamazepine-agranulocytosis; Phenytoin-anemia

Respiratory – Clonazepam, Nitrazepam- Bronchorhea –

Dermatology- Carbamazepine, Lamotrigine- steven Johnson syndrome

Cardiac – Phenytoin infusion - arrhythmia

Severe drowsiness, or sedation can be produced by all especially benzodiazepine like clobazam and clonazepam. Gingival hyperplasia of Phenytoin can be reduced by advising for good oral hygiene through regular brushing and cleaning mouth.

“Start low; go slow” – that is the dictum in AED usage. That is- start with a low dose and increase slowly – at least in a weekly basis. This will prevent development of side effects like steven john syndrome with Carbamazepine or lamotrigine and behavioral and psychotic changes of Levetiracetam.

7.6 STRATEGY OF DISCONTINUING ANTI-EPILEPTIC DRUG THERAPY

In patients who had been seizure-free for at least two years a trial of AED therapy withdrawal can be tried.

For children whose seizures took long time for control may have to wait for 3-5 yrs of seizure freedom before stoppage. Patient with juvenile myoclonic epilepsy (JME) may require lifelong treatment. Stoppage should not be abrupt. Depending on the previous seizure status and duration of treatment reduction can be attempted gradually in 3-6 months. If at any juncture seizure recurs, initial dose must be restarted.

7.7 STATUS EPILEPTICUS

Status epilepticus is defined as a continuous seizure lasting more than 30 min, or two or more seizures without full recovery of consciousness between any of them. Current recommendation is to consider any seizure lasting more than 5 minutes as status. The managements consists of –

- Initial stabilization by maintaining airway, breathing and circulation.
- Correcting hypoglycaemia if present.

First line AEDs -

- Diazepam 0.15 mg/kg IV up to 10 mg per dose, may repeat in 5 min
- Lorazepam 0.1 mg/kg IV up to 4 mg per dose, may repeat in 5–10 min
- Midazolam 0.2 mg/kg IM up to maximum of 10 mg
(If an IV line cannot be established, undiluted diazepam is placed into the rectum by a syringe and a flexible tube at a dose of 0.3–0.5 mg/kg.
- Sublingual lorazepam in 0.05–0.1 mg/kg. with serial seizures
- Midazolam nasal spray or buccal midazolam also can be given.)

2nd line

- Fosphenytoin 20 mg PE/kg IV, may give additional 10 mg/kg (PE= phenytoin equivalent)
- Phenobarbital 20 mg/kg IV, may give an additional 5–10 mg/kg
- Valproate sodium 20–40 mg/kg IV, may give an additional 20 mg/kg or Levetiracetam 20mg/Kg IV

3rd line

- Midazolam- 0.2 mg/kg; administer at an infusion rate of, then 0.75-10.00 µg/kg/min,
- Propofol -Start at loading dose of 12 mg/kg IV, followed by 2-10 mg/kg/hr
- Thiopental -2–7 mg/kg, administer at an infusion rate < 50 mg/min
- Pentobarbital 5–15 mg/kg, may give additional 5–10 mg/kg; administer at an infusion rate < 50 mg/min
- Start mechanical ventilation along with 3rd line drugs.

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Management of Cerebral Palsy

Dr P A Mohammed Kunju¹ & Dr Hashma Mohammed P²

¹Prof of Pediatric Neurology & Consultant Pediatric Neurologist, CDC, ²IAP Fellow, CDC

Key points : Early Identification features include: (i) Abnormal behavior: colicky behavior; excessive docility or irritability, poor eye contact, irregular sleep pattern, feeding problem (failure to establish breast feeding and failure to thrive), (ii) Oromotor problems: frequent vomiting, poor sucking, tongue retraction, grimacing, difficulty in chewing and swallowing, (iii) Poor mobility: poor head control, abnormal tone, hand preference before 2yrs of age, abnormal crawl, abnormal posturing, (iv) Persistent fisting (cortical thumb > 50 % of time before 2 months of age and at any time after 2 months).

Prognosis: (i) A child who has attained head control by 9 months has a good prognosis for independent walking (by 4yrs), (ii) A child who is able to sit by 2 year has a good prognosis for independent walking, (iii) A child who has floor mobility by 30 months has a good prognosis for independent walking, (iv) A child who cannot stand by 5 to 6 years may not walk

Early Interventions: (i) Key to child's improvement is by mother-child participation, (ii) Regular passive exercises can be done at home by the parents as per the assessment. (iii) By utilizing the head steadiness, sitting, standing and walking developmental observation, manipulative techniques can be utilized for facilitating achievement of each milestone, (iv) Multilevel and repeat sensory inputs and appropriate experiences in early life will contribute to information gains and achievement in various developmental spheres.

Treatment Options: (i) Physiotherapy, (ii) Splinting & Casting, (iii) Oral medications
(iv) Surgery.

8.1 DEFINITION OF CEREBRAL PALSY

CP is a group of permanent disorders of movement and posture causing activity limitation which are attributed to non-progressive disturbances that occur in the developing fetal or infant brain.

Following aspects are to be considered – **Non progressive central motor deficit due to disorders affecting developing brain.**

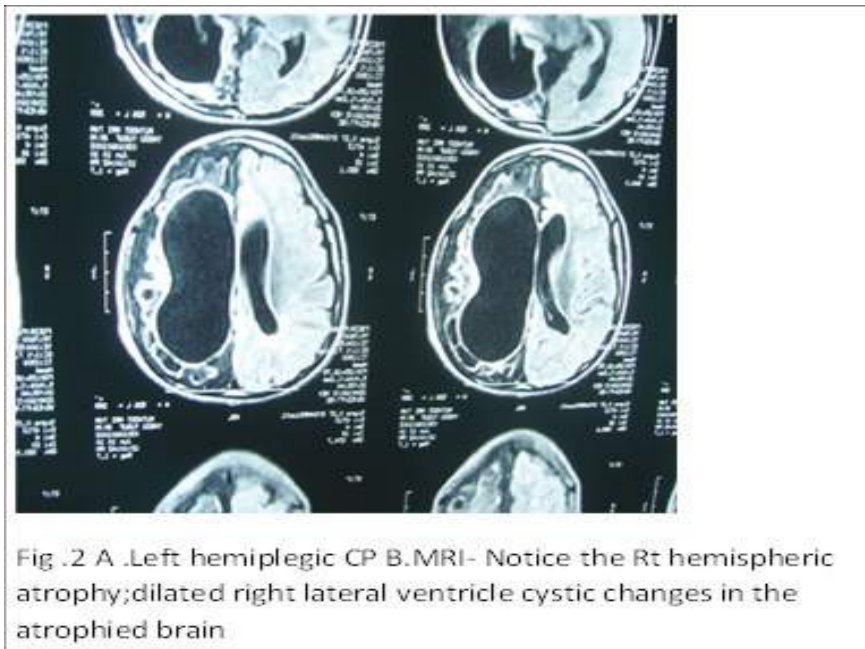
- “ **Non progressive**” – to be differentiated from progressive disorders like metabolic or progressive genetic disorders by loss of acquired milestones or occurrence of systemic manifestations

- **“Central”** – to be differentiated from peripheral nervous system disorders by presence of UMN signs and cognitive dysfunctions
- **Motor deficit** – dominant motor and less mental and sensory disturbances. All disturbances of motor system can be present in varying degree. Weakness, tone changes (hypotonia, spasticity, rigidity), incoordination, and abnormal movements
- **Due to disorders affecting developing brain** – ie, it can occur due to problems from first trimester to 2 yrs; and not a problem of mature brain
- The term ‘non-progressive’ in the definition of CP denotes the brain damage in the child. But the effects of the brain damage are dynamic and the clinical features evolve with time. Usually, an acquired milestone is not lost.

8.2 CLASSIFICATION OF CP

CP may be classified according to the pattern of neurologic involvement, neuropathology, and etiology.

- Area of brain involvement and clinical features - Pyramidal (spastic, hypotonic) extra pyramidal (choreoathetoid, dyskinetic) and cerebellar (ataxic).
- Topography: diplegic (Little’s disease) tetraplegic, hemiplegic,



However, these labels should not be used as a substitute for thorough investigation of underlying causes and to differentiate from degenerative disorders.

8.3 TOPOGRAPHIC DEFINITION OF CP

- **Diplegia:** when the legs are more affected than arms.Approximately 80% of preterm infants who manifest motor abnormalities have spastic diplegia (fig 1 A).
- **Quadriplegia:** weakness of all four extremities along with weakness of trunk, neck and face.
- **Hemiplegia:** weakness of upper and lower limb on one side of the body ; upper limbs will be more affected than legs.(Fig 2 B)
- **Double hemiplegia:** weakness of all four extremities, arms are more affected than legs.

- **Tripiegia:** weakness of both lower extremity and one upper extremity.
- **Monoplegia:** weakness of a single extremity. It is a very rare condition..

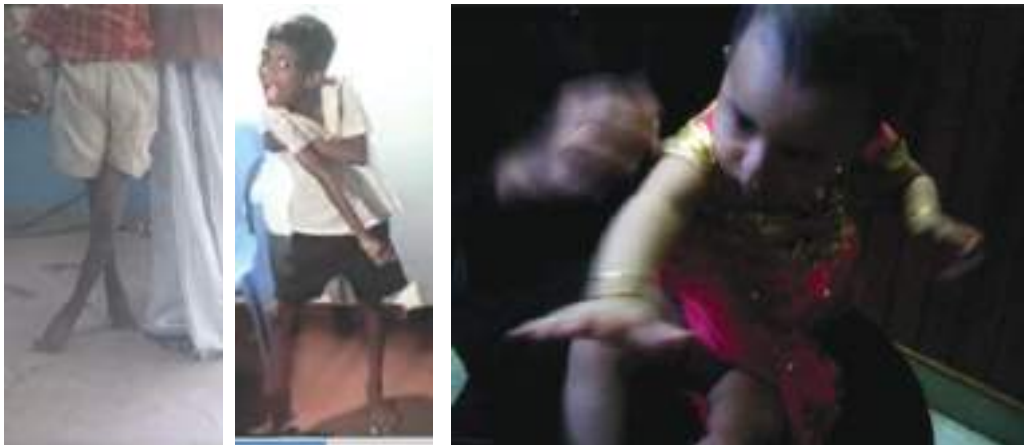


Fig1 A. Types of cerebral palsy. Diplegic CP - notice the scissoring

Fig 2 B.Choreoathetotic CP – Notice the twisted posturing; finger posturing

C .Ataxic CP- early evindenced of inco-ordinated approach



8.4 Evaluation of CP

The risk of CP in survivors of perinatal asphyxia is 5 to 10% as compared to 0.2% in general population. Only 3 to 13% of infants with CP have evidence of perinatal asphyxia.

The common pathologies occurring in perinatal asphyxia resulting in CP are,

1. Parasagittal cerebral injury of term babies leading to a hip shoulder type of weakness resulting in quadriplegia
2. Periventricular leukomalacia in preterm babies resulting in diplegia (Fig 3)
1. Focal and multifocal brain necrosis with cognitive defects and seizures
2. Selective neuronal necrosis producing varying degrees of spastic cerebral palsy, or spastic hemiparesis-
3. Status marmoratus (marbled basal ganglia and thalami) with resultant extrapyramidal cerebral palsy
4. Diffuse neuronal injury producing mixed or severe forms

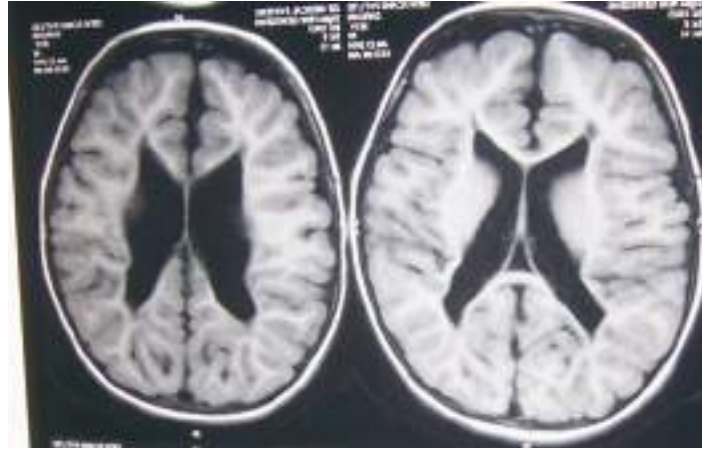


Fig 3 Periventricular leukomalacia (A. Dilatation of the lateral ventricle by the loss of Periventricular white matter B. Squared posterior horn)

8.5 What are the clues towards early diagnosis of CP?

A newborn with high risk factors and following -

Abnormal behavior: colicky behavior; excessive docility or irritability, poor eye contact, irregular sleep pattern, feeding problem (failure to establish breast feeding and failure to thrive)

Oromotor problems: frequent vomiting, poor sucking, tongue retraction, grimacing, difficulty in chewing and swallowing

Poor mobility: poor head control, abnormal tone, hand preference before 2yrs of age, abnormal crawl, abnormal posturing (fig 4)

Persistent fisting (cortical thumb > 50 % of time before 2 months of age and at any time after 2 months (Fig 5)

Delayed milestones: social smile not attained by 3 months, inability to sit without support by 8 months

Persistence of neonatal reflexes (eg. ATNR – asymmetric tonic neck reflex) or late or non-appearance of infantile reflexes (eg. Landau reflex)

Utilization of a simple *developmental observation card* with following items will help in identification and early intervention

1. Social smile by 2 months completed
2. Head steadiness by 4 months completed
3. Sitting without support by 8 months completed
4. Standing without support by 12 months completed
5. Make sure that baby sees, hears and listens



Fig 4 an early sign of CP .On ventral suspension abnormal head and shoulder retraction ; stiff extension of lower limbs



Fig 5 Persistent fisting

8.6 DYSKINETIC CP

Dyskinetic CP is a form of CP in which involuntary movements dominate the clinical picture. It could be either choreoathetoid or dystonic. Athetosis is the form of dyskinesia most often seen. The involuntary movements are not seen till the child is 2yrs or more. This is because some extent of pyramidal tract maturation is required for the involuntary movements to occur.

It occurs most often due to (a) hyperbilirubinemia and kernicterus affecting the caudate and lenticular nuclei of basal ganglia (b) Status marmoratus (marbled basal ganglia and thalami) due to acute severe asphyxia. The clinical clues to the role of kernicterus in dyskinetic CP are known as “*athetoid tetrad*”.

- 1.Choreoathetosis
- 2.Upgaze palsy
- 3.High tone deafness
- 4.Enamel hypoplasia (Greenish discoloration of dental enamel and poor formation of teeth)

A trial of levodopa to try to identify cases of *dopa-responsive dystonia* is recommended in a dyskinetic CP.

8.7 STAGES OF CLINICAL EVOLUTION OF SPASTIC DIPLEGIA

Spastic diplegia (Little’s disease) is weakness of all limbs with bilateral leg involvement more than the upper extremity. The most common risk factor for spastic diplegia is preterm delivery with HIE, periventricular watershed infarct and its sequelae periventricular leukomalacia. Preterm periventricular – intraventricular hemorrhage also produces the same pathology.

Typical evolution has the following steps. In the immediate postnatal period child is lethargic, have feeding difficulty, sometimes they may be overactive, jittery. This is followed by a latency period of 6 – 12 weeks. Gradually this progresses through stage of hypotonia, stage of dystonia to the final rigid-spastic stage. The rate of evolution through the various stages allows an estimate of prognosis. Children who pass rapidly through the stage of hypotonia and dystonia to reach the rigid – spastic stage have a relatively good prognosis. Children who are hypotonic for longer duration have poor prognosis.

Some specific clinical features differentiate diplegia of asphyxia from that of prematurity.

Seizures and cognitive impairment is common with HIE and squint is common with prematurity. Seizures are not commonly seen in the latter group.

8.8 HYDROCEPHALUS IN CP

Hydrocephalus is commonly associated with ataxic CP. Ataxic CP is relatively uncommon and occurs in 10% of cases of CP. Many may be due to an underlying congenital cerebellar hypoplasia rather than HIE. The presentation may be as pure ataxia or ataxic diplegia. Certain stage of motor development is needed before cerebellar deficit can be elicited. Hence diagnosis often becomes late. Reaching for objects is delayed and when attained obvious intentional tremor is seen. Sitting is delayed and when it occurs truncal ataxia and titubation are noticeable. The child walks by wide based ataxic gait or spastic and ataxic gait

8.9 DYSEQUILIBRIUM SYNDROME

Dysequilibrium syndrome is a subgroup of ataxic CP which is inherited as an autosomal recessive character. These children have severe motor delay and they seldom walk before 9 years of age.

8.10 COMMON ASSOCIATED CONDITIONS WITH CP

The common associated conditions with CP are: intellectual disability, epilepsy, ophthalmologic defects (strabismus or hemianopia. 25 to 39 %), speech and language disorders, hearing impairment (8 to 18 percent), oromotor problems, dental problems, respiratory problems, bowel and bladder disturbances, and psychosocial problems like ADHD, learning problems etc..

Higher incidence of epilepsy among CP cases is seen in spastic quadriplegia (50 to 94%) and hemiplegia (30%). Epilepsy is rarely noted with dyskinetic CP.

Dysarthria, phonation difficulty, impaired speech intelligibility are the common language problems. They occur due to spasticity or athetosis of muscles of tongue, mouth and larynx, and corticobulbar dysfunction. Gastrointestinal problems like vomiting, constipation, or bowel obstruction are also very common.

Recurrent pneumonia occurs due to gastroesophageal reflux, aspiration and spasticity of respiratory muscles.

8.11 COMMON CAUSES FOR APPARENT REGRESSION IN STATIC ENCEPHALOPATHY

Apparent regression in static encephalopathy may be noticed due to new onset seizures, new onset movement disorders (usually during second year), increasing spasticity, progressive hydrocephalus enlarging porencephalic cyst and parental misperception of attained milestones.

8.12 DIFFERENTIAL DIAGNOSES OF CP

Presence of following should be an indicator for alternative diagnosis:

- Absence of high risk factors or absence of perinatal insult
- Occurrence in siblings (family history of “cerebral palsy”)
- Developmental regression
- Presence of visual or oculomotor abnormalities,
- Systemic involvement

8.13 NEUROIMAGING IN A CHILD WITH CP

As per AAN guidelines 2004, neuroimaging is recommended in the evaluation of a child with CP if the etiology has not been established, for example by perinatal imaging. MRI when available is preferred to CT scanning because of yield of suggesting an etiology and timing of

insult is more with MRI. Imaging will help in differentiating HIE from congenital malformations like schizencephaly (fig 6).

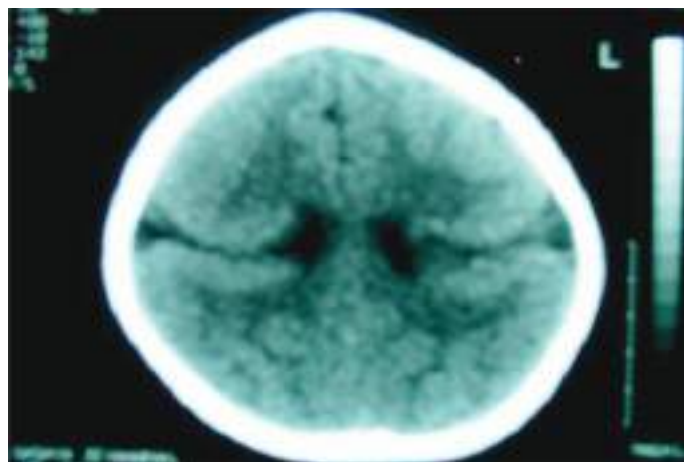


Fig .6.Bilateralschizencephaly presented with quadriplegic cerebral palsy

8.14 FUNCTIONAL STATUS ASSESEMENT IN A CHILD WITH CP

Classification used to categorize for habilitation, prognostication and need for assistive devises

For early identification of tone changes

Amiel - Tison passive angles

Adductor angle

Popliteal angle

Dorsiflexion angle

Scarf sign

Gross motor functional classification system

- o Level 1: clumsy child; no assistive devices
- o Level 2: walks independently but limited in outdoor activities
- o Level 3: walks with assistive mobility devices
- o Level 4: self-mobility severely limited even with assistive devices
- o Level 5: no self-mobility even with assistive devices



Manual ability classification system

- o Handles object easily and successfully
- o Handles most objects, but with a reduced quality and/or speed of achievement
- o Handles objects with difficulty and needs help to prepare and/or modify activities
- o Handles a limited selection of easily managed objects in adapted situations
- o Does not handle objects

Assessment of spasticity

- o Ashworth scale

8.15 CLINICAL PREDICTORS FOR INDEPENDENT WALKING IN A CHILD WITH CP

A child who has attained head control by 9 months has a good prognosis for independent walking (by 4yrs)

A child who is able to sit by 2 year has a good prognosis for independent walking

A child who has floor mobility by 30 months has a good prognosis for independent walking

A child who cannot stand by 5 to 6 years may not walk.

8.16 EARLY INTERVENTION MEASURES FOR CP

In early intervention programs the primary care giver (either a pediatrician or a developmental therapist) works to create a developmental setting in which the key to child's improvement is by mother-child participation.

The basis of early intervention is that there are critical periods of development and if interventions happen before that, delay and disabilities can be minimized. This focuses on mobility, manipulation, and communication.

So anticipate CP in high risk babies including preterm and use early screening for motor milestone delay and tone change by Amiel Tison angles.

Regular passive exercises can be done at home by the parents as per the assessment. (fig.7)

By utilizing the head steadiness, sitting, standing and walking developmental observation, manipulative techniques can be utilized for facilitating achievement of each milestone. Multilevel and repeat sensory inputs and appropriate experiences in early life will contribute to information gains and achievement in various developmental spheres. The components of early intervention depend on the primary impairment and can be tailored as per the needs.

8.17 VARIOUS TREATMENT OPTIONS FOR SPASTICITY



Fig. 7. Parent doing foot passive physiotherapy

- Physiotherapy**
 - Positioning
 - Exercises
 - Stretching
 - Neurofacilitation
 - Electrostimulation
- Splinting & Casting (eg. Ankle foot orthoses Fig 8)**
- Oral medications**
 - Baclofen
 - Diazepam
 - Clonazepam
 - Dantrolene
 - Tizanidine
- Intrathecal medications**
 - Baclofen
 - Morphine
 - Clonidine
- Neuromuscular blocks**
 - Local anesthetics
 - Phenol
- Botulinum Toxin Injections – Multilevel injection after assessing spasticity and deciding point of injection sites of giving injection gastrosoleus for tendoachillis spasm is given in fig 9.

□ **Surgery**

- Selective dorsal rhizotomy
- Tendon lengthening, release /transfer
- Multilevel surgery – tendon transfer / osteotomy
- Obturator neurectomy
- Longitudinal myelotomy

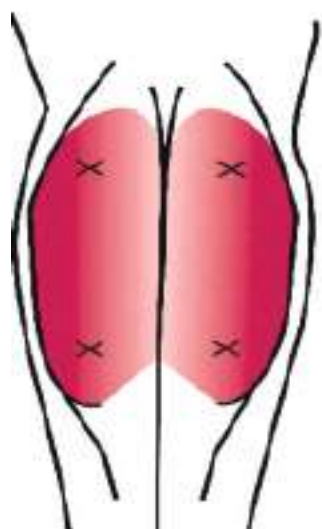


Fig. 8 AFO (Ankle foot orthoses) for improving equinus posture

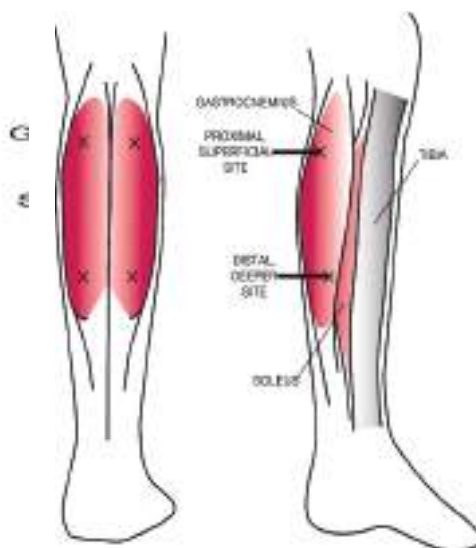


Figure 8 sites calf muscle injection for tendoachilles spasm

8.18 ROLE OF ORTHOPAEDIANS AND NEUROSURGEONS IN THE MANAGEMENT OF SPASTICITY

Role of orthopaedicians

Orthopaedic surgery has a major role in spastic CP. Elongation of achilles tendon on one or both sides and procedures to reduce adduction of hip and flexion of knees greatly improve the function. The various orthopedic surgical procedures are listed below.

Types of CP	Surgical procedures most often performed
Quadriplegic	Hip adductor flexor release, osteotomy Spine fusion
Diplegic	Hamstring-gastrocnemius lengthening Hip adductor-flexor lengthening Derotation osteotomy Rectus femoris transfer
Hemiplegic	Gastrocnemius lengthening Split tibialis anterior & posterior transfer Tibialis posterior lengthening

Role of neurosurgeons

A more promising procedure to spastic CP may well prove to be selective dorsal rhizotomy. In selective dorsal rhizotomy sectioning of selected rootlets (L2-S2) is done. Diplegic child in age 3 to 10 years with no fixed contractures are the suitable candidates for this procedure. Few other neurosurgical procedures are Stereotaxic encephalotomy, Cerebellar stimulation, Cervical rhizotomy, Obturator Neurectomy

8.19 FUTURE SCOPES OF TREATMENT IN CEREBRAL PALSY

The potential for treatment with pluripotent stem cell is based on the hypothesis that intravenous, intrathecal or direct intracerebral injection of stem cells can repair the damaged cells in the brain. This can occur especially when the brain cells and tracts have maximum potential for plasticity. But at present there is no reliable medical evidence to prove the benefit. Further evidences are required to support its use

Nanomedicine offers a new frontier in the development of therapies for prevention and treatment of brain injury resulting in cerebral palsy. But at this time their role in management of CP is proven only in preclinical experimental studies.

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Assessment and Management of Cerebral Visual Impairment

Dr Anitha Balachandran

Additional Professor at Regional Institute of Ophthalmology, Thiruvananthapuram

Key points: The progress in technology and better neonatal care have led to improved survival of children at risk for CVI.

CVI is becoming one of the most common causes of visual impairment in children as in the developed country.

Prevalence of visual impairment in developed countries varies from 10 to 22 cases/10,000 births in children <16 years of age, while it is reported to be around 10/10,000 births in developing countries.

CVI is caused by visual malfunction due to the retrochiasmal and visual association pathway pathology.

Functional vision assessment plays a key role in CVI assessment.

Each child is unique, and management has to be planned based on each child's functional vision.

Managing a child with CVI is always a teamwork

9.1 Clinical Features

The term CVI stands for cerebral visual impairment and is also referred as cortical visual impairment or neurologic visual impairment. The term cerebral is ideal than cortical visual impairment because cortex is seldom involved in seclusion. Neurologic visual impairment includes both cortical visual impairment and cortical blindness. Formerly, it was mentioned as cortical blindness, but blindness can be confusing as these children are not completely blind. In a developing country such as India, because of progress in technology and better neonatal care, CVI is becoming one of the most common causes of visual impairment in children as in the developed country. Prevalence of visual impairment in developed countries varies from 10 to 22 cases/10,000 births in children <16 years of age, while it is reported to be around 10/10,000 births in developing countries. (1) In an African study, 47.7% of children with cerebral palsy were found to have CVI, while in an Indian study, only 28% of cerebral palsy patient found to have CVI. (2,3)

CVI is caused by visual malfunction due to the retrochiasmal and visual association pathway pathology. Injury to retrochiasmal pathways may alter visual acuity, color vision and contrast sensitivity, visual fields, and perception of movements (dyskinetopsia). Shortcomings in higher visual center may affect cognitive functions, main cognitive pathways are the dorsal stream (connecting the occipital cortex, the posterior

parietal lobes, the motor cortex, and the frontal cortex) and the ventral stream (connects the occipital lobes and the temporal lobes). The impairment of dorsal stream alters visual scene processing, coordination of body movements, and focusing in a particular area of visual scene, which can cause optic ataxia (impaired visual guidance of movement), apraxia of gaze (inability to move the eye to target), and limited ability to simultaneously see many items at the same time (Simulatagnosia). These constitute the triad of Balint's syndrome. Ventral stream dysfunction alters identification of people and objects, route finding, and visual memory which can cause prosopagnosia (impaired recognition of faces despite adequate vision) and topographic agnosia (severe difficulty in route findings predominantly in new places). Other visual disabilities include eye movement disorder such as strabismus, nystagmus, unstable fixation, inaccurate fast eye movements, deficit of smooth pursuit movements, and paradoxical eye movements. These children also have hypoaccommodation which may or may not be associated with hyperopia. Apart from visual malfunction, these children may have cerebral palsy leading to delayed motor and speech development. (4)

Causes of CVI:

1. Hypoxic ischemic encephalopathy
2. Hydrocephalous.
3. Malformations and focal brain lesions.
4. Traumatic brain injury.
5. Brain infections- TORCH
6. Neonatal hypoglycaemia.
7. Epilepsy especially infantile spasms.
8. Metabolic/ genetic disorders.

9.2 Assessment of CVI:

Functional visual assessment:

Here an attempt is made to understand how much vision is being used for activities of daily living. In a small child of about 4 months, it would be spontaneous mouth opening on seeing a spoon with food, reflex smiling on seeing large moving objects, staring at a light source etc.

- In infants more than 6 months: Assess the distance of detection of an object.
- Contrast is preferred for detection.
- Colored objects are preferred for detection.
- Time taken to detect.
- How long is it maintained.
- Also assess if there is any difficulty in eye movement.
- Visual acuity can be measured using:
 - Lea paddles, puppet face, mirror test in small children.
 - Lea symbols, symbol chart- pre school children
 - Logmar chart- school going children
- Visual field: confrontation technique, Puppet face, Lea wand
- Contrast sensitivity: Hiding Heidi test

Lea low contrast symbols

Cognitive visual assessment:

Suspect cognitive visual dysfunction:

When a child with normal/ reasonable vision (>6/36 visual acuity) has difficulty in using it.

Inability to recognize family members.

Forgetting routes.

Clinical tests:

- **Lea Puzzle-** tests the ability to analyse the dorsal stream.
Explain the test to the child. Give one shape at a time. Note the manner in which the child holds and manipulates the shape.
Keep all the symbols and ask the child to pick one and place it in the slot which matches the shape of the chosen symbol.
Repeat the test with black and white symbols also.
- **Lea mail box:**
Here the child is given a card and is asked to pass it through a slot which is oriented in different directions.
Dorsal stream- see the way the child grasps- whether he overshoots or under shoots.
Ventral stream- understanding the orientation of the object.
Object sorting test:
Mix up objects of different shapes and colours. Ask the child to pick up the named ones. Here the dorsal stream is being evaluated.
Motion perception
Finger counting when waving. If it is difficult, it is called dyskinetopsia.
- **Pepi test:**
Fix at a central object on a computer screen. Move an interesting object which pops up suddenly from one corner to another. Follow the eye tracking.
Roll a ball- see the eye tracking.
- **Simultagnosia-**
Ask the child to describe all the objects he can see in the room. A child with the problem will not be able to point out the objects.

9.3 Management of CVI:

General principles:

- Each child is unique.
- Understand the baseline capacity of the child and start working from there.
- Prepare the child before a session- activate the attention and energy.
- Posture is very important.
- Radio Language- clear and unhurried speech using well spaced words helps them interpret and remember the visual stimulation better.
- Look at the looking behaviour- they take time to look.
- Use simple objects which are used daily. Present them singly against a simple background.
- Multisensory stimulation is the best. Combine vision with sound and touch.

Methods to infuse vision into daily activities:

- Ongoing meaningful experience.
- Avoid bright focused light source.
- Uniform illumination of the room.
- Avoid clutter in the room.
- Encourage to use the other senses- hearing/touch/smell.
- Teach only one thing at a time.
- Keep repeating in a consistent way by the same caretaker whenever possible.

Connecting vision with other therapies:

The physiotherapist should be made aware of lower visual field defects, optic ataxia, poor balance due to poor vision.

Speech- The ability to see lip movements and expressions can influence speech.

Interdisciplinary care is of prime importance- 60% children with CVI have delay in one or more areas of development.

Managing a child with CVI is always a team work and we aim to train the child to use his vision and equip him to perform his daily activities.

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3

P A R T - C

CDC Model Group Therapy in ASD

The ASD group therapy is organized as 3 sessions. Three group of professionals have a vital role in planning group therapy for ASD.

Session A. Developmental therapy focusing on general aspects of group therapy

Session B. Speech therapist focusing on social communication

Session C. Occupational therapist focusing on sensory intergration

The ASD group therapy is organized as 3 sessions. Three group of professionals have a vital role in planning group therapy for ASD.

Session A

Developmental therapy focusing on general aspects of group therapy

Prasanna GS

Developmental Therapist, CDC,

Key points: Group therapy (GT) offers a structured and supportive environment where children can work on various social, communication and emotional skills

In a G T session, there are small groups consisting of 2or more kids, who will be directed by a trained therapist.

Group sessions can focus on improving verbal and nonverbal communication skills, including understanding and using social cues.

Children with autism often benefit from routines and predictability which is followed in sessions

Including parents in the therapeutic practices can enhance the effectiveness of group therapy. Educating parents about strategies used in therapy allows for consistent support at home and also during the group sessions.

In G, the collaboration between therapists, parents, and educators ensures a holistic and integrated intervention approach.

When parents receive consistent information and support in a group setting, they are more likely to implement behavioral strategies consistently at home.

Group interventions may provide opportunities for parents to connect with professionals, therapists, and experts in the field of autism. This networking can lead to additional support and resources for their family.

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by persistent challenges in social communication and interaction, as well as restricted and repetitive behaviours. The term "spectrum" reflects the wide variation in challenges and strengths possessed by each person with autism.

Why group intervention is more effective than individual therapy

The main concern with an autistic child is his deficits in social interaction. Group therapy provides a natural setting for children with autism to practice and develop social skills. Interacting with peers who have similar challenges allows them to learn from each other's experiences, observe social cues, and practice communication skills in a supportive environment.

In a group setting, children can observe and learn from each other's behaviour. They can witness appropriate social interactions and communication styles, which they may then mimic or learn from. This **modelling** can be a powerful tool for children with autism who often learn better through observation.

Children with autism may feel more motivated to participate in therapy when they are surrounded by peers with whom they can relate. Group therapy sessions often incorporate activities and games that are engaging and enjoyable for children, which can further enhance their motivation to participate and learn.

In a group setting, children receive feedback not only from the therapist but also from their peers. This multisource feedback can help them gain insight into their own behaviour and learn from others' perspectives. Additionally, the supportive atmosphere of the group can provide children with encouragement and validation as they work towards their therapeutic goals.

Role of a Developmental Pediatrician/Pediatrician/Medical Practitioner

Medical practitioners play a critical role in the multidisciplinary approach to autism diagnosis, treatment, and support, working collaboratively with other professionals and caregivers to optimize outcomes for individuals with autism and their families.

Medical practitioners, such as paediatricians, child psychiatrists, and developmental paediatricians, are often involved in the initial diagnosis of autism. They assess developmental milestones, social communication skills, behaviour patterns, and use standardized assessment tools to diagnose ASD. Medical practitioners conduct medical evaluations to rule out other conditions that may present with similar symptoms to autism or may co-occur with autism. This can include hearing testing, neurological evaluations, metabolic screenings, and other medical assessments to identify any underlying medical issues that may require treatment. Medical practitioners guide children with autism to specialists for further evaluation and management of specific needs. This may include referrals to speech therapists, occupational therapists, behavioral therapists, psychologists, and other professionals who specialize in autism and related conditions. Medical practitioners collaborate with other professionals and caregivers to develop comprehensive treatment plans tailored to the individual child's needs. This may include recommendations for behavioral interventions, educational supports, medication management (if applicable), and other therapies aimed at addressing the core symptoms of autism and associated challenges. In some cases, medical practitioners may need to prescribe medications to manage symptoms associated with autism, such as anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), or sleep disturbances. Medical practitioners provide guidance, information, and support to families of children with autism. They help families understand the diagnosis, access resources and services, navigate healthcare systems, and address any questions or concerns they may have about their child's development and well-being.

Need for diagnosis

A formal diagnosis from a medical practitioner or a clinical psychologist, help families and other professionals to understand why they may experience certain challenges or differences in social communication, behavior, and sensory processing. A formal diagnosis allows for the implementation of targeted interventions and strategies tailored to the individual's specific strengths and challenges.

Why parents should get trained before group intervention

Children spend most of their time with their parents. Instilling parents about the unique condition of their child, and equipping them with the knowledge and skills will help in implementing the intervention programmes in an effective way. Parent training helps parents learn how to generalize intervention

techniques from therapy sessions to daily routines and activities at home, increasing the likelihood of skill retention and transfer. Parent training goes beyond addressing immediate concerns; it equips parents with lifelong skills to support their child's development and navigate various stages of their life. Effective autism intervention requires collaboration between professionals and parents. Parent training fosters collaboration by involving parents as active partners in the intervention process, leading to better coordination and continuity of care.

Benefits of group therapy for children with ASD

Group therapy can be a valuable intervention for children with ASD. It offers a structured and supportive environment where children can work on various social, communication and emotional skills

Group therapy is mainly focused on teaching social and communication skills in children with autism. These groups are small groups consisting of 2 or more kids, who will be directed by a trained therapist. More over;

- In a social group, children learn how to behave in a social situation.
- They can learn about the importance of friendship and companionship
- Improve their social participation.
- Help in the reduction of anxiety symptoms and depression to an extent.
- Group therapy help children to follow the rules of a game and develop their cooperative play skills
- This encourages children to communicate well.
- Learning of social rules such as greeting others, understanding humour and understanding emotions of others.
- Help them to interpret nonverbal and verbal communication cues.
- Prepare them to follow the rules and thus help them to enrol in a social system.
- Help to reduce behavioural deviations to an extent.
- The development of social skills can help them to be successful in academic and vocational settings.
- Develop their empathy, helping and sharing skills.
- Increase participation in recreational activities.

CDC model early detection and intervention for children with ASD

Early screening and identification

Routine developmental monitoring and screening for ASD is being conducted during newborn follow up programmes and also for those children referred from the community. Different developmental assessment tools like TDSC, LEST, DDST and TABC etc are used to assess the developmental status of the child. Some concerns will arise during the process of evaluation and it eventually mandates the need for a detailed evaluation. Early identification allows for timely intervention and support

Comprehensive assessment

If concerns are identified, a comprehensive developmental evaluation as per recommendation can be carried out. Tools like INDT-ASD (Indian diagnostic tool for autism) for the age group 2-9 yrs or ISAA (Indian scale for assessment of autism) for the age group 3 – 22 yrs can be used for the purpose.

This assessment involve professionals with expertise in ASD, including developmental paediatricians, developmental therapist, child psychologists, speech-language pathologists, and Occupational therapists.

Individualized treatment plans

- Considering the developmental need of the child an intervention plan to be prepared, which need to consider the needs of the parents. For eg; the need of the parent usually will be to make the child speak just like other neurotypicals, but the need of the child is to communicate and to develop minimum social skills. Prepare the general goals and the specific goals as the short term

goals in order to achieve developmental progression

- Effective interventions will be provided through group therapy settings which include developmental therapy, behavioral therapy, speech therapy, occupational therapy, and social skill training which is being provided as Group therapy initially and then as individual therapy. Because the major need of a child with ASD is to have development in his social communication skills rather than to have betterment in his cognitive or vocabulary skills. Engaging a child in a group setting creates a ground for further skill acquisition.

Family involvement

Families play a crucial role in the development and well-being of children with ASD. Making the parents aware about the current situation or status of the child is crucial in further intervention programs. The need for involving in therapy sessions, how to manage the behavioural issues, how to impart different skills among their own wards etc has to be taught prior to engaging them in group therapy sessions. All family members should get the opportunity to understand the child and to implement the strategies at home. Training programmes for the parents should be conducted for the same. Well being of the parents are also much crucial in the implementation of the programmes. The SWOC analysis may help to understand the parents better and the concerns of parents are also need to be addressed.

Early start of intervention

The earlier intervention begins, the more likely it is to be effective. Early intervention help address developmental delays, improve communication and social skills, and enhance overall functioning and better integration into the society.

Collaborate among professionals

A multidisciplinary approach involving collaboration among various professionals, such as developmental paediatricians, developmental therapists, psychologists, speech therapist, occupational therapists, and healthcare providers, is provided as part of comprehensive care. Proper diagnostic evaluation and other management approaches from the part of Developmental paediatrician enables the para professionals to implement individual specific intervention for children with ASD.

Role of professionals in group therapy

As it is a multidisciplinary program different therapists in CDC/DEIC can play their own role in the session.

Developmental therapist (DT): A DT will be the person who can evaluate the overall developmental assessment and have to play a vital role in the group session. The major skill training viz; the social skill training should be implemented by them and other professionals can assist it. In areas where DTs are not available, other professionals can have training for that and then then can do instead.

Psychologist: the strategies which are implemented through the approaches of behaviour therapy can be supervised by the psychologist. They do behavioural assessment of children recruited in the sessions

Speech therapist (ST): Social communication modalities like visual schedules, Augmentative and Alternative Communication (AACs) etc are being practised under the guidance of speech therapist. They do communication and language development assessment of children with ASD participating in the group sessions.

Occupational therapist (OT): An OT has lot more to do in a group therapy session for ASD. They do sensory integration assessment and provides sensory diet during the sessions. In places where OT is not available a Physiotherapist can serve as an OT

A special educator can also participate in the whole session in order to provide assistance and guidance for parents to implement the strategies in a much effective way.

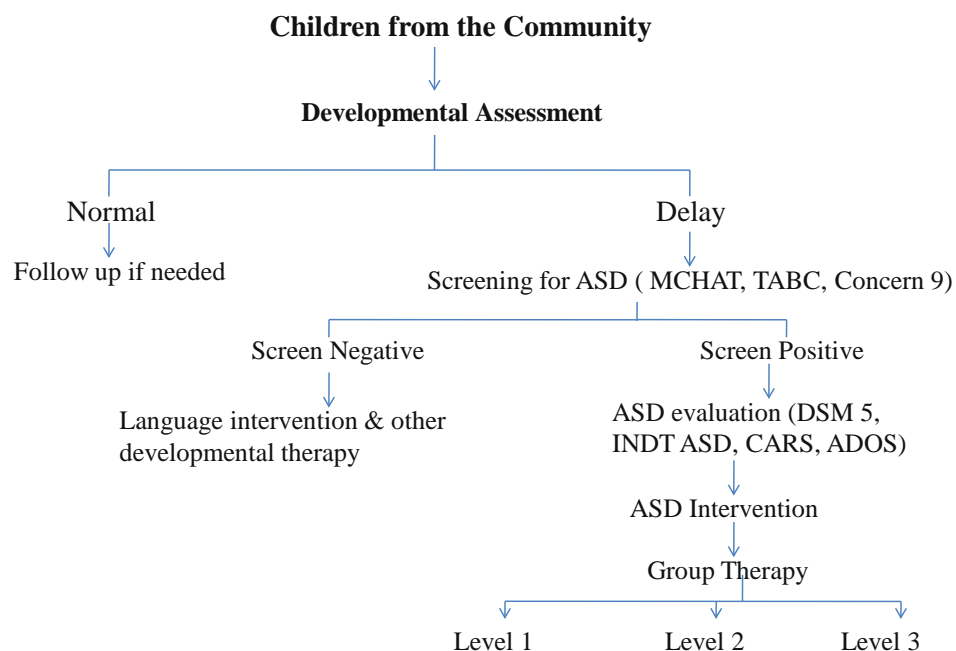
Continuous monitoring and adjustments:

Progress should be regularly monitored, and intervention plans should be adjusted based on the child's evolving needs. Regular re assessment after 6 months of intervention helps to understand the progress of the child and to make the parent convinced.

Inclusion in natural environments

Early intervention should occur in a variety of settings, including home, community, and educational settings. Skills that are being trained in institution setting need to be practiced in natural environments which help to generalize the skills and promote social communication.

The flow chart of CDC ASD clinic



CDC model group intervention therapy- the protocol

Child centered, developmentally sequenced behaviour based intervention is being provided

Comprised of around 8-10 children, approximately with similar social, emotional and behaviour skills , are grouped in 3 levels

Generally employed with children of age 2-6 years. But older children can also be included to get them trained in advanced social skills

Provide a way for them to learn and connect with other people, in a format that they understand

In group sessions, Intervention is being provided to promote in the areas of social skill development, communication skill development, play skill development, cognitive and perceptual skill development, and self help skill development

In this parent mediated child centred developmental intervention programme, Mother/ caretaker will accompany the child throughout the session in level 1 and 2. Interaction of children as pairs will be facilitating in Level 3.

The activities are implemented by them with the **supervision** of the therapist.

Depending upon the feasibility sessions can be conducted **daily/twice a week/weekly or monthly**

Sessions typically lasts for 2 hrs

Number of sessions/ child depends on rate of attainment of skills.

Principles of behaviour therapy viz; Positive reinforcement – Rewards/ social reinforcements, Negative reinforcement, Prompting-(Physical/verbal), Prompting paired with reward, Punishment, Time out, extinction etc are being practiced as well.

CDC model group intervention therapy- Pre-intervention assessment

Before starting the intervention programme each child will undergo a detailed developmental and condition specific assessment procedure. The following test are being used for the purpose

- Childhood autism rating scale (Optional)
- Autism treatment evaluation checklist (Mandatory)
- Vineland social maturity scale(mandatory)
- Carolina curriculum for children with special needs(optional)
- Receptive expressive emergent language scale(mandatory)
- Short sensory profile(mandatory)

CDC model group intervention therapy- the procedure

1. Grouping of children: there are 3 levels of group intervention for ASD kid in CDC viz; Level 1 Level 2 and Level 3. Children will be grouped according to the age, Linguistic Skill of the child, presence of prerequisite skills, and Social- emotional / sensory aspects of the child.

Level	Profile of child	Age
Level 1	Newly diagnosed With severe symptom manifestation More comorbidities like ADHD, ID etc.	Below 6 years
Level 2	Children with mild – moderate symptoms Child possesses minimal attention skills, minimum sitting tolerance	Below 6 yrs
Level 3	Children with verbal fluency, better attention/concentration and instruction understanding.	Below 6 years

2. Level 1 is the basic level group, Level 2 is the Intermediate level and level 3 is the advanced group of children with ASD.

3. The schedule: A pre-assigned schedule for the smooth implementation of the program is established.

Parent training program

Just before initiating the group session all parents of children who will be participating in the group session will be provided with a detailed training regarding the condition of a child with ASD, the symptomatic manifestations, the developmental deviations, the savant abilities they possess, the modifications need to do in the implementation of skill training. They will be provided with greater awareness on principles of behaviour therapy, different techniques that should be used for e.g. prompting, rewards, prompt fading, differential reinforcements etc...). The concerns of the parents will be addressed and make them ready to be the part of the group intervention program at the centre and to act as an individual therapist at home also.

Parents has to practice intervention at home for a minimum of 5 hours per day and it can be 5 days in a week. Training will be more fruitful if they have a prepared timetable schedule, which includes all the routines of their child along with training session slots.

It is advised to provide the child with a minimum of 2-3 hrs of play school time and 1hr outdoor time and 1 our outdoor activity time. This will help the child to expand his social world regularly, and to adjust and prepare with different social situations and demands.

One of the parent will assist the child during the group therapy sessions, and will act as the therapist for their wards. Onsite training and modifications will be done by the therapist during the sessions as and when required, this will help the parents to do better in home training

ASD group therapy unit

Physical infrastucrure

The room selecting for implementing the group activity should be safe and secure for ASD children and should be large enough to accommodate the parents accompanying and the therapists and other staffs. Total area should be a minimum of 20x20ft, well illuminated, ventilated clean surroundings. The unit should not be overcrowded with furnitures and it should be a less crowded, less congested room.

Other amenities needed:

- Table -1
- Chair-3- 4 nos
- Mat-12-15 nos
- Shelf/Cupboard-2 -3 nos equipped with TLM, mats,torch,
- Foot step- 1 no
- Mirror-1 no
- Marker board (to be hanged on wall)- 1
- Display board- 1 no
- Audio player- 1

Stationary (A 4 size paper, pen, file, stapler, scissor, gum, punch, ink Marker pens etc..)

1. Skill assessment and recording/Pre intervention status recording
2. Parent training program prompting and rewards and other reinforcement techniques
 - A notebook mentioning the task allotment, progress monitoring and other remarks should be maintained by the parent.
3. Recruiting in group therapy sessions
 - 2 hours per day for a period of 6 months
 - (Weekly once/twice as per convenience)
 - Task allotment for the subsequent week

Regular monitoring of progress by revaluation every 6months

Post intervention status recording

Materials for social commnicaion training

• Peg board with pegs	• Baskets
• Beads with thread	• Vegetable models
• Puzzles	• Fruits models
• Bubble wand	• Puzzles of fruits vegetables
• Nesting cups	• Shape sorter
• Stacking toys	• Animals, vehicles
• Dolls	• Shape puzzle
• Balls of differentsizes	• Doctor set

<ul style="list-style-type: none"> • Kitchen set • Mats – 8 nos 	<ul style="list-style-type: none"> • Xylophone • Coloured stone
<ul style="list-style-type: none"> • Picture books/cards (single picture) 	<ul style="list-style-type: none"> • Crayons
<ul style="list-style-type: none"> • Pair of animal toys 	<ul style="list-style-type: none"> • ADL activity card
<ul style="list-style-type: none"> • Mirror 	<ul style="list-style-type: none"> • Beads & bottles
<ul style="list-style-type: none"> • Stacking cup 	<ul style="list-style-type: none"> • Drums
<ul style="list-style-type: none"> • Beads with different shapes 	<ul style="list-style-type: none"> • Mask
<ul style="list-style-type: none"> • Puppets 	<ul style="list-style-type: none"> • Ball with tray
<ul style="list-style-type: none"> • Stacking rings 	<ul style="list-style-type: none"> • Socket

Materials for sensory motor training

<ul style="list-style-type: none"> • Sensory/ tactile texture floor mats 	<ul style="list-style-type: none"> • Therapy mat
<ul style="list-style-type: none"> • Rattle toy for sensorymotor 	<ul style="list-style-type: none"> • Thera-putty
<ul style="list-style-type: none"> • Brush and touch stimulation set 	<ul style="list-style-type: none"> • Balance beam
<ul style="list-style-type: none"> • Therapy ball 	<ul style="list-style-type: none"> • small balls- 100nos
<ul style="list-style-type: none"> • Vestibular or swing system 	<ul style="list-style-type: none"> • Play dough
<ul style="list-style-type: none"> • Ball pool 	<ul style="list-style-type: none"> • Mirror
<ul style="list-style-type: none"> • Trampoline 	<ul style="list-style-type: none"> • Stair
<ul style="list-style-type: none"> • Scooter board 	<ul style="list-style-type: none"> • Baby chairs
<ul style="list-style-type: none"> • Shape sorter 	<ul style="list-style-type: none"> • Shape puzzle
<ul style="list-style-type: none"> • Put together set apart toy 	<ul style="list-style-type: none"> • Stacking cup
<ul style="list-style-type: none"> • Beads with different shapes 	<ul style="list-style-type: none"> • Pull toys
<ul style="list-style-type: none"> • Bean bag 	<ul style="list-style-type: none"> • Rocking toys

The schedule of group programme

1. Warming up time -10 min
2. Floor time activities -30 min
3. Break time/ ADL time -15 min
4. Social play time -15 min
5. Communication time -10 min
6. Sensory activity time -15 min
7. Unorganized play -15 min
8. Parental guidance -10 min

1. Warm up time

Group therapy commence with the warm up session which will be welcomed by the therapists along with the parents into the therapy unit. They will be welcomed with the greeting gestures and they have to do it back which will be prompted by the parent. Children will be prompted to greet themselves with their names. After entering the unit, they will have to stand in a row for the prayer session. During the session the children have to stand still with their hands folded just like doing the prayer while the therapist and parents singing the prayer song.

After prayer, physical imitation session will be there. Parents should prompt their wards to do the activity (eg; exercises like hands up-side-down, turn right die- turn left side- clap hands etc...) all the actions need to

be prompted both physically and verbally by the parents while it is being demonstrated by the therapists. Physical imitation is repeated in between the schedules to maintain the social modeling skills.

Followed with prayer is attendance call. Each child will be called by their name and they have to raise their hands to note their presence in the unit. This action is to be prompted by the parent by raising his hands when his name is being called.

Group action play will be carried out then. Children will hold their hands together, will be prompted by the parent who is standing behind them and will follow the rule of doing the tasks (Eg; the song, "Ring-a-ring-a-roses.....") It allows everyone to take part in the fun, which is good for developing social skills. It enhances motor skills includes entire body required to be able to walk, jump etc. and it is a form of social imitation.

2. Floor time activities

- Floor time is conducted by using the principles of **behaviour therapy**.



- Includes activities involving Teaching Learning Material (TLM) that develops and improves eye-hand coordination, fine motor skills, communication skills, cognition, attention/concentration, reduce hyperactivity, object perception, social skills etc.
- TLM are presented according to the **child's age and level** (level 1, level 2, level 3)
- Different TLMs like building blocks, stackable toys, sorting toys, large stringing beads, puzzles, painting, flash cards, social rule cards, sensory materials etc. are used according to the developmental level and need of each child.
- The main objective of the floor time is to improve sitting tolerance, improve attending skills, to train them to obey the social rules, to follow the rules, to train turn taking and waiting skills and to understand the concept of start-end or first-then.
- Activities are being taught using physical and verbal prompts paired with rewards. Prompt fading and reward frequency reduction will practice accordingly

Procedure during floor time

After the group social play children will be guided to their assigned spaces in the unit. They need to collect the floor mat from the shelf and to be spread over the floor to sit. The whole activity is being prompted by the parent and both the child and the parent sit on the mat and will wait for their name call.

The therapist then call each child by his/her name and the parent prompts the child to get up from the mat and approaches the therapist to receive the TLM. The selection of the TLM is based on the developmental need of the child. In order to get the TLM the child has to "ask" for it either verbally, or through the gesture. Parent prompts the child to show the gesture and to receive the TLM. After receiving it, the child return to his place and sit with the TLM. With the physical, verbal and gestural prompting of the parent, child will acquire the skills. Parents practices prompt fading as the session progresses. Minimum of 3 trials will be practiced with each TLM and they have to

return it back to receive another TLM.



3. Break time

When the assigned duration for the floor time is over, the therapist announces break time. The break time or the ADL time is to practice the daily living skills. Here, children are taught to open and close the snack box independently and to feed by themselves and to share the snacks. After that they will be prompted to teach the steps of hand washing.



4. Social play time

Different interactive cooperative play activities will be practiced in social play time. Passing the ball, catch and roll the ball, Role play with doll are some of the activities that can be done.



5. Communication time

Verbal imitation (using pictures)

One word imitation Noun--- Elephant/ flower/ cat

Two word imitation Noun & verb ----/ boy/ sleeping

Three word imitation Noun , Verb & adjective--- /Boy/ eating/chapathi

Procedure

Children along with parents will be sitting on the floor. The therapist shows a picture card and tell the name

of the picture aloud. The parent repeats the word and prompts the child to recite the same. The therapist repeats the activity with more picture cards. One word and the combination of words are being practiced likewise.

1. Sensory diet time

- Walking over balance beam
- Jumping from a chair to the floor
- Trampoline jumping
- Jumping into a ball pool(tactile stimulation)
- Zig Zag walking
- Circle jumping

2. FREEPLAY TIME

The session will be ended by providing a free play time for children. They are allowed to select toys of their own choice and to do unorganized play with the guidance of the parent and the supervision of the therapist. Skills like social interaction, negotiations, sharing, waiting, obeying rules, turn taking etc are being monitored and promoted in this session. Activities include:

- Bubble play
- Tricycle riding
- Rocking horse activity
- Bean bag jumping
- Ball pool play
- Trampoline jumping
- Balance beam walking
- Zig zag walking
- Obstacle course

Parent guidance session



At the end of the session each parent will be revised regarding the tasks assigned for the previous week, its progress, hurdles if any and remotivated the parent to practice the home training in a better way. New strategies will be noted in the note book which is kept by parent.

Social skill activities in group sessions

Social stories: simple social stories with pictures and short sentences that illustrate various social situations. Stories can be read with the child and appropriate responses can be discussed.

Role playing: allows children to practice social situations in a safe and controlled environment. Common scenarios such as greetings, taking turns, and sharing etc, can be acted out.

Emotion cards: different emotions can be expressed through facial expressions and body languages and by using emotional cards. This helps kids recognize and understand various emotions in themselves and others

Interactive games: simple card games that require turn-taking and sharing can be effective in teaching social skills. Games like "Simon Says" or "Red Light, Green Light" are also great for practicing listening and following instructions

Puppet activity: use puppets to act out social situations. This can make it more engaging and less intimidating for the child. Encourage the child to interact with the puppets and express themselves.

Visual schedules: visual schedules to help children understand the sequence of social activities. This can reduce anxiety and make transitions between activities smoother

Group activities: engage in group activities such as art projects or simple group games(older children). This can help children learn to work together and share in a supportive environment

Video modelling: short videos can be used to demonstrate appropriate social behaviors. This visual aid can be particularly effective for children with autism who often learn well through visual cues

Social skill stories: create personalized social stories based on the child's experiences. This can help them navigate specific social situations they may encounter regularly. To tailor these activities to the individual needs and preferences of the child, it's essential to be patient, provide positive reinforcement, and celebrate small successes. Additionally, involving parents and caregivers in these activities can help reinforce social skill development in various settings.

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The ASD group therapy is organized as 3 sessions. Three group of professionals have a vital role in planning group therapy for ASD.

Session B

Sensory integration therapy in ASD

Ms Bismi David

Occupational Therapist, CDC

Key Points: Sensory processing disorder is a condition in which a person has difficulty organizing and integrating sensory information for use.

Sensory dysfunctions can be over-responsive, under-responsive or sensory seeking.

Rates of sensory processing dysfunction may be as high as 90% in individuals with ASD. There comes the role of sensory groups.

The goal of sensory based intervention is to improve the client's ability to process sensory information to increase function.

A carefully designed group of sensory activities called sensory diet, helps keep the nervous system calm, organized and focused.

Sensory interventions works directly on a child's nervous system functioning, capitalizing on plasticity within his or her nervous system, and resulting in the development of adaptive behaviours and increased ability to learn.

Studies support the use of active participation in multi-sensory activities for at least 60 minutes per week to improve occupational performance, autism symptoms, and behaviours.

Autism spectrum disorder (ASD) is an umbrella term to describe a group of complex impairments in social behaviors, communication skills, and restrictive repetitive patterns of behavior, interests, and activities [1]. Ayres (1972) defines sensory integration as "the neurological process that organizes sensation from one's own body and from the environment and makes it possible to use the body effectively within the environment". Sensory processing disorder is a condition in which a person has difficulty organizing and integrating sensory information for use. Rates of sensory processing dysfunction may be as high as 90% in individuals with Autism Spectrum Disorder [2].

Sensory dysfunction:

Sensory modulation issues can be under responsive, over responsive or sensory seeking. Sensory over responsivity is defined as responses to sensation that are quicker in onset, and stronger in intensity that would be expected for most children that may met behaviourally by withdrawal and avoidance of the sensations. Sensory under responsivity is defined as disregard or passive response to sensory stimuli, responses are less intense or slower on onset than those typically expected. The individual find it difficult

to get engaged feels lateritic and self-absorbed. Sensory seeking/craving is defined as an intense insatiable desire for sensory input, available input appears to be less than what is needed for the individual to feel satiated individuals energetically engage in actions geared to adding more intense sensations, constantly moving, touching, watching moving objects, seeking loud sound or unusual olfactory or gustatory experiences.

Tactile:

- o Bothered by tactile aspects of a day living activities
- o Bothered by Specific types of clothing
- o Does not respond to pain such as bumping falling
- o Engages in pinching, biting and scratching

Auditory:

- o Distressed by environmental noises (vacuum cleaner, blender, toilet flush)
- o Does not respond when name is called
- o Make noises for the sake of making noise

Visual:

- o Bothered by Visually cluttered environment.
- o Does not notice activity in a busy environment
- o Excessive preference for fast changing images on TV

Vestibular and Proprioception:

- o Avoids climbing activities
- o May have a weak grasp
- o Fidgets, wiggling and restless throughout day

Olfaction:

- o Bothered by food smells as well as smell of household of hygiene products
- o Does not seek food when hungry
- o Smells people/objects during play

Gustatory:

- o Avoids mixed consistencies
- o Able to tolerate spicy foods more than cultural norm
- o Licking, Sucking and chewing non-food items

Tactile activities:

Skin has numerous receptors that perceive touching, pressure, texture, heat, pain and movement. A signal is transmitted to the related parts of the brain when tactile receptors are stimulated with touch, heat or vibration. Sense of touch is important for neural organization and praxis development [3].

Brushing therapy: Brushing therapy was created by Patricia Wilbarger, an occupational therapist and clinical psychologist. Brushing therapy is often a part of a sensory group. The co therapist (mother) is the one who will be administering the technique.

- The first step involves using a soft, plastic, sensory brush or therapressure Brush which is run over the child's skin, using very firm pressure; it is like a deep pressure massage. Brushing starts at the arms and works down to the feet. The face, chest, and stomach area are never brushed because these are very sensitive areas. Brushing these areas may cause adverse reactions including vomiting.

- After the brushing therapy, therapists may also prescribe gentle joint compressions to the shoulders, elbows, wrists, fingers, hips, knees/ankles for a count of 10.



2. Neutral warmth:

Neutral warmth acts through stimulating the thermo receptors and activating parasympathetic responses. It is one of the best calming techniques and the most commonly used methods to inhibit postural tone and muscle activity for autistic children.

Materials needed for neutral warmth:

- Bed sheet/ blanket
- Therapy ball/ pillow

Procedure: Spread the bed sheet or blanket on the floor or the bed, and have the child lie down on one corner of the blanket in the supine position and roll the blanket tightly around him/ her (should cover from shoulder to feet).

Precautions

- Should not wrap the blanket tightly around the neck of the child
- The child should be able to breathe and speak comfortably
- Pressure should be moderate, and should not cause discomfort to the child
- Do not apply pressure over the chest, abdomen, and genitals.



Recent studies suggests that there is significant effectiveness of Wilbarger protocol and neutral warmth for treating children with sensory defensiveness and aggressive behavior [4].

3. Ball pit activities:

Ball pits are a fantastic toy for stimulating sensory development and processing in autistic children. They are often used in therapy contexts, but make the perfect in sensory groups to help your children feel safe and to have fun.

Potential advantages:

- Improves sensory processing skills
- Improves fine motor skills
- Increases focus and attention
- Improves gross motor skills (crawl, reach).
- Balance and coordination



4. Play dough activities:

The intervention of play dough activity can improve the cognitive development of autistic children [5].

Benefits:

- Fine motor skills
- Tactile sensory challenges
- Bilateral coordination
- Sensory development
- Self-regulation tool
- Eye-hand coordination



5. Sensory mat activities:

Sensory mats are great toys for children with Autism. These small mats utilize a different texture for each piece. Children can then use their hands or feet to feel and play with the different types of textures.

Benefits:

- Sensory stimulation
- Gross motor stimulation
- Strengthen the muscles of the feet
- Provide prevention from flat feet
- Improve proprioception, balance and posture



6. Sand activities:

Sand tray play is a great way for children with disability, autism or other additional needs to have a rich sensory experience, especially if they can't get outside or into natural environments.

Requirements:

- A wooden or plastic tray with a small lip on the sides
- Clean sand or dry rice
- A selection of small objects like toys, animal figurines, cars, pebbles, small containers, leaves or coloured blocks
- A towel for dusting sand off after the activity

How to do sand play

- Put the sand or rice in the tray.
- Let the children explore at their own pace. They might want to trace lines or letters through the sand, make patterns or slowly tip sand from one hand to another.
- Give the children some objects to use for imaginative play in the sand tray, like pebbles, toys, animal figurines and so on.
- Try using different objects each time you play.

Benefits:

- The tactile experience of sand can be especially beneficial for children with autism, as it can provide a calming and soothing sensation.
- Many children with autism may seek out tactile stimulation to regulate their sensory systems, and sand's rough and grainy texture can provide a satisfying sensory experience for them [6]



7. Massages:

Sensory massages help to normalize the Sense of touch in children with ASD, thus the symptoms of autism would improve. Studies suggest that massage decreased the severity of all aspects of autism [7].



Vestibular Activities:

As humans, we move all day long. Therapists use movement and play based tasks with sensory tools like obstacle courses, sensory swings, scooter boards, and slides to develop coordination and motor planning in daily activities. The vestibular stimulation received from spinning is intense and shouldn't be utilized for more than 10 minutes.

1. Swinging:

Sensory swings can be used to add vestibular movement in various directions, speeds, and motions.

Types of swings: Platform swing, bolster swing and tyre swing

Types of movements: Prone swinging, seated swinging, standing swinging, linear movements, vertical movements, rotatory movements and angular movements.



- For children with low arousal (under responsive) in the vestibular system, the therapist would use fast, irregular and rotational movement, as these tend to be alerting.
- For children with high arousal (over responsive) in the vestibular system, the therapist would use slow, linear and rhythmical movement as such movements tend to be calming.

- Children with gravitational insecurity requires increased vertical movement and gradually moving the head and body in varied planes of space and against gravity during playful activities.
- The therapist might encourage the child to practise falling on to soft pillows and mats. Proprioception can also be used to help the child modulate the fear response to movement.

2. Therapy ball exercises:

Therapy balls are used by Occupational Therapists for balance and coordination training, strengthening, gross motor and proprioceptive activities.

Ball Rolling:

Have your child lay on their stomach on the floor with their head facing to one side. Then place the ball on their back and provide some pressure on the ball as you roll the ball over your child's body. Providing deep pressure can help calm your child's body down and improve regulation.



Bouncing:

Sitting: Gently bouncing a sitting child on the therapy ball offers increased vestibular input. In the same sitting position if the therapy ball is rocked front and back, it enhances the balance and postural control of the child while providing vestibular input. Slow bouncing or slow rocking on the therapy ball for a period (specific to each child) brings about a calming effect on the child. On the other hand, fast bouncing or rocking on the therapy ball brings about alertness in a child.



Prone lying position: Here the child lies on his tummy on the therapy ball, wheelbarrow walks out using his hands and reaches for objects in front of him. It also helps the child to focus on a task for a period of time, thus working on their endurance level. As they bear their own weight through their arms and shoulders, it increases the strength and stability at the shoulder girdle which is very important for developing their fine motor skills like writing.



Trampoline:

A trampoline is a device consisting of a piece of taut, strong fabric stretched between a steel frames often using many coiled springs.

1. Jumping and crashing on the trampoline
2. Jumping and locating visual targets around the room
3. Musical statues on the trampoline (having to stop jumping/ balancing and keep balanced whilst music is stopped)
4. Rhythmic bouncing/jumping with singing



Scooter board

The Scooter board is an ideal tool in vestibulo proprioceptive therapy sessions. Make the child to prone on scooter board and do activities like sorting, puzzle and blocks.



Balance board:

Balance board is a device used for balance training

- Getting children to catch small beanbags or balls while balancing on the board
- Passing beanbags or other objects between hands while balancing
- Doing clapping games or popping bubbles while balancing.

**Balance beam:**

It is a long, narrow, horizontal wooden beam.

- Forward walking
- Backward walking
- Sorting activities can be done.
- Enables kids to be challenged while improving balance and coordination
- Kids improve vestibular balance, movement coordination, and concentration while understanding their body's centre of gravity
- The balance beam also helps to improve self-confidence, learning stability and sense of reaction.

**Foam wedges:**

- Foam wedges are used for crawling up and down or walking up or down.
- This climbing & crawling foam to help your child develop hand-eye coordination and motor skills.

**Motor planning activities:**

Motor planning is part of a group of skills that help us move our body the way we want to. Motor planning refers to the ability to conceive, plan, and carry out a skilled, non-habitual motor act in the correct sequence from beginning to end [8].

As you design your obstacle course, keep in mind the ages, abilities, and number of children involved as well as the space you have. Make the obstacle course simple at first and change the stations as they're mastered.

Here are a few ideas to get you started on building an indoor obstacle course for your kids:

1. Crawl under or over a row of chairs.
2. Crawl under a string stretched between two chair legs.
3. Walk on a balance board.

4. Throw a beanbag into a laundry basket
5. Run while balancing a beanbag on your head.
6. Do a ring toss.
7. Ride a tricycle along a predetermined route.
8. Do a handstand.



Precautions for Vestibular Sensory Input

- Vestibular input is extremely powerful. Negative reactions to sensations may not be apparent for several hours following input.
- The vestibular stimulation received from spinning is intense and shouldn't be utilized for more than 10 minutes.
- Another important consideration is that a small amount of vestibular input goes a long way (8 hours).
- Sensory overload presents with pupil dilation, sweaty palms, changes in respiration, and disorientation.
- Use caution with essential oils and scents in general with children. Not all scents are safe for kids.

Proprioceptive activities:

The proprioceptive system is located in our muscles and joints. It provides us with a sense of body awareness and detects/controls force and pressure. The proprioceptive system also has an important regulatory role in sensory processing as proprioceptive input can assist in controlling responses to sensory stimuli [9].

- Weight bearing activities e.g. crawling, push-ups
- Resistance activities e.g. pushing/pulling
- Heavy lifting e.g. carrying books
- Cardiovascular activities e.g. Running, jumping on a trampoline
- Oral activities e.g. chewing, blowing bubbles
- Deep pressure e.g. tight hugs

Benefits:

Proprioceptive input can be very calming for those who are easily overwhelmed by sensory stimulation.

Proprioceptive input can be alerting for those who need increased sensory stimulation to facilitate attention and learning.



Auditory activities

The sound information from each ear goes to auditory cortex of opposite hemisphere. The relation between the auditory system and vagus nerve is important in sensory modulation [10]. Auditory processing activities are a tool for many auditory processing disorders or issues. Suggested activities are: Whistling, snapping fingers, hammering, tearing paper, ringing a bell, clapping, drumming with fingers and crumpling paper.



Visual activities

Integration of visual inputs with different senses provides our awareness about our environment. Visual and vestibular system work together for perceptual motor integration and visual perception [11]. Visual activities include visual stimulation by using projector lamp, sensory bulb and optic filaments.



Olfactory activities:

Smell is directly processed via limbic system and creates memories and associations that influence some of our choices and preferences [12]. There are many different ways to approach therapeutic intervention related to the olfactory sense. Some of the activities are:

- Different scents can be used in therapeutic manners
- Try calming scents to soothe or relax: vanilla, floral, chamomile
- Try alerting scents to stimulate or alert: citrus, peppermint

Gustatory and oro motor activities:

Different senses of tastes ensure that we like the food we eat and distinguish those that may be harmful [13]. Oral sensory input or challenges with oral motor skills can impact self-regulation in kids as well as improving attention, focus, and adding a calming component to slow down a sensory seeking child. Suggested activities are: Blowing balloon, candle blowing, blowing bubble, sipping, chewing tube, chewing gum, vibrating tooth brush, whistling and massage



Interventions for sensory dysfunction – Summary

Tactile: Activities

- o Brushing therapy,
- o Neutral warmth-wrapping,
- o Ball pit,
- o Play dough,
- o Sensory mat
- o Sand therapy
- o Massage

Vestibular: Activities

- o Swinging
- o Therapy ball
- o Trampoline
- o Scooter board
- o Balance board
- o Balance beam
- o Foam Wedge
- o Zig zag walking
- o Motor planning

Proprioceptive: Activities

- o Pushing
- o Pulling
- o Crawling
- o Weight bearing

Auditory: Activities

- o Auditory stimulation
- o Whistling
- o Clapping
- o Snapping

Visual: Visual stimulation

Olfactory: Olfactory stimulation

Gustatory: Oro motor stimulation

SENSORY DIET-

Sensory diet is a term used to denote a carefully scheduled diet of sensory activities, in the child's daily routine, to help keep the nervous system calm, organized and focused. The sensory diet program has a positive effect on the impulsivity of children with ASD [14]

General Calming Activities

Bear hugs, neutral warmth.	Physical relaxation exercises.
Brushing	Pillow press/sandwiching
Chew gum	Play-Dough
Deep pressure massage	Sitting on bean bags,
Feeling different textures and fidget toys	Slow rocking
Hand massage	Snuggling in blankets, pillows, bedding.
Joint compressions	Soft lighting
Lotion rubs	Soft, slow music.
Painting with shaving cream or whipping cream.	Water play.

Effectiveness of sensory integration therapy

Sensory integration therapy is useful for autism spectrum disorders (ASD) in younger age. In a study of 72 subjects on sensory integration therapy, communication skills (expressive, receptive), socialization (coping skills), and daily living skills (personal, community) were improved significantly. SI-OT with Ayres theory in 60 min, twice a week for 12 weeks improved positive behaviors [15].

Negative Side Effects Include: Becoming flush or pale in colour, Becoming very lethargic, falling asleep,

Dilating pupils, Irregular breathing, Nausea, vomiting, Sweating, Very silly, over-active, Yearning, and hiccupping. If child shows any signs of agitation and distress, stop the activity

Importance of sensory group in autism:

Research studies revealed that the parts of brain which control and coordinate communication, social interaction and sensory skills are not functioning properly in children with autism. By intensive training we are helping other parts of brain to take one of these functioning. The goal of SI or sensory-based interventions is to improve the client's ability to process sensory information to increase function [16].

Group therapy is mainly focused on teaching social and communication skills in children with autism. These groups are small groups consisting of 2 or more kids, who will be directed by a trained therapist with mother as co-therapist. Some children have the motor skills when playing alone but they have difficulties when they start playing in a group game. There are several brain benefits of sensory groups for childhood development. When a child plays a game or complete an activity with others, so many motor skills are required than during solo play time.

Participating in sensory-motor group games requires additional executive functions than playing alone. Sensory-motor groups add on another level of cognitive load i.e. impulse control, higher motor planning, self-regulation, etc. during the activities. Providing group therapy sessions or offering additional opportunities for group motor play may help with executive functions, coordination skills and higher level motor tasks.

Evidence Based Reasons to Use Sensory Groups:

Research indicates that increasing the mental engagement in physical activity by adding coordination and cognitive demands result in superior effects on executive functions when compared to physical activities without increased cognitive loads. Skills acquired during complex motor tasks and cognitively demanding group games may transfer to executive functions. Studies support the use of active participation in multi-sensory activities for at least 90 minutes per week to improve occupational performance and autism symptoms and behaviours [17].

Case study:

Anna is 5 year old diagnosed autism spectrum disorder with sensory processing disorder; she loves swinging at the playground, singing and listening to music. Additionally she often becomes dissociative (out of touch with reality) when distressed or triggered. Additionally she has poor social and communication skills, over responsive tactile, auditory and gustatory system, poor body awareness, gravitational insecurity and poor fine motor skills. Sensory over responsive patterns impact Anna's ability to tolerate dressing, tooth brushing, different food textures and for being touched or held. Problems with sensory discrimination impact safety awareness. Problems with fine motor skills impact the ability to write, colour and cut with scissors in an age appropriate manner. At times she becomes so frustrated she bites herself, head bangs, has tantrums and may dissociate. The occupational therapist used clinical reasoning skills to provide an integrative approach combining sensory integration therapy and behaviour modification therapy. One example of a therapeutic session was the client directed and family centred use of sensory integration therapy room with both Anna and her mother. Encouraging mother's active participation the child was initiated the use of cuddle swing, ball pit, and trampoline. Sensory interventions like brushing therapy, wrapping, play dough activities, auditory integration therapy and oro motor exercises are administered.

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The ASD group therapy is organized as 3 sessions. Three group of professionals have a vital role in planning group therapy for ASD.

Session C

Communication Intervention for Children with Autism Spectrum Disorders

Ms Sharon Susan Sam

Speech Pathologist and Audiologist, CDC

Key Points: Impairments in Social interaction and Social communication are considered as core impairments in children with Autism Spectrum Disorders (ASD). Hence building communication skills and meaningful social interactions are central to Autism intervention.

The foundation of an effective intervention program is a comprehensive evaluation. The assessment of communication skills should account for the child's communicative strengths as well their style of language processing (Analytic Vs Gestalt).

A detailed evaluation of communication styles and processing should help us to create an intervention plan that is custom made for each child. It should be remembered that in therapy, there is no one size, fits all.

Communication intervention sessions should be trauma- informed and incorporate neurodiversity- affirming practices.

Traditional approaches tend to focus on teaching neurotypical social skills like eye contact and sitting tolerance to these children and restrict them to spoken communication only without considering their interests, emotions and sensory needs.

More recent approaches have now explored accommodating autistic interests, autistic play and autistic communication styles as part of neurodiversity- affirming therapy practices. These tend to take advantages of the child's strengths in order to help them overcome the challenges they face in multiple domains ensuring access to social participation and opportunities.

Play is the framework in which intervention is built upon and the strategies used needs to take into account whether the child is an Analytic Language Processor (ALP) and Gestalt Language Processor (GLP).

Reinforcement is intrinsic to the task and is not in the form of verbal praises or tangible tokens. The focus of our sessions is to build communication through connection rather than through compliance.

Introduction

Impairments in Social interaction and Social communication are considered as core impairments in children with Autism Spectrum Disorders (ASD). Hence building communication skills and meaningful social interactions are central to Autism intervention. A detailed evaluation is the foundation of a well-planned

communication intervention. Communication assessment for children with ASD begins with an informal evaluation that looks into the child's communication strengths, styles and challenges during activities of the child's interest. It will also help us to gain information regarding the style of language processing. A large majority of children with ASD show Gestalt Language Processing tendencies. A detailed language evaluation should help us identify indications of Gestalt processing and this information should be pivotal while planning intervention strategies. A formal evaluation may be conducted using the Receptive-Expressive Emergent Language Test (REEL-3; Brown, Bzoch & League, 2003) or an Assessment of Language Development (ALD; Lakkanna, Venkatesh, Bhat, Karuppali, 2021). However, it should be kept in mind that, scores in these tests do not give a clear picture regarding the communicative competence of a child with ASD. In addition to supplementing with informal observations, one could also use the Communication Matrix (Rowland & Fried-Oken, 2004) to get a profile of the communicative abilities of these children.

Matrix is an online assessment tool created to help professionals and family members to understand the communication status, progress and unique needs of anyone functioning at the early stages of communication or using forms of communication other than speaking or writing. It helps to determine an individual's current communication level and gives a framework for determining future goals. The Matrix includes all types of communication including Augmentative and Alternative Communication and covers seven levels of development in the earliest stages of communication. The Matrix is organized into four major reasons to communicate- (i) to refuse things that we don't want, (ii) to obtain things that we do want, (iii) to engage in social interaction and (iv) to provide or seek information. Under each of these reasons are 24 specific questions that are used to assess the individual. The questions are arranged based on levels and reasons. The levels addressed include (i) pre-intentional, (ii) intentional, (iii) unconventional communication, (iv) conventional communication, (v) concrete symbols, (vi) abstract symbols and (vii) language. These levels are based on the pragmatic approach to communication development originally put forward by Bates, 1979; Bates, Benigni, Bretherton, Camaioni & Volterra, 1979) that acknowledges the communicative intent of pre-linguistic behavior in young children. This tool can be used to get an idea regarding the level of performance of each child and goals can be tailor made for each individual child based on their performance.

Children with Autism Spectrum Disorders may struggle with getting their needs met as well as with communicating their emotions, interests and feelings. Most often, the interests, needs and feelings of these children are ignored when planning intervention. These struggles quite often present as problem behaviors. Therefore it makes sense to identify and help children advocate for their emotional, sensory and physical needs before addressing problem behaviors directly. The foundation of building an effective communication intervention is regulation and connection. The initial sessions in communication intervention should focus on building connection with the child and finding ways to help them with sensory regulation. Often, therapists spent a lot of time and effort on getting the child to maintain eye contact and in making the child sit on a chair. Growing evidence has highlighted the drawbacks of such approaches, prompting therapists' to embrace strategies that accept and accommodate ASD children's differences. These approaches attempt to modify the way teaching is executed maximizing learning opportunities instead of making the child act/learn in a prescribed way. Lastly, it should be remembered that communication intervention is tailor-made for each individual child. Sensory preferences and regulation needs of each child needs to be taken into consideration while planning communication intervention whether it be in group or in individual sessions. There is no one size fits all, when it comes to planning communication intervention. One of the primary considerations to guide intervention planning is the concept of neurodiversity.

The Concept of Neurodiversity

Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits (Baumer & Frueh, 2021). The concept of neurodiversity emerged in the 1990s and aims to increase acceptance and inclusion of all people while embracing neurological differences. The term

“Neurodiversity” was coined by Judy Singer, an Australian Sociologist based on the concept of biodiversity, the central precept being everyone’s brain develops in unique ways. Neurodiversity is to be considered as a biological fact and not as a perspective, approach, belief or a political position. It is also not a trait that an individual possess. Neurotypical (NT) individuals are those who have a neurocognitive functioning that fall within the dominant standards of “normal”. Neurodivergent (ND) individuals are individuals who have a mind that functions in ways that diverge significantly from the dominant societal standards of “normal”. Autism Spectrum Disorders (ASD), Attention Deficit Hyperactivity Disorder, Down’s Syndrome, Specific Learning Disability are all forms of Neurodivergence. Neurodivergent individuals and their families often carry the burden of change until the neurodivergent individuals look and behave as neurotypical. This often leads to **masking or camouflaging** where neuro-divergent individuals hide their actions and characteristics in order to appear neuro-typical which ends up creating a huge mental health risk to neuro divergent individuals. The goal of communication intervention is not to make a neurodivergent individual learn the ways of neurotypical individuals. It is common for neurotypical individuals to assume that individuals with ASD lack social skills. However, since social interactions are bidirectional, understanding another neurotype’s social interaction style is not just the responsibility of individuals with ASD. The role of a therapist begins in educating the caregivers and the society at large, about the peculiarities of neurodivergent communication styles and in helping to build acceptance for these individuals. The concept of neurodiversity is about shifting the burden of change away from the neurodivergent individual and ascertaining that society has a role in acceptance and accommodation of these individuals.

How to be a Neurodiversity- affirming therapist?

1. Listen to Neurodivergent Voices: Many individuals with ASD have come out with their experience of growing up as a ND individual in therapy and have reiterated that going through interventions that forced them to adopt neurotypical skills were detrimental to their mental health. It is vital to take their experiences into consideration while planning intervention.
2. Accept and validate autistic diversity in social intelligence: Individuals with ASD are capable of sharing information with other individuals with ASD as effectively as neurotypicals. But it may breakdown when the conversation partners involved are of two different neurotypes. This is termed as the **double empathy problem**. A neurodiversity affirming therapist should make efforts to overcome this double empathy problem by adopting strategies that support understanding and communication in individuals with ASD. Always assume that children with ASD are capable of learning and communicating and find ways to maximize their functioning instead of forcing them to mask or camouflage.
3. Try to understand why an individual with ASD may be acting in a way that is attracting negative attention while keeping in mind, the person’s ability to effectively communicate with spoken language, unmet needs, neurodivergent styles of communication, neurodivergent play, joint referencing, individual sensory system, over or under responsiveness and barriers to environment. Once identified, try to figure out how to change the environment, accommodate sensory needs, remove barriers and implement practical solutions to help them meet whatever needs- physical, social or emotional- that they are not yet able to successfully communicate.
4. Learn about neurodivergent differences in social communication styles, and monotropic interest systems (individuals with ASD tend to get pulled in by their items/subjects of interest making it hard for them to change track and transition) and reject practices that induce trauma, masking and camouflage, loss of autonomy and personal agency.
5. Write goals in co-participation with clients and family focusing on goals that improve the self-determined quality of a client’s life.
6. Adopt a strength based approach while making intervention goals: Neurodivergent individuals have their own communication and cognitive processing styles. Goals that focus on eye contact, sitting tolerance, compliance to instructions and undue focus on spoken communication ignore

these styles. To enable these individual to reach their full potential as citizens, our goals should start taking into consideration their strengths and try to make use of these to help them learn. For e.g., a child who cannot sit still may benefit from activities that involve movement (dancing, exercise routines) and heavy work, rather than being forced to sit confined on a chair for 30 minutes.

7. Protect communication in all modalities: The primary goal of communication intervention is to enable individuals with ASD express their needs, ideas and feelings as well as to enable them to advocate for themselves. Considering the fact that a large number of them begin as non-speaking individuals, it is important to adopt and accept all modalities of communication.
8. Communication intervention should include self-advocacy, problem solving and metacognition goals: Self- advocacy goals are focused on helping these individuals advocate for their needs as well as their rightful accommodations in a variety of settings. We should be teaching them that they have the right to say no, to protest and to give or retract consent. We also need to teach them how to establish and maintain their personal boundaries and respect the boundaries of those around them. Problem solving goals will help them find solutions for their day to day challenges by themselves and metacognitive goals will help them identify factors that will facilitate problem solving, learning and attention in their day to day life.
9. Provide neutral information for navigating social situations with intent to empowering them to interpret social situations and navigate them on their own terms. While creating social stories or teaching them pragmatic skills, allow them to creatively use this information according to their capabilities instead of insisting that they stick to the script. For instance, many children with ASD resort to offering handshakes or saying 'hello' while avoiding eye contact. It is important to acknowledge that social gesture instead of insisting on eye contact, thus accommodating for their neurodivergent peculiarities.

Neurodivergent Communication Styles: The following are few communication styles seen in neurodivergent individuals. It should be remembered that the goal of communication intervention is not to replace them with neurotypical communication styles, but to help the gain skills that allows them to connect, communicate and advocate for themselves while accommodating these differences.

1. **Infodumping:** Indicates talking about a topic in great detail. The topic is very often one of their special interests. ND individuals frequently use it as a way of building a connection and initiating interaction with someone. It involves longer conversational turns.
2. **Echolalia:** Could indicate differences in cognitive processing (e.g., gestalt language processing). Echolalia serves many pragmatic and communicative functions including self-regulation and need not be discouraged during intervention. Almost 75-90% of children with ASD develop language in this manner.
3. **Asynchronous Communication:** Children with ASD often require longer durations for processing. Hence constantly giving instructions and expecting immediate responses may not be appropriate for them. Giving longer duration to respond allows them to plan what they want to say while synchronous communication can induce anxiety in many individuals with ASD.
4. **Direct Communicators:** Individuals with ASD mean what they say and say what they mean. They are often found to skip social politeness and be called "rude."
5. **Differences in body language:** These individuals may need to move more, slouch, lean or use exaggerated gestures, seek proximity to feel grounded or come close and stare to filter sensory stimuli.

Monotropic Interests

Monotropism is a common characteristic that we see in individuals with ASD. Monotropism is a theory of autism based on the lived experience of autistic people. It conceptualizes that individuals' interest

guide their allocation of attention and different interest can be salient at different times. Here, interest is understood as anything that commands an individual's attention. Meanwhile, attention is conceptualised as a limited resource for which different cognitive processes are competing. Murray and colleagues (2005) posit that a monotropic mind has fewer interests aroused at any given time, with each one being allocated attention at a high concentration – this attention allocation strategy tends to apply to autistic people. In contrast, non-autistic individuals are hypothesised to be **polytropic**: they allocate attention at varying intensity levels to cover a broader range of interests, which may be co-aroused at any given time. Most intervention sessions are tailored for polytropic minds which can attend and process multiple stimuli at the same time and can transition from one task to another quickly and smoothly. This is not the case of monotropic individuals with ASD and hence put them at risk for incomplete learning.

Gestalt Language Processing

Gestalt language acquisition is a style of language development with predictable stages that begins with production of multi-word “gestalt forms” and ends with production of novel utterances. At first, children produce “chunks” or “gestalt form” (e.g., echolalic utterances), without distinction between individual words and without appreciation for internal syntactic structure. As children understand more about syntax and syntactic rules, they can analyze (break down) these “gestalt forms” and begin to recombine segments and words into spontaneous forms. Eventually, the child is able to formulate creative, spontaneous utterances for communication purposes. A growing body of research has identified various communicative functions of echolalia (e.g., turn-taking, labeling, requesting, affirming, and protesting) and has suggested its role in gestalt language acquisition (Prizant, 1982, 1983; Prizant & Duchan, 1981; Prizant & Rydell, 1984; Stiegler, 2015). Children who are gestalt language processors use scripts from movies, videos and things overheard and memorized. It is also called as the Natural Language Acquisition Pathway (Blanc, 2012). There are six identified stages in GLP.

Stage 1: **Echolalia**- Strings of language repeated from communication partners, songs, and media. They can be short or long.

Stage 2: **Mitigated**: Strings of language that are mixed and matched. Freeing part of something and using it in different ways.

Stage 3: **Isolation of single words**: Language that is more in context. Gestalt are being broken down

Stage 4+: **Self generated language**: Language that's in context and looks like grammar (even if it's not perfect grammar). Starts off simple then increases in complexity.

Stage 5: *More advanced grammatical development* detailed by developmental sentence analysis (Lee, 1974). Language is best learnt in this stage through modeling, meaning, emotional content and context. Highlights include advanced pronouns, verb forms, negatives, wh-question words, and conjunctions. By the end of stage 5, and GLP can say a sentence as “When we couldn't find the money for ice cream, we called our mom who brought enough for all of us.”

Stage 6: This stage shows the **emergence of complete grammar** that can be used in academic areas and the rest of their lives.

Both Gestalt and Analytic Language Processing are natural ways of language acquisition. However, GLP is the most common style of language processing in children with ASD and analytic approaches that begin in single words and teaches children to build and combine vocabulary may limit and hamper development of communication in children with ASD. It is important to consider the child's style of language processing before adopting a particular practice.

Basics of Communication Intervention

1. **Focus on the child's strength than on the weaknesses**: The strengths-based approach presumes competence, acknowledging that “all individuals have the ability to learn, to communicate, to participate in their own way...[and] respect[s] the value of human diversity” (Autism Women's Network).

2. **Use a positive affect:** Use a clear, genuine and natural positive affect throughout the episode. The adult matches their affect to that of the child - to their needs and capacities, making sure not to over arouse the child and ensures learning. We try to create a positive emotional state thus enhancing the reward value of social interaction and recalibrate the child's responsivity to voices, faces and eyes. This includes use of pleasurable social sensory routines focused on dyadic social experiences and highly preferred object routines that are accompanied and embedded in strongly social and communicative actions. Our goal is to make social engagement and communication an intrinsic part of the reward. This technique helps build reward value for social interactions through associative learning process.

3. **Play is the framework of intervention:** Joint activity routines (Bruner, 1977) are play activities in which both partners have key roles and build on each other's contributions. They are also called as social sensory routines or social games. They involve objects and activities that are typically found in natural environments for children of this age. These activities hold a really prominent position among communication intervention and are considered primary vehicles for teaching. Communication intervention is embedded in emotionally rich joint activity routines with or without objects. The adult shares control of the play selecting what objects are available as choices for the child, what actions are modeled and reinforced, and how activities are sequenced.

4. **Focus on Co-regulation:** We attempt to shift from compliance-driven models that may condition the person to ignore what their body is telling in order to please another person and get a reinforcer. We need to teach NDs to listen and respond to their body signals through co-regulation. The first step here is to identify the child's emotional triggers- sensory stimuli to social situations- address proactively and help in preventing emotional outbursts. We also focus on creating a calming environment by reducing sensory triggers, establishing routines and providing a safe space. Co-regulation banks on the adults' ability to regulate themselves in emotionally charged situations, to be calm and be present for the child who is going through a tantrum. Additionally we may teach some emotional regulation skills through social stories, visual supports to help with regulation. However, children with ASD may need continued support for longer periods.

5. **Reinforcement is intrinsic to the task:** Reinforcer is a natural part of activity. E.g., When a child speaks/ communicates, we don't say "good talking". We respond by restating and expanding the child's words and give the desired object or activity.

How to facilitate child motivation during communication intervention?

When children are highly interested in something, they are motivated to attain the object, observe the spectacle and repeat the exchange. Motivation should be demonstrated as any of the following interest or approach behavior: watching with positive affect or interest (as opposed to wariness) leaning or moving toward or trying to attain something. Most children with autism can be highly motivated to obtain objects, to handle favorite objects, create interesting effects with object and to get help with objects they enjoy. Many enjoy activities involving physical contact- rough house, musical games, tackle games, bouncing and swinging. Select materials and activities that stimulate child interest, energy, positive affect (find the smile!) and approach. This should be individualized for each child.



Sensory Social Routines can be useful tools for eliciting motivation to engage in interactions.

During the initial rapport sessions put the child in a situation -where there are many age- appropriate objects, well organized and accessible and watch what happens. In case of low-drive children who do not approach toys, we may use object spectacles- that create interesting physical or sensory effects- bubbles, balloons, pompoms, wind-up toys that make little movements, water being poured in a basin, beads, bells and shakers and pinwheels- sensory social toys. If they do not respond to these toys, play gentle (or lively) physical games. This includes creepy fingers, bouncing on knees, hand and feet games, bouncing on a trampoline or small therapy ball, being rolled or wrapped in a bean bag and dragged around in the room. If food is the only factor that motivates the child, have a snack with them. Those who do not respond to any of these will benefit from adult directed and didactic discrete trial teaching.

How to draw the child’s attention once you have established motivation

Children with ASD tend to focus more on objects. We need to become the spotlight of their attention to help them learn from us. We begin by eliminating the competition- put the toys that you are not using away and out of sight, thus becoming the source of everything interesting and desirable. Set up interactions such that children have a clear view of our face and we can draw attention to our face and eyes- help children to look at us, make repeated eye contact, to have clear views of our face, expressions and gaze patterns and mouth movements as we speak. One beneficial technique is to hold the object of interest near our lips so as to get their attention to our face. We need to sit face to face with the child at their eye level with objects between us and child easily brought near the face. If the child is averting the gaze, turning their head, covering their eyes to avoid gaze, try not to get in their face, but move slightly back and evaluate the effect. The following positions can be beneficial:

- Sitting on the floor facing the child is a good option
- Placing the child on a small chair or on a step stool, while the therapist sit on the floor is also a good option.
- Seating the child low in a beanbag or a toddler size chair with good back support is a great position for book activities and greeting and dressing routines. This is a great position to make animal sounds, give key words, point to pictures, prompt points and provide sound effects.
- Make the child sit on the lap facing you for lap games.
- Adult sitting on the floor with child lying on their back the adults legs or on the floor between the adult’s legs is a good position for creepy fingers, round and round the garden, peekaboo etc.



Strategic sitting positions are a great tool is getting into the child’s attention spotlight.

Join the child in such a way that you become a part of the activity in the child’s mind. Do it in a way that the child’s motivation is not lessened- you might want to hold back or regulate yourself a bit in the beginning. Observations regarding the child sensory processing peculiarities will be a great asset. Adults have to adjust their level of participation sensitively by observing child cues in order to minimize signs of discomfort. Increase the child’s comfort with our presence and add to his or her motivation for the activity by making the child’s goal easier to attain or the activity more interesting. You could do the following:

- *Watch and comment*- watch the child with interest, nodding and smiling in a natural approving fashion. This conveys your presence and your attention
- *Narrate the child's action with lively emotion* using words or phrases that are appropriate for the child's level. Add sound effects. Describing child's play without interrupting or changing the child's focus. This will help to maintain the child's attention to the activity and provide opportunities for language learning.
- *Be helpful*- start assisting the child without requiring anything from the child. This establishes your presence as a helpful one and reassures that your handling of materials will not impede the child and helps you to develop a reinforcing value of your own. Continue doing this until the child readily accepts your help.
- *One very beneficial option* is to pack the toys in difficult to open containers- ziplock bags, clear lidded containers with difficult lids
- If the child protests you touching his or her materials, go back to parallel play in the early stages.
- Try to resolve conflicts faster in order to avoid any problem behavior.
- You may also elaborate the play by adding to it in some way- add a bridge when you are building a train track, if you are building towers, crash down yours, (not the child's) or adding blocks in dump trucks etc.

How to take a role in play?

Once the child is comfortably accepting of your presence and your handling of materials we can start co-constructing further activities with the child. Several strategies may be beneficial.

- Imitate the child-This allows creating parallel play. Further, children with autism demonstrate positive responses to being imitated (Dawson & Adams, 1984; Dawson & Galpert, 1990). If the child wants to control all the materials i.e., wants your materials, give them freely, take others and start again.
- You can also join the child in creating shared goals- e.g., if the child is stacking, add blocks in between the child's turn. If the child is doing puzzle, you put a piece or two. This will help build awareness of the social partner and builds the framework for interactive, reciprocal play.

If the child protests you touching his or her materials, go back to parallel play in the early stages. Try to resolve conflicts faster in order to avoid any problem behaviour. You may also elaborate the play by adding to it in some way- add a bridge when you are building a train track, if you are building towers, crash down yours, (not the child's) or adding blocks in dump trucks etc.

How to become more active in sessions:

Once the child accepts you easily, you can begin to be more active in play. Timing of these transitions are individual, some move through these phases in a single hour, others may need several sessions. Once the child has started accepting you, the following methods can be employed to embed teaching into play.

- **Controlling the materials:** once the child has selected materials and begun an activity, remove the rest of the pieces. Possession of these allows control over powerful reinforcers and puts you in the spotlight. Be sure to give freely until the child is completely at ease with your handling of materials in many situations
- **Taking Turns:** involves handling materials and completing steps yourself. Taking turns is a more intrusive action. The child should be prepared at this stage by all the previous parallel play and object handling that you have done Turn taking begins when the child is engaged in a one-person activity. E.g., banging table with a hammer. After the child acts on the material for a minute or two take a very brief turn by saying "my turn" extending your hand and taking the toy quickly to do

what the child just did, narrating your action as you do it and then quickly handing it over fast to the child while saying “your turn.” Some level of struggle may be necessary before the child learns that the object will be returned immediately.

If the child is not going to release the toy to you, hand them an alternative and make it a trade for a while, until the child realizes that the objects you take will quickly come back. If the child leaves the toy and refuses to interact more, return to less intrusive partnering to reestablish foundation. Take turns frequently in play in order to facilitate learning. Proceed through these previous steps slowly and consciously to ensure smooth transitioning between levels. Do not put something away or end an activity during your turn. If you ask for a turn, always give the child their turn.

12.10 How to work on imitation during communication intervention

Young children with autism are much less inclined to imitate words, gestures and actions of others than their age mates (Rogers & Williams 2006; Rogers et al., 2003). However, they are capable of learning with a little bit of help. The following domains need to be addressed

- Imitation of actions on objects
- Imitation of body movements without objects- gestural imitation
- Oro-facial imitation
- Vocal imitation of sounds and words

The basic teaching approach involves capturing children’s attention with a motivating activity, modeling the action, then, prompting the child to imitate before continuing the rewarding activity. Teaching of imitation can be done during play activity, during snack, stories etc. The following are useful opportunities to teach imitation:

- Making silly faces can be a social game.
- Imitating body postures and movements can occur in games of pretense- imitating different animals- walking on all fours, hop like a kangaroo
- Pretend play with pantomime i.e., imitating gestures.
- Using double set of toys is also a very helpful strategy for object imitation.

If the child is too focused on his or her materials, then trade the materials back and forth using a turn taking frame or hold back the second set till you have demonstrated with the first, then give the child the second set to use for imitation. No particular verbal instruction is needed for imitation; the adult model is the stimulus. Saying “look”, “you do it” “your turn” or no specific instruction are all acceptable. You should always mark the act with language or some type of vocal sound effect which is preferably a phrase that fits the child’s complexity level.

We often begin with object imitation since it is easy for the child to learn and easy for us to prompt. Begin with actions that are in the child’s repertoire. For e.g., if the child is hammering, you may take the hammer saying “my turn” then “bang bang bang” as you hit with the hammer and give it back to the child. If the child does not imitate, use a full physical prompt, adding sound effects. We try 8-10 different actions in the child’s repertoire and after the child has acquired imitating based on your initial prompt we move on to imitating new actions with those objects.

Gestural imitation is taught during sensory social routines. Begin with hand over hand prompt and make sure you fade it off later. Don’t prompt frequently to get perfect imitations. Let the child do it sloppily but independently is more acceptable. Orofacial imitation is the last step. Begin after the child is fluidly, consistently and independently imitating 8-10 or more body actions. We could use exaggerated blows for bubbles, funny faces, mirror play and so on. The final stage is vocal imitation, which we begin with increasing their, own vocalizations and then differentiating it.

How to introduce Augmentative and Alternative Communication (AAC) in sessions:

AAC refers to all of the ways that someone communicates besides talking. Augmentative means to add to

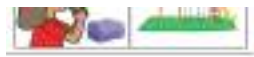
someone's speech. **Alternative** means to be used instead of speech. AAC can be used by all children with Autism (and other conditions) who are not developmentally ready to speak. Anyone can benefit from AAC especially ones with complex communication needs. There are no specific set of prerequisite skills that the child needs in order to be eligible for an AAC. AAC can also be introduced to children as early as possible and should be introduced along with spoken language. The therapist will evaluate the child's level and a system based on their needs can be adopted. AAC has been proven to facilitate verbal communication and will not hurt or delay development of speech. Any device from the following list may be chosen based on the child's need, level and affordability.

- Gestures/Body Language
- Sign Language
- Object Symbols (objects glued to cards)
- Picture Boards
- Picture Exchange
- Written Messages (paper or typed)
- Single Button Voice-Output Devices
- Multi-Button Voice-Output Devices
- Dynamic-Display Voice-Output Devices like Avaz, Jellow or Playtalk.

Introducing the device in the session should be done as naturally as possible. Avaz, Jellow and Playtalk are examples for a high-tech AAC application developed indigenously and use pictures and text to help users express themselves. These applications can be extremely useful in opening ample opportunities for self-expression in children with ASD. They are robust and can be used to support communication in both Analytic (ALP) and Gestalt Language Processors (GLP). The following steps should be kept in mind when designing a plan that includes AAC.

1. **Get familiar with the child's system:** The therapist/parent should get themselves familiar with the AAC system that the child is using so that they can plan for naturally incorporating the use of AAC during the session. They should check for the arrangement of the system, where to find the vocabulary needed for the session and also be familiar with system controls if it is an electronic device.
2. **Model AAC use around the child:** The therapist and the parent should be ones who models AAC use in day-to-day situations. Make sure the AAC device is accessed and modeled in all situations by both partners not just the child. For example: for a child who is still vocalizing, when he/she reaches for the ball, the mother picks up the ball, points to the ball and says "ball" before giving it to the child. She could later introduce a picture card in place of the ball, say "ball" and then hand over the ball to the child. She could also use an App based device to click on the picture of the ball which says "ball" and then hand it over to the child. The parent can also model this when she is requesting something from the child. She may start with a hand stretched out, say "give ball" or hold the picture card of a ball and stretch out hands to say "give ball". This could also be done with an App based device. If the child is in single word level and says "ball" while stretching out hands towards the ball, the mother can model "want ball" using two pictures from a communication book or an App.
3. **Begin with core vocabulary:** Intervention typically begins with a selected set of words called the core vocabulary. Most of the basic communication needs can be met using these core vocabulary. Examples of core vocabulary include want, like, more, stop, help, up, down, go, all done, mine, on, off, more etc.
4. **Feel free to include as many words** as possible which belongs to the core vocabulary in the grid. This will ensure that all the necessary vocabulary for seamless communication is available to the child in the early stages itself and hence will ensure maximum communication opportunities for the child. Longer sentences may be used when working with children who are gestalt language processors (GLP).

5. **Encourage the child when they attempt to use** it and provide differential reinforcement: encourage all attempts to use the AAC with an intrinsic reinforcer. Withhold reinforcement and engagement in case of non-communicative or repetitive use of the system. Do not be wary of them experimenting and playing with their AAC system. By repeatedly modeling communicative use and reinforcing all of their communicative attempts, regulated use of AAC systems can be established.
6. **Have the device present at all times:** the device should be kept handy so children can use them whenever a need arises.
7. **Set up opportunities** to model and use AAC device in all settings that the child is functioning in: the device should be set for use at home, in classroom and in the various intervention programs that the child may be attending.
8. **Train other adults** on how to set up opportunities and provide differential reinforcement: the use of AAC system/device should be generalized across people and setting. An amount of advocacy may be needed in order to educate other adults in the child's life regarding the use of AAC and to ensure acceptance of the systems. Seeing AAC being used by multiple adults will empower the child regarding AAC use and motivate them to use it as well.



Example of an AAC grid

Settings to practice AAC use.

1. During snack time, keep the system handy. Point to “more” and say “more” each time you are offering a piece to the child. After 2/3 exposures, move the device towards the child and let them point to more before offering the next piece. If the child fails to respond, you may use a physical prompt to elicit a response, while vocalizing “More” and offering the snack again. No need to say it if you are using a speech generating device as it is already providing the speech model.
2. When playing ball, model pointing to “my turn”, “throw” and “catch”
3. While listening to music words “on and off” can be modelled. Select vocabulary related to the songs may be modelled as well.
4. While at the playground on the side, have them point to “go”, “slide” “more”, “fun” etc.

Incorporating visual supports in intervention

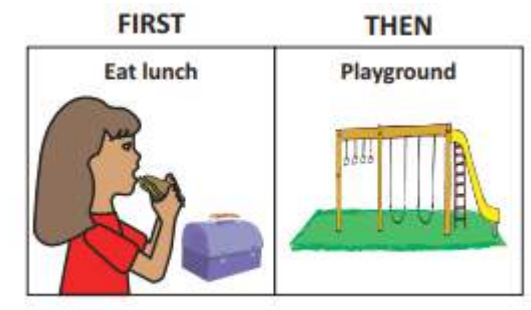
A visual support refers to using a picture or other visual item to communicate with a child who has difficulty understanding or using language. Visual supports can be photographs, drawings, objects, written words, or lists. Research has shown that visual supports work well as a way to communicate. Visual supports are used with children who have autism spectrum disorders (ASD) for two main purposes. They help parents communicate better with their child, and they help their child communicate better with others.

Types of visual supports to be used with children with ASD

First-Then Board: A First-Then Board is a visual display of something your child prefers that will happen after completing a task that is less preferred. It will also convey the order in which a task will be executed.

A First-Then Board is helpful in teaching children with ASD to follow directions and learn new skills. A First-Then Board motivates them to do activities that they do not like and clarifies when they can do what they like. A First-Then Board lays the language foundation needed to complete multi-step directions and activities and to use more complex visual systems.

Decide what task you want your child to complete first (what goes in the “first” box) and the preferred item or activity (what goes in the “then” box) that your child can have immediately after the “first” task is done. This preferred item/activity should be motivating enough to increase the likelihood that your child will follow your direction. Put the visuals on the board (e.g., photos, drawings, written words) that represent the activity you identified. Present the board to the child with a brief, verbal instruction. Talk naturally but use simple sentences.



For example, before beginning the “first” task, say, “First, put on shoes, then swing.” If needed, refer to the board while your child is doing the task. For example, say “One more shoe, then swing” when your child is almost done. When the “first” task is completed, refer back to the board. For example, say “All done putting on shoes, now swing!” and immediately provide the preferred, reinforcing item or activity. In order to teach children with ASD the value of the First-Then Board, you must give them the reinforcing activity or item after they complete the “first” task. Otherwise, your child may not trust the board the next time you use it.

Visual Schedule: A visual schedule is a visual representation of what is going to happen throughout the day or within a task or activity. A visual schedule is a visual representation of what is going to happen throughout the day or within a task or activity

After your child understands the concept of sequencing activities through the use of a First-Then Board, you can develop a more complex schedule for a series of activities during the day. Decide the activities that you will picture in the schedule. Choose activities that really will happen in that particular order. Try to mix in preferred activities with non-preferred ones. Put on the schedule the visuals (e.g., photos, drawings, written words) that show the activities that you have identified. The schedule can be portable, for example, on a binder or clipboard, or it can be fixed to a permanent place, like a refrigerator or wall. Your child should be able to see the schedule before beginning the first activity on the schedule. It should continue to be visible to your child during the rest of the activities. When it is time for an activity on the schedule to occur, cue your child with a brief, verbal instruction. For example, say “Check the schedule.” This helps your child pay attention as the next activity begins. At first, you may need to physically guide your child to check the schedule (e.g., gently guide by shoulders and prompt your child to point to the next activity on the schedule). You can gradually decrease physical prompts as your child begins to use the schedule more independently. When a task is completed, cue your child to check the schedule again, using the procedure described above, and transition to the next activity. It may be helpful to use a timer that your child can hear to make transition times clear to your child. Mix variability into the schedule by introducing a symbol that represents an unknown activity (e.g., “oops” or “surprise activity”). Begin to teach this concept by pairing this with a positive activity or surprise. Gradually use this for unexpected changes in the schedule. Make sure to create the schedule and timings while keeping the child’s neurodivergent peculiarities in mind.

If challenging behaviors occur, continue by physically prompting your child to complete the task that is occurring. Keep your focus on the task rather than on the challenging behavior. Then transition to the next activity as communicated by the schedule and still provide the reinforcing item or activities indicated on the schedule, since the focus of the schedule is on completing the tasks, and not on addressing challenging behaviors. If you think challenging behaviors may happen, begin by introducing the visual schedule during tasks that your child usually completes willingly and successfully. If challenging behaviors become more difficult to control, it may be appropriate to consider behavioral consultation with a professional to address these behaviors directly.



Object Schedules



Picture Schedules



Real Photo Schedules



Color-Coded Picture schedules



Binder Picture Schedule



Paper Picture Schedule



Written Paper Schedule

Visually Setting Parameters: Setting parameters involves using visuals to set clear boundaries around items or activities and to communicate basic expected behaviors, like waiting. Visually setting parameters is helpful in communicating limits that are part of an activity and that may seem unclear to your child. Some examples of situations where this might be useful follow. Communicate physical boundaries of an area or activity; for example, use a “stop” sign to mark where to stop in the backyard. Or show how much of an item or activity is available before it is gone. For example, place a “not available” picture on the computer when it is not time to play on the computer. Or place pictures of 3 juice boxes on the refrigerator and remove or cover one each time.

Begin to teach the use of these visuals in situations that have clear, defined, brief parameters. As your child understands these visuals better, gradually increase their use in more long-term activities and with more abstract parameters.

Physical boundaries: Place the visual on physical boundaries that already are defined (e.g., a door) and refer



to it when the rule is followed. For example, when your child stops at the door, point to the stop sign and say, “Stop.” Give feedback/support for complying with this parameter. After you have taught the concept, use the same visual during other activities or in other settings where the same boundary is needed but is not as clear, such as a “Stop” sign on the playground.

Limited availability: Decide the number of times or length of time that the item or activity is available. Indicate that through the visual, for example, 3 pictures of a juice box on the refrigerator to indicate that 3 juice boxes are allowed that day. After the item or activity has been used or done, show the change by using the visual, for example, cross out or remove one of the juice box pictures. When the item is no longer available, use the visual to show this. For example, show your child that there are no more pictures of juice on the refrigerator after they have used them all.

Wait: Begin by presenting the symbol for “wait” for a very brief amount of time before your child can have a preferred item or activity. It may help to pair the use of the “wait” symbol with a timer. Have your child trade the “wait” card for the item or activity. For example, when your child asks for a snack, hand your child the “wait” card, set the timer for 10 seconds, and then praise your child’s waiting and trade the snack for the “wait” card. As your child learns to use visuals for setting parameters, gradually increase the length of time or the number of situations in which your child is expected to wait for items or activities.

If you think that challenging behaviors may occur, introduce these parameters during less difficult situations or begin with simple expectations. If problem behaviors occur, be consistent with the parameters you have set. Focus on providing feedback for any aspects of the parameters that are being followed, rather than shifting your focus to the challenging behaviors. Using visual supports can help you and your child with ASD communicate and manage everyday activities in positive ways.

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P A R T - D

CDC Model Group Therapy in ADHD

Dr Mini AO, Bismi David, Jasmine George, Dr Juby Raj AR

The ADHD group therapy is organized as 4 sessions. Four professionals who have a vital role in planning group therapy for ADHD, handle the sessions.

SESSION A: Organizing ASD Group therapy and management of Inattention, Hyperactivity, Academic Intervention in ADHD.

SESSION B: Occupational Therapy in ADHD

SESSION C: Parent Training on Behavior Management in ADHD

SESSION D: Physical Activity Interventions for ADHD

Group Therapy in Attention Deficit Hyperactive Disorder (ADHD):

SESSION A:

Organizing ASD Group therapy and Academic Intervention in ADHD

Dr Mini AO

Development Therapist, CDC

Key points: Attention-deficit/hyperactivity disorder (ADHD) is the most frequent childhood neurobiological disorder with estimated worldwide prevalence at about 3.4%.

Group therapy is the treatment of multiple patients at once by one or more healthcare providers.

The goals of group therapy are to facilitate patients' growth in comfort and function within the group.

The outcome goals of group therapy are applied to the patient's life outside of the group and include behavior corrections, development of interpersonal and relationship skills, education, the installation of preventative measures and coping skills, and an eventual return to normal functioning within society.

Group therapy will be useful for the treatment of patients who exhibit interpersonal difficulties and shows deviation from normalcy, show hyperactivity, low attention span, academic issues especially in problems with writing, reading arithmetic and behavioral issues.

Introduction

Attention-deficit/hyperactivity disorder (ADHD) is the most frequent childhood neurobiological disorder with estimated worldwide prevalence at about 3.4% (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). The current DSM-5 diagnostic criteria feature three forms of presentation: ADHD/I (predominantly inattentive), ADHD/H (hyperactive and impulsive), and ADHD/C (combined), each with different specific difficulties and responses to treatment (Grizenko, Paci, & Joobar, 2010).

Group therapy is the treatment of multiple patients at once by one or more healthcare providers. It can be used to treat a variety of conditions including attention deficit hyperactivity disorder (ADHD). This activity outlines the principles of group therapy and explains the role of the inter professional team in evaluating, treating, and improving care for patients who undergo group therapy.

Goals

The goals of group therapy are to facilitate patients' growth in comfort and function within the group.

The outcome goals of group therapy are applied to the patient's life outside of the group and include behaviour corrections, development of interpersonal and relationship skills, education, the installation of preventative measures and coping skills, and an eventual return to normal functioning within society.

Selection of Patients

Children who had features of hyperactivity, inattention, impulsivity, and other signs like oppositional behaviour, behavioural issues, and scholastic issues will be screened for ADHD in the Developmental Evaluation Clinic. Those children who got positive result with NDST items for ADHD and INDT ADHD will be referred to the ADHD clinic. There they will be undergoing Vanderbilt diagnostic tool, Conner's parent rating scale, Problem Behaviour Checklist. The IQ also will be assessed before the intervention. After the diagnosis intervention strategies as well as remedial teaching will be planned based on the intervention package prepared. At the time of each visit mothers / parents will be given guidelines about child's condition, importance of early & appropriate interventions at the right time.

Children diagnosed with ADHD with average IQ will be grouped in to 7 – 9 cases per group and they will be given 12 group therapy sessions once in two weeks with the help of a structured intervention package. The duration of one day session will be 4 hours from 9 am to 1.30 pm (1 hour session for Occupational Therapy (OT), 1 hour session for Academic Intervention, Snack break 10 minutes in between, 1 hour session for Behaviour Therapy (BT), and another 1 hour for Physical exercises and games.). Those whoever needed medication or individual session on Behaviour therapy will also be arranged. In the very first session the parents, grandparents along with their children will get an awareness class about management of ADHD, will give guidance & counselling by the multi-disciplinary team members (Developmental Paediatrician/ Paediatrician, Developmental Therapist, Special Educator, clinical Psychologist, Occupational therapist, Neurologist, Psychiatrist, counsellor etc. wherever and whenever necessary.)

Group therapy will be useful for the treatment of patients who exhibit interpersonal difficulties and shows deviation from normalcy, and show hyperactivity, low attention span, academic issues especially in problems with writing, reading arithmetic and behavioural issues. Those who are not fitting for group therapy (i.e. with IQ below 85 or with any comorbid conditions etc.) will be sent to individual therapy session as well.

Duration of Treatment

The duration of the group therapy will be up to 6 months (2 sessions per month a total of 12 sessions). Pre assessment will be done at 1st session, mid assessment will be done at 6th session and post assessment will be done at 12th session.

Generally, group therapy is an effective treatment for ADHD. A study conducted at CDC, over a period of 10 months from November 2014 to December 2015, to find out the effectiveness of an ADHD intervention module as a group therapy mode, showed significant improvements in post intervention scores in areas such as; Inattention, Hyperactivity – Impulsivity, Learning problems, Executive functioning, Aggression and Peer relations. There are many studies which show that group therapy can help people with ADHD manage their symptoms and may even improve functioning in those with more severe cases of the disorder.

When done properly, group therapy offers several advantages to individuals struggling with attention-deficit/hyperactivity disorder (ADHD). No treatment has yet been proved to cure ADD/ADHD, but all may provide symptomatic relief to alleviate some features. According to CDC study (2014), some of the common effective intervention modalities we can choose for ADHD group therapy are; Bio-Psycho-Social training for behaviour modification (at home and school), guidance and approaches towards remedial teaching, Attention work up, hyperactivity – impulsivity management strategies, social skill training, self-control monitoring, calming techniques, manipulation of the environment, medications if needed, dietary advice, managing emotion, coping strategies etc.

Steps in group therapy

Here are the steps to conduct group therapy

- 1. Find a suitable meeting space:** The first step is to find an appropriate meeting space that is comfortable and convenient for the members. (Ref: therapy room specifications and equipment mentioned in DEIC clinic set up – operational guidelines by RBSK)
- 2. Establish guidelines:** Establish ground rules and expectations for the group, such as respectful behaviour, confidentiality, and punctuality.
- 3. Establish a format:** it should be clearly defined what topics or areas or activities to be included at what extent.
- 4. Gather members:** Invite potential members to join the group and provide them with information about what it is, how it works, and why you are organizing it.
- 5. Connect with professionals:** Building relationships with professionals in the field of ADHD can be beneficial for the group. These could include doctors, therapists, psychiatrists, psychologists, and teachers.
- 6. Establish resources:** Make sure the members have adequate resources and equipment to provide remedial services.
- 7. Monitor progress:** Regularly assess the progress of each case and provide feedback and guidance when needed. This will ensure the effectiveness and positive results.

Basics of ADHD coaching

The basics of ADHD coaching include-

- Goal development
- Time management
- Organization
- Break tasks into steps
- Use visual aids
- Provide clear instructions
- Establish routines
- Reward positive behaviour
- Encourage social skills

The following domains have to be taken care of while giving group therapy for children with ADHD:







1. **Hyperactivity management**
2. **Attention work up**
3. **Behaviour modification**
4. **Scholastic Intervention(Both in English & Malayalam languages initially)**
 - a. Reading skill work up
 - b. Writing skill work up
 - c. Arithmetic skill work up

Hyperactivity management (Activities to reduce Hyperactivity)

Signs of a hyperactive child include: Fidgeting or tapping hands or feet, squirming in their seat, leaving their seat when they are expected to remain still, running around or climbing in situations where it is not appropriate, unable to play or take part in leisure activities quietly, on the go or acting like they are driven by a motor, talking excessively, blurting out an answer before the question has been completed, difficulty waiting their turn, interrupting or intruding on others etc.






There are structured 12 sessions for Hyperactivity management, Attention work up, Behaviour modification, Reading skill work up, writing skill work up, and pre math skill work up. The corresponding tables are given below.

Table 1 HYPERACTIVITY MANAGEMENT

Activity	Short-term Goals	Responses
Session 1 Physical play	<ul style="list-style-type: none"> Outdoor sports Obstacle games Football Swimming etc. 	
Session 2 Activity games	<ul style="list-style-type: none"> Dance Lazy 8 walking Follow the leader game 	
Session 3 Sensory activities	<ul style="list-style-type: none"> Play dough activities Clay activities Sensory bins swinging 	
Session 4 Art & creativity	<ul style="list-style-type: none"> drawing colouring crafts building models 	
Session 5 Mindfulness & relaxation	<ul style="list-style-type: none"> yoga meditation breathing exercise guided imagery 	
Session 6 Puzzles & games	<ul style="list-style-type: none"> jigsaw puzzles board games snake & ladder basket ball 	

<p>Session 7 Structured activities</p>	<ul style="list-style-type: none"> • karate, dance • skipping, hula hoop • swimming, football 	
<p>Session 8 Quiet time activities</p>	<ul style="list-style-type: none"> • reading • silent time • writing silently • timed activities silently • listening music with head phones 	
<p>Session 9 Outdoor exploration</p>	<ul style="list-style-type: none"> • nature walk • scavenger hunt • physical exercises 	
<p>Session 10 Fine motor activities</p>	<ul style="list-style-type: none"> • shaping kinetic sand • play dough activities • finger painting • playing instruments 	
<p>Session 11 Regular exercise</p>	<p>neck rolls, shoulder rotation, arm rotation, elbow movement, wrist rotation, butterfly, jumping jacks, etc.</p>	
<p>Session 12 Free play</p>		

Table 2. ATTENTION WORK UP

Activity	Short-term Goals	Responses
<p>Session 1 Concentration & Breath control exercises</p>	<ul style="list-style-type: none"> • Deep Breathing • Square Breathing Or • Triangle breathing 	 <p>The response for Session 1 includes two diagrams for breath control. The first diagram shows a person sitting cross-legged with arrows indicating 'Breathe In' (upward arrow on the left) and 'Hold your breath' (top horizontal arrow), followed by 'Breathe Out' (downward arrow on the right) and 'Hold your breath' (bottom horizontal arrow). The second diagram is a purple card titled 'Triangle breathing' showing a candle with a triangle drawn around it, with the number '1' and the text 'Hold your breath' below it.</p>
<p>Session 2 Brain Gym</p>	<ul style="list-style-type: none"> • PACE • Cross crawl • Lazy 8 • Positive points • Double doodle 	 <p>The response for Session 2 features several images related to brain gym activities. It includes a 'WHAT IS A CROSS CRAWL EXERCISE?' graphic with illustrations of a child performing the exercise, a photograph of a child's hands on a floor, a 'Kneeling' exercise illustration, and a 'Double doodle' activity where a child is drawing a complex maze-like pattern on a whiteboard.</p>
<p>Session 3 Sustained attention work up Timed activities</p>	<ul style="list-style-type: none"> • Letter cancellation • Timed task • Limit visual distraction 	 <p>The response for Session 3 includes a large grid of letters for cancellation tasks and a photograph of a hand holding a sand timer. Text on the right side of the grid reads 'SAND TIMERS AND KIDS' and lists 'MEALTIME', 'PLAYTIME', and 'DAILY ACTIVITIES' with brief descriptions for each.</p>
<p>Session 4 Executive function work up</p>	<ul style="list-style-type: none"> • ADL • Routines • To-do-list • Chunking • Breaks • Rewards 	 <p>The response for Session 4 shows a 'My Morning Routine' chart with icons for tasks like 'Wash my face', 'Brush my teeth', 'Get dressed', 'Eat breakfast', and 'Go to school'. It also includes a simple 'TO DO LIST' with checkboxes and a 'Chunking' chart with a grid of colored boxes and icons representing different tasks.</p>
		 <p>The response for the final row includes a 'MOVEMENT BREAK' graphic with instructions for 5, 10, and 15 minutes of movement, and a 'My Reward Chart' with a grid of colored boxes and icons for tracking rewards.</p>

<p>Session 5 Learning & memory</p>	<ul style="list-style-type: none"> • Chunking • Active reading • Matching game • Story telling • Mind maps • Rhymes • Puzzles with pictures 	
<p>Session 6 Perceptual Motor control</p>	<ul style="list-style-type: none"> • Building blocks • Lego toys • Threading • Colouring • Painting • Puzzles • Cutting • Trampoline 	
<p>Session 7 Social cognition</p>	<ul style="list-style-type: none"> • Emotion recognition & regulation • Turn taking • Group games • Pretend play/role play • Emotion charades • Passing the ball • Cooperative drawings 	







<p>Session 8 Distraction management</p>	<ul style="list-style-type: none"> • Use fidgeting toys • Squishy, puffer balls • Physical activity • Bouncing balls • Listening music 	
<p>Session 9 Practice mindfulness & meditation</p>	<ul style="list-style-type: none"> • Mindful breathing (body scan) • Mindful colouring • Meditation • Guided imagery 	
<p>Session 10 Enhance attention span</p>	<ul style="list-style-type: none"> • Cross words • Puzzles • Finger pointed reading • Backward counting • Focus games 	
<p>Session 11 Enhance working memory</p>	<ul style="list-style-type: none"> • Number sequence • Chess • Listen & repeat from auditory memory • Visual memory 	
	<ul style="list-style-type: none"> • Complete jigsaw puzzles 	
<p>Session 12 Class room management Psycho education for parents</p>	<ul style="list-style-type: none"> • Find out learning style • Empathetic • Movement breaks • Reduce distractions • Rewards • Motivation 	

Table 3 BEHAVIOUR MODIFICATION

Activity	Short-term Goals	Responses
Session 1 Rules	<ul style="list-style-type: none"> Classroom rules good manners Dos and Don'ts Positive classroom behaviour Good habits 	
Session 2 Reduce oppositional behaviour	<ul style="list-style-type: none"> Proactive strategies In the moment strategies Post problem strategies support 	
Session 3 Interventions for conduct disorder	<ul style="list-style-type: none"> 10 tips Moral story Social stories 	
Session 4 Behaviour modification strategies	<ul style="list-style-type: none"> Moral story Home rules Class rules 	
Session 5 Anger management	<ul style="list-style-type: none"> Deep breathing Backward counting Punching bag 	
Session 6 Reduce telling lies	<ul style="list-style-type: none"> Moral story Psycho education Reward Good models 	
Session 7 Reduce sibling rivalry	<ul style="list-style-type: none"> Set goals Proactive behaviour Sibling goals Social stories 	







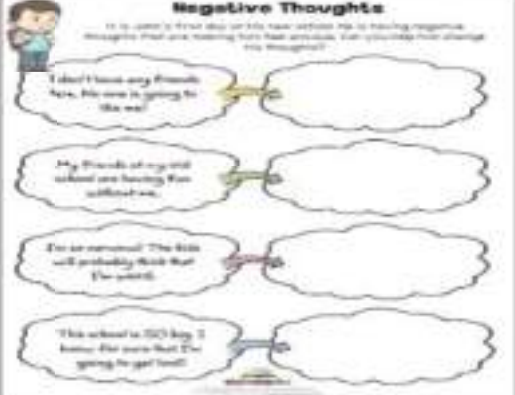
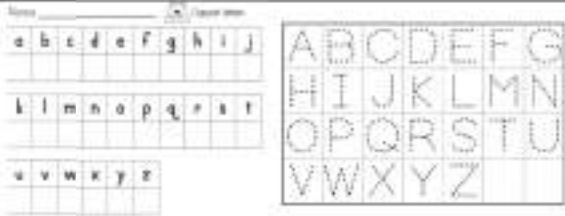

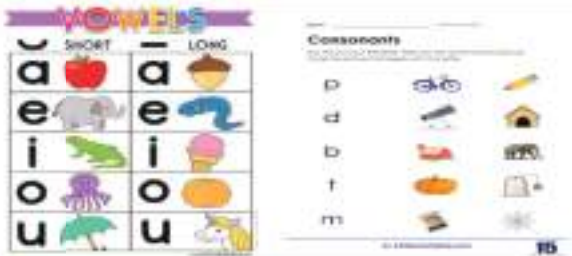



<p>Session 8</p> <p>Exercise for coping with emotional outbursts</p>	<ul style="list-style-type: none"> • Exercise • Rainbow breathing • Calm down activities • Social rules • Role play 	<p>Rainbow Breathing Put your finger at the bottom of the rainbow, follow the arc, and breathe in. On the next color, follow the arc and breathe out.</p>  <p>Calm Activities for Kids Who Need to Move</p> 
<p>Session 9</p> <p>Meditation</p>	<ul style="list-style-type: none"> • Mindfulness • Meditation • Guided imagery • Concern based remedy 	<p>Illustration ADHD With the help of ADHD, you can:</p> 
<p>Session 10</p> <p>Reduce destructive behaviour</p>	<ul style="list-style-type: none"> • 10 tips • Reward • Avoid provocation • Chart activities 	
		<p>Finish Faces</p> 
<p>Session 11</p> <p>Enhance habit of destructive behaviour</p>	<ul style="list-style-type: none"> • Share & care • Games • Set models • counseling 	
<p>Session 12</p> <p>Discipline</p>	<ul style="list-style-type: none"> • Models • Pro-social behaviour • Moral education • Alternative thinking • Effective communication • Social skill training • Family therapy 	<p>Negative Thoughts</p> <p>It is easier to find out if the new person is having negative thoughts that are making him feel nervous. Ask yourself these things:</p> 

Table 4 READING SKILL WORK UP

Activity	Short-term Goals (Eng & Mal wherever necessary)	Responses
Session 1 Letter identification	<ul style="list-style-type: none"> Worksheets Copying Tracing Joining dots Both cases 	
Session 2 Phonemic awareness	<ul style="list-style-type: none"> Phonic song Letter-sound identification Worksheets 	
Session 3 Vowels & consonants	<ul style="list-style-type: none"> worksheets 	
Session 4 Phonic 3 letter words	<ul style="list-style-type: none"> Worksheets Kalikudukka Magic pot Text books 	
Session 5 Sight words	<ul style="list-style-type: none"> Worksheets Pre kg LKG UKG 	
Session 6 Rhymes & Rhyming words	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text 	

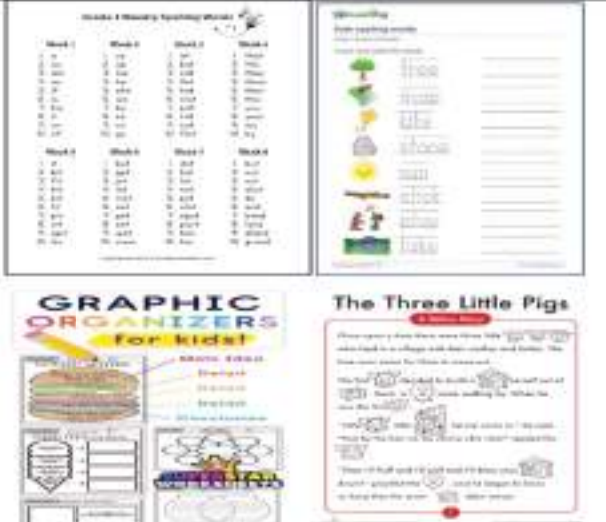
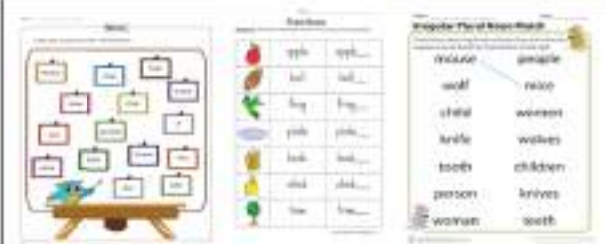










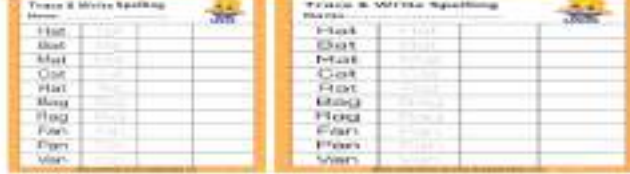


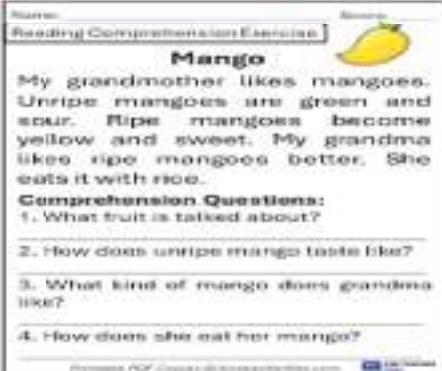

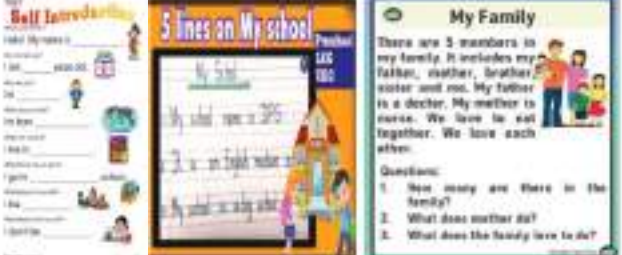
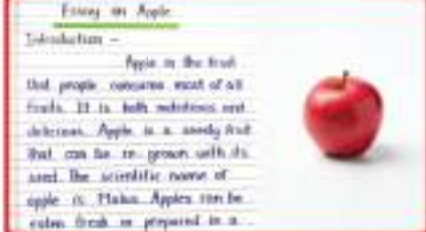
<p>Session 7</p> <p>Listening</p> <p>Comprehension</p>	<ul style="list-style-type: none"> • Story telling • New vocabularies • Read words • Graphic organizers • Worksheets 	
<p>Session 8</p> <p>Nouns</p> <p>Plurals</p> <p>Irregular plurals</p>	<ul style="list-style-type: none"> • Worksheets • Magic pot • Kalikudukka • Text books 	
<p>Session 9</p> <p>Opposites</p>	<ul style="list-style-type: none"> • Worksheets • Magic pot • Kalikudukka • Text books 	
<p>Session 10</p> <p>Adjectives</p> <p>Prepositions</p> <p>Verb + ing</p>	<ul style="list-style-type: none"> • Worksheets • Magic pot • Kalikudukka • Text books 	
<p>Session 11</p> <p>Sentence reading</p>	<ul style="list-style-type: none"> • Worksheets • Magic pot • Kalikudukka • Text • 1 minute reading • 2 minute reading 	
<p>Session 12</p> <p>Reading comprehension</p> <p>Reading fluency</p>	<ul style="list-style-type: none"> • Worksheets • Magic pot • Kalikudukka • Text books 	

Table 5 WRITING SKILL WORK UP

Activity	Short-term Goals	Responses
Session 1 Foundation skills	<ul style="list-style-type: none"> Pencil grip Posture Prewriting patterns Number tracing 	
		
Session 2 Therapy putty activities	<ul style="list-style-type: none"> Clay Play dough FM activities Writing letters, numbers 	
Session 3 Writing simple words	<ul style="list-style-type: none"> Tracing Joining dots Worksheets Magic pot Kalikudukka Text 	
Session 4 Simple sentence writing	<ul style="list-style-type: none"> Worksheets 	
Session 5 CVC combination Word blending	<ul style="list-style-type: none"> Worksheets 	
Session 6 Dictation spelling	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	

<p>Session 7</p> <p>Sight words writing words / Simple sentence</p>	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	 <p>chat hat nat gat slat that brat drat</p> <p>SENTENCE WRITING</p> <p>1. I like to swim.</p> <p>2. The bike is green.</p> <p>3. What time is it?</p> <p>4. It is cold outside.</p>
<p>Session 8</p> <p>Paragraph writing Number names</p>	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	 <p>Numbers:</p> <p>1 _____</p> <p>2 _____</p> <p>3 _____</p> <p>4 _____</p> <p>5 _____</p> <p>6 _____</p> <p>7 _____</p> <p>8 _____</p> <p>9 _____</p> <p>10 _____</p>
<p>Session 9</p> <p>Write and comprehend</p>	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	
<p>Session 10</p> <p>Q & A</p>	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	
<p>Session 11</p> <p>Writing about; Self School family</p>	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	
<p>Session 12</p> <p>Sentence writing</p>	<ul style="list-style-type: none"> Worksheets Magic pot Kalikudukka Text books 	

Activity	Short-term Goals	Responses
Session 1 Counting Count & trace	<ul style="list-style-type: none"> 0 to 10 11- 25 1- 50 1- 100 	
Session 2 Pre math skills	<ul style="list-style-type: none"> Before & after Missing numbers Big & small Far & near Heavy & light worksheets 	
Session 3 Skip counting	<ul style="list-style-type: none"> Worksheets 	
Session 4 Patterns 3 digit	<ul style="list-style-type: none"> Worksheets 	

Session 5 Clock Simple addition	<ul style="list-style-type: none"> Worksheets 	
Session 6 Simple subtraction	<ul style="list-style-type: none"> Worksheets 	

<p>Session 7</p> <p>Less than</p> <p>Greater than</p>	<ul style="list-style-type: none"> Worksheets 	<p>The hungry Alligator: $12 > 10$ $17 < 22$</p> <p>Greater Than or Less Than?: A grid with numbers and arrows indicating comparisons.</p>
<p>Session 8</p> <p>3 digit addition</p> <p>Time</p>	<ul style="list-style-type: none"> Worksheets 	<p>3 digit addition: A grid of 3-digit addition problems.</p> <p>Addition: A grid of 3-digit addition problems.</p>
<p>Session 9</p> <p>Place value</p> <p>Tables</p> <p>Number names</p>	<ul style="list-style-type: none"> Worksheets 	<p>Identifying place value: A table with numbers and their place values.</p> <p>1-5 Times Tables Chart: A colorful chart of multiplication facts from 1 to 5.</p> <p>Fill out the place value chart: A grid for writing numbers in tens, ones, and tens of thousands.</p>
<p>Session 10</p> <p>Fractions</p> <p>Time</p>	<ul style="list-style-type: none"> Worksheets 	<p>Fractions: A grid of fraction problems with visual aids.</p> <p>What time is it?: A grid of clock faces for time-telling practice.</p>
<p>Session 11</p> <p>Math drills</p>	<ul style="list-style-type: none"> Worksheets 	<p>Math drills: A grid of simple arithmetic problems.</p>
<p>Session 12</p> <p>Math drills</p>	<ul style="list-style-type: none"> Worksheets 	<p>Math drills: A grid of simple arithmetic problems.</p> <p>Addition: A grid of simple addition problems.</p>

Conclusion

In conclusion, the therapeutic process in group therapy sessions provides a dynamic and structured journey guided by a trained, qualified, experienced professional to maximize the collective healing and well-being in children and their parents. The critical elements to be focused in group therapy model are; group formation, skill mastery, psycho education, group sharing and exploration, skill practice and application, overcoming behavioural challenges, etc. Each child with ADHD is different and each needs a specifically designed programme. There is no “one” programme or set accommodations for children with ADHD. It has far reaching implications for children, families, and child care professionals. Much can be achieved by adopting a positive attitude and working collaborates with families to support the child’s development. It is vital that this occurs early in the child’s development. Therefore early intervention services for children with ADHD must be implemented in each and every health sectors and educational sectors and awareness programmes for the same should be initiated.

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**Group Therapy In Attention Deficit Hyperactive Disorder (ADHD):
Session B:
Occupational Therapy in ADHD**

Ms Bismi David
Occupational Therapist, CDC

Key Points: Structure, organization and repetitions are implemented to enhance an individual's functional performance in meaningful occupations by decreasing the symptoms of inattention, hyperactivity and impulsivity.

When people with ADHD are in a group, they learn to interact and communicate better with others. They also get the opportunity to develop the knowledge and skills needed to manage their symptoms and learn how to cope with difficult situations.

Occupational therapy strategies include problem solving, self-reinforcement, self-redirection, modelling, role playing and self-instruction to manage behaviour and increase self-control.

Sensory processing issues are more common in children with ADHD than in typically developing children. Combination between cognitive behavioural therapy and sensory integration therapy gives a better improvement.

Improvements in seated behaviours, attention skills, completion of class work and regulation of aggressive behaviour were observed as a result of sensory integration therapy.

Brain gym exercises are movements whose objective is to connect the body and the mind which improve and strengthen cognitive functions to learn.

Gross motor exercises are the essential part of ADHD group therapy for managing issues associated with ADHD in school children.

Fine motor training in ADHD can be effective in improving writing skills and in hand manipulation skills.

15.1 Introduction

Attention deficit hyperactivity disorder is one of the most common childhood behavioural disorders. ADHD is characterized by persistent inattention, hyperactivity and or impulsivity [1]. Individuals with ADHD have impairments in functioning and maintaining social relationships in multiple environments including home and school. ADHD is two to three times more frequent in boys than in girls [2].

Evidence base for OT in ADHD

Structure, organization, and routines are implemented to enhance an individual's functional performance in meaningful occupations by decreasing symptoms of inattention, hyperactivity, and impulsivity. Occupational therapists (OTs) focus on the social, motor, behavioural and sensory processing needs of individuals in the natural environments of the home, school and social settings. Occupational therapists can also work with individuals to improve or enhance interpersonal relationships and social skills [3].

Occupational therapists focus

Behaviour: For children whose impulsive behaviour is creating conflict at home and getting them into trouble at school, therapy can help them rein in the behaviour that's problematic and establish more positive relationships with the adults in their lives. It is generally called, parent training, because it involves working with parents and children together. It trains parents to interact differently with children, in order to elicit desirable behaviour on the part of the child and discourage behaviour that's causing him trouble [4].

Motor: ADHD is associated with gross motor skill deficits such as balance and poor simple tasks performance. Interventions with children suffering from ADHD should also focus on activities that enhance and improve gross motor functioning [5].

Sensory: Children with ADHD experiences sensory processing difficulties when engaging structured tasks and activities resulting in limitations with sequencing and planning motor tasks and regulating emotions [6]. Sensory processing problems impact the responses of children to sensory events in daily life [7]. Many ADHD children are vestibular seekers. Vestibular seekers appears to have hyperactivity, constantly be in motion, impulsivity and have trouble concentrating while sitting [8].

Social skills: Social skills training for ADHD seeks to improve and maintain social interaction and prevent interpersonal difficulties. Interventions tend to focus on problem solving, control of emotions, and improving verbal and non-verbal communication [9].

Conceptual background

Sensory differences are now considered ubiquitous in the population of individuals with ADHD [10]. Specific evaluations of SI and processing concerns allow occupational therapists to determine the nature and severity of the difficulties and the impact that the difficulties have on arousal, attention, praxis, and ultimately on occupational performance and participation in desired activities. The remarkable potential for change of the developing brain or Neuroplasticity throughout the life course [11]. An adaptive response defined as the ability to adjust one's action on environmental demand [12]. Sensory processing disorders resulting in limitations with sequencing and planning motor tasks and regulating emotions [13]. Structure, organization and repetitions are implemented to enhance an individual's functional performance in meaningful occupations by decreasing the symptoms of inattention, hyperactivity and impulsivity [14].

ADHD group:

Group therapy is effective in addressing ADHD. The reason is that when people with ADHD are in a group, they learn to interact and communicate better with others. They also get the opportunity to develop the knowledge and skills needed to manage their symptoms and learn how to cope with difficult situations.

Assessment

General Evaluation: An initial assessment carried out by the occupational therapist will determine the type and severity of difficulties the individual is experiencing and how they are affecting their functioning in everyday tasks. An initial assessment will use diagnostic tools, questionnaires and a detailed case history when evaluating individuals with ADHD. Assessment results and a discussion with the individual and their parents will help to decide on what the most appropriate treatment will be.

Parent and child interviews: Parent interview is a very useful way to obtain information about the child. Semi

structure interview is mandatory so that the conversation flows well which helps build the relationship with the child.

Observation: A lot of information can be learned from observing a child. The therapist can gather a lot of objective information as they observe the child.

Formal assessment tools

- Child behaviour checklist (CBCL): CBCL is used to detect behavioural and emotional problems in children and adolescents. The CBCL is completed by parents. The other two components are the Teacher's Report Form (TRF) (completed by teachers), and the Youth Self-Report (YSR) (completed by the child or adolescent himself or herself) [15]
- School function assessment (SFA): SFA assesses a student's ability to perform important non-academic functional activities that support or enable participation in the academic and related social aspects of an educational program [16]
- Visuo motor integration Test (BEERY VMI): VMI Assesses visual-motor skills in children and adults that can lead to learning, neuropsychological and behaviour problems [17].
- WEE FIM (WEE Functional Independence Measurement): The WeeFIM is a useful tool for assessing functional status in children with ADHD. WeeFIM is an 18-item, 7-level ordinal scale instrument that measures a child's consistent performance in essential daily functional skills. Three main domains (self-care, mobility, and cognition) are assessed by interviewing or by observing a child's performance of a task to criterion standards.
- Cognition and perception: Absence of quick and continual eye movements or saccades causes perceptual skill deficits in ADHD [18]. Focus should be on the following; alphabets, attention, colour perception, concentration, figure ground perception, form perception, numbers, shape concept, and size concept.
- Handwriting evaluation: Studies found that among students diagnosed with ADHD, 59% had dysgraphia and 92% had weaknesses in graphomotor skills [19]. Focus should be on; fluidity, legibility, line rules, mirroring, omission of letter/words/lines, pencil grasp, and spacing.
- Thinking process evaluation: Focus on capacity for decision making, planning, problem solving, sequencing, and sorting.

Short sensory profile (SSP): The Short Sensory Profile (SSP) is a caregiver report questionnaire used to measure sensory processing abnormalities in children. The SSP questionnaire contains 38 items organized into 7 empirically derived subscales: tactile sensitivity, taste/smell sensitivity), movement sensitivity, under responsive/seeking sensation, auditory filtering, low energy/weak, and visual/auditory sensitivity [20]

Occupational therapy interventions

There are three levels of occupational therapy interventions that may follow each other or occur simultaneously depending on the individual's goals.

1. **Preparatory methods:** These include techniques and activities that prepare someone for participating in a specific activity.

2. **Purposeful activities:** These are activities to improve their skills toward a specific goal. There is a vast range of potential activities that largely depend on the individual but could include communication, sports, volunteer work, gardening, or social work.

3. **Occupation-based intervention:** Occupation-based interventions involve an individual working towards a goal and completing tasks under supervision. Again, these activities vary significantly from person to person, but some possibilities include completing schoolwork, following directions, or getting dressed. As the occupational therapist observes the individual, they can assess their performance. This allows them to adapt to the activity and further increase independence, skill acquisition, and self-efficacy.

Sensory integration therapy:

Sensory processing problems are more common in children with ADHD than in typically developing children [21]. Sensory integration is the neurological process that organises sensation from one's own body and from the environment and makes it possible to use the body effectively with the environment [22]. Combination between cognitive behavioural therapy and sensory integration therapy gives a better improvement [23]. SI therapy include structured exposure to sensory input, movement therapy, balance treatments, carefully designed and customised physical activities and accommodations.

1. Sensory activities:

1. Brushing therapy: Brushing therapy is often a part of a sensory group. The co therapist (mother) is the one who will be administering the technique.

The first step involves using a soft, plastic, sensory brush or Thera Pressure Brush which is run over the child's skin, using very firm pressure; it is like a deep pressure massage. Brushing starts at the arms and works down to the feet. The face, chest, and stomach area are never brushed because these are very sensitive areas. Brushing these areas may cause adverse reactions including vomiting.

After the brushing therapy, therapists may also prescribe gentle joint compressions to the shoulders, elbows, wrists, fingers, hips, knees/ankles for a count of 10.



2. Neutral warmth:

Neutral warmth acts through stimulating the thermo receptors and activating parasympathetic responses. It is one of the best calming technique. Materials needed for neutral warmth:

- Bed sheet/ blanket
- Therapy ball/ pillow

Procedure: Spread the bed sheet or blanket on the floor or the bed, and have the child lie down on one corner of the blanket in the supine position and roll the blanket tightly around him/ her (should cover from shoulder to feet).

Precautions

- Should not wrap the blanket tightly around the neck of the child
- The child should be able to breathe and speak comfortably
- Pressure should be moderate, and should not cause discomfort to the child
- Do not apply pressure over the chest, abdomen, and genitals.

Recent studies suggests that there is significant effectiveness of brushing therapy and neutral warmth for treating children with sensory defensiveness and aggressive behavior [24].



Brain Gym: Brain gym is a set of movements whose objective is to connect the body and the mind, stimulate the use of the cerebral hemispheres through physical and mental strategies, and also improve and strengthen cognitive functions to learn. Brain Gym® intervention are effective in enhancing participants' attention span and working memory performance [15].

Cross Crawls

Have your child stand up straight and lift their left knee. Instruct them to put their right hand on their left knee, crossing the midline of body. After they put their right hand on their left knee, have the child switch by lifting the right knee and putting the left hand on the right knee. Movements should be done slow and accurate. It improve communication between the right and left hemispheres of the brain for higher-level reasoning (critical thinking, problem-solving, auditory, organization, and more).

Brain Buttons

Have your child or student stand up straight and place one hand over their navel (bellybutton). At the same time, have your child take their thumb and index finger and place the two fingers directly under their collar bone (clavicle). Both hands should be on the tummy and the collar bone at the same time. Have your child or student hold that position for at least 30 seconds or as long as it takes for the child to begin feeling re-energized.

Hook up:

If your child is standing, have them cross one foot over the other (legs always straight). Now, have your child stretch out their arms and cross them in front of their body. As they are crossed, have the palms of the right and left hands touch together and lock fingers.

Lazy Eight's

This exercise requires your child to draw the figure eight either on a sheet of paper or in the air using their hands. This loosens the muscles in his arms and wrists and activates the creative side of your child. It also improves eyesight with eye muscle coordination and peripheral vision.



Double Doodle

This is a bilateral drawing exercise where your child draws two images with both his/her hands. This helps improve several skills like learning spelling accuracy, writing and recognition of symbols, calculation, etc.



The Thinking Cap

Your child is required to hold both their ears with the thumb and the index finger and then roll and unroll the outer portion of the ear. This improves your child's short-term memory, hearing, and peripheral vision.



Breathing exercises and yoga:

For children with ADHD, as a rule, the part of the brain that is responsible for the regulation of brain activity - the reticular formation - is deficient. This leads to the fact that they often experience states of inadequate hyperactivity, increased distraction and exhaustion. Breathing exercise like diaphragmatic rhythmic deep breathing - belly breathing helps to better supply the brain with oxygen and helps the reticular formation to better cope with its role. When the reticular formation receives enough oxygen, it begins to better regulate the child's state of activity [26].



Belly breathing:

Find a comfortable, quiet place for the child to sit or lie down.

For example, ask the child to sit in a chair cross-legged, or lying on the back with a small pillow under the head and another under the knees.

Place one hand on the upper chest and the other hand on the belly, below the ribcage.

Allow the belly to relax, without forcing it inward by squeezing or clenching the muscles.

Breathe in slowly through the nose. The air should move into the nose and downward so that the child feel the stomach rise with the other hand and fall inward (toward the spine).

Exhale slowly through slightly pursed lips. Take note of the hand on the chest, which should remain relatively still.

Rhythmic breathing:

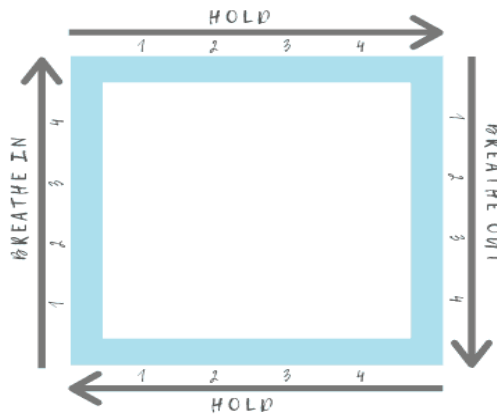


Triangular breathing:

- Breathe in for 3 seconds
- Hold the breath for three seconds
- And breathe out for 3 seconds.

Square breathing

- Begin by slowly exhaling all the air out.
- Then, gently inhale through the nose to a slow count of 4.
- Hold at the top of the breath for a count of 4.
- Then gently exhale through the mouth for a count of 4.
- At the bottom of the breath, pause and hold for the count of 4.



Fine motor activities:

1. **Paper mosaic:** Paper mosaic is a great activity for ADHD kids. Glue the pieces of paper over the sketch the child made. Leave a small gap between each piece for a tiled effect, or place them close together or overlapping for a different effect.



2. **Picture collage:** Collages are art and craft works that involve selecting, assembling, and pasting materials together.



3 . Montage: Montages are art that involves sticking buttons or seeds over the sketch you made.



4 . Paper beads:

Cut strips of magazine into long triangles. Take one of your magazine strips and begin wrapping it around the stick, starting with the wider end. Wrap it near the end of the stick so that it will be easy to slide off when you're done.



5 . Paper tree:

Roll a sheet of green paper into a cone. Take a sheet of green construction paper and roll it lengthwise into a cone shape. Staple or glue the paper together. Cut some wide and narrow strips of green paper. Stack the strips together to make your cutting faster. Let your tree dry, then decorate it as desired. Glue pompoms or buttons to the tree for a rustic look. The child can also cut shapes out of craft foam or felt, and use those instead. For a more natural look, paint the ends of the fringes with white paint.

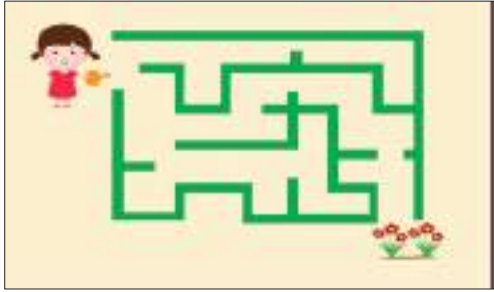


6 . Paper rings:

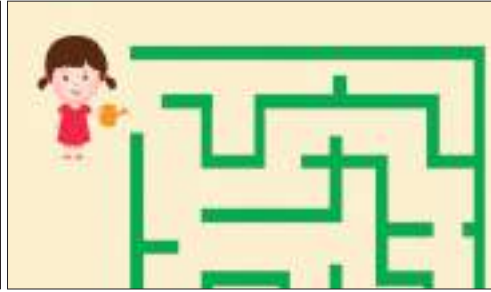
- Make a strip of paper into a ring and glue it together
- Slide another strip of paper through the ring and glue it into a ring.



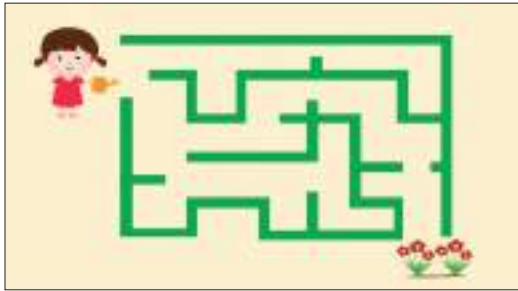
7. Puzzles



8. Shape counting



9. Beads activity



10. Maze activity



11. Play dough activity

Cut strips of paper. Make one strip of paper and make a loop. Glue the ends of paper strips together, making a paper loop. Glue the loops on one side of the paper circle. Apply some glue onto the green paper straw and press it in the middle of the flower.



Gross motor activities:



1. Therapy ball exercises: prone



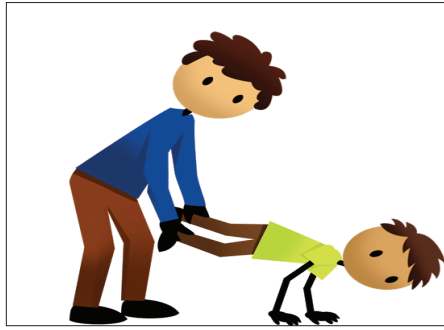
2. Ball passing:



3. Ball sorting activity



4. Motor planning



5. Wheel barrow walking



6. Basketball



7. Balance board activity



8. Bean bag toss



9. Therapy ball exercises: Sitting



10. Crawling / creeping activities



11. Hopping on rings



12. Ball sorting on tandem walk

Benefits:

Group therapy can be effective in addressing ADHD. The reason is that when people with ADHD are in a group, they learn to interact and communicate better with others. They also get the opportunity to develop the knowledge and skills needed to manage their symptoms and learn how to cope with difficult situations.

ADHD GROUP OCCUPATIONAL THERAPY INTERVENTIONS: SUGGESTED SCHEDULE

OCCUPATIONAL THERAPY: ADHD GROUP			
SESSION		GROSS MOTOR ACTIVITY	FINE MOTOR ACTIVITY
SESSION-1	BRAIN GYM& BREATHING EXERCISE	Therapy ball exercise: Prone	Paper mosaic
SESSION-2		Ball passing	Picture collage
SESSION-3		Ball sorting	Montage
SESSION-4		Motor planning	Paper beads
SESSION-5		Wheel barrow walking	Paper tree
SESSION-6		Basket ball	Paper rings
SESSION-7		Balance board: Ball throwing	Puzzles
SESSION-8		Bean bag toss	Shape sorting & counting
SESSION-9		Therapy ball exercise: Sitting	Beads
SESSION-10		Crawling exercises	Play dough
SESSION-11		Hopping on rings	Maze activity
SESSION-12		Ball sorting and tandem walk	Paper flowers

OCCUPATIONAL THERAPY : ADHD GROUP HOME TRAINING	
MORNING	Brushing Therapy, Neutral warmth
EVENING	Brushing Therapy, Neutral warmth, Activity therapy:30 minutes
NIGHT	Brushing Therapy

Case study:

Aadhi is 6 year old diagnosed attention deficit hyperactivity disorder; he loves jumping at the playground, running and bumping. Additionally he has poor sitting behaviour, impulsivity and poor attention span. Problems with fine motor skills impact the ability to write, colour and cut with scissors in an age appropriate manner. Moreover he has poor self-help skills and difficulty with sleeping. The occupational therapist used clinical reasoning skills to provide an integrative approach combining sensory integration therapy and brain gym exercises. . One example of a therapeutic session was the client directed and family centred use of sensory integration therapy room with both Aadhi and his mother. Encouraging mother's active participation with the child was practiced anger management strategies and brain gym. Sensory interventions like brushing therapy, wrapping, play dough activities, are administered. Multi sorting tasks are suggestive to improve attention span and concentration.

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Group Therapy in Attention Deficit Hyperactive Disorder (ADHD):

SESSION C:

Parent Training on Behavior Management in ADHD

Ms Jasmine George
Clinical Psychologist, CDC

Key points: Behavioural problems are common among children with ADHD with Oppositional Defiant Disorder and Conduct Disorder as the most common co-morbidities of ADHD. If left unmanaged, these behavioural problems worsen and may lead to an emergence of anti-social personality disorder in adulthood.

Parent training for behaviour management begins with psycho-educating them about ADHD, its aetiology, and the behaviour problems associated with it.

Parents are given an understanding as to why children misbehave, and positive parenting is introduced.

All (mis)behaviours are learned and can hence be modified with use of reinforcements and punishments.

Behaviour modification involves a functional analysis of behaviour and using appropriate techniques (e.g. Extinction, differential reinforcement, token economy, time out, etc).

For Oppositional and defiant behaviours, Errorless Compliance Training is used as a graduated and success focused approach.

Managing anger requires an understanding that anger is a normal human emotion and that children need to be taught to express it in appropriate ways.

Parents need to provide support and guidance, and be model for their child in managing anger effectively.

Different distraction and calming down techniques need to be taught and practiced with the child.

Introduction

At least 25% of children with ADHD also have behavior characteristic of ODD, and around 13.3% of these children will subsequently develop conduct disorder (CD) where overall prognosis is worse yet again. Significant amount of research has provided evidence that parent training for families of children with ADHD results in improved parenting behavior, reduced parent stress, and reduced disruptive child behaviour.

The suggested mode of treatment for children with ADHD/ODD is parent training. The aim is learn particular strategies for parenting that modify the way a child and parent interact, encouraging prosocial behaviour compliance and reducing disruptive behaviour. Parents will adapt to and cope with ADHD behavior while modifying defiance and aggressive disruptive behavior.

Parent training in management of children includes the following:

1. Psycho educating parents about ADHD

Parent training begins with providing the parents with information about ADHD in terms of its behavioural symptoms, and etiology. Information about ODD and why many children with ADHD also develop ODD has to be provided.

ADHD children have difficulty in three areas: impulse control, over activity, and attention. The distinctive feature of ADHD is impulsiveness, or a lack of behavioral inhibition. There may be an inability to delay a response (e.g., there may be a short latency between antecedent events and behavior) or sustain an inhibited response. Executive functions (e.g., rules) may have little control over behavior. For example, children may act as if they are not thinking about the consequences of their behavior or be unduly influenced by immediate rewards and escape opportunities. Compared with other same-age children, children with hyperactive behavior have far higher rates of motor behavior, including vocal behavior. Poor attention can be manifested in two ways. Children may present with shorter sustained attention, particularly in the context of long, repetitive, and passive tasks. Children with ADHD are readily distracted by events and opportunities around them, particularly stimuli embedded within the task with which they are engaged.

2. Psycho educating parents about Oppositional Defiant Disorder (ODD)

Many children with ADHD present with another separate childhood disorder called Oppositional Defiant Disorder. The essential characteristic of oppositional defiant disorder is a recurrent pattern of negativistic, defiant, disobedient, and hostile behavior toward authority figures that is clearly more frequent, more intense, and more persistent across the child's development than is typically observed in individuals of similar age and developmental level.

Negativistic and defiant behaviors are expressed by persistent stubbornness, resistance to directions, and unwillingness to compromise, give in, or negotiate with adults or peers. Defiance may also include deliberate or persistent testing of limits, usually by ignoring orders, arguing, and failing to accept blame for misdeeds. Hostility can be directed at adults or peers and is shown by deliberately annoying others or by verbal aggression.

How does ADHD, a biologically based neurological disorder, develop to include ODD?

- a. **Stepping Stone Model.** One explanation points that ADHD is causally related to ODD. Children with ADHD may not pay attention or listen to instructions. They may not follow directions for a long duration, they may respond quickly and carelessly, or they may not finish the assigned task. Children with ADHD could find it difficult to focus or follow directions. They might react quickly and carelessly, they may fail to finish the task given to them, or they might not follow instructions for an extended period of time.
- b. **Coercion.** A behavior analysis helps to explain the development of ODD in children with ADHD. Adults might give in to their children's protests sooner than they otherwise would because of the persistent intensity of ADHD behavior. For example, in their verbal interactions parents present repeated commands, verbal reprimands, and correction more often to children with hyperactive behavior. However, when children with ADHD behave well, their parents give fewer rewards for compliance, initiate fewer verbal interactions, and attend less to appropriate behavior and vocalizations initiated by the child.

An example of a coercion analysis of child behavior that might grow to ODD follows:

A = Parent tells a child to put toy away.

B = Child whines noisily.

C = Parent does not make the child put the toy away.

Future = Child cries and whines more when told to put fun things away.

3. Positive Parenting

Training parents in behavior management involves teaching them skills involved in positive parenting. Positive parenting is parental practices that benefit the full development of children through non-violence, care, recognition, guidance and the establishment of limits. It is important to have discussions with parents about what makes children behave in challenging ways. Children do not usually misbehave just to upset or annoy their parents. There is often a reason behind a child's behaviour. It may be:

- they are upset or anxious about school;
- they feel jealous of their brother or sister;
- they want their parent to listen to them;
- they want their parent to spend time with them.

Behaviour patterns can get stuck. At some point most children will misbehave to get attention. If a parent doesn't pay much attention when children are behaving well, some children will try 'acting up' to get attention, even if it results in a telling off.

Tip 1: Talk and Listen

- Try to use positive words. Tell your child what you want them to do, not what you don't want them to do. Instead of "don't make such a mess" try "tidy up your toys please".
- Speak to the child in a calm voice. Sometimes changing your tone or volume can be enough to stop a fraught situation or get your child to do what you want.
- Encourage your child to talk to you – sit beside him/her – they'll find it easier to talk and listen to you if you're not standing over them. Spend some time with your child each day to talk about the day, what they did, how they felt.
- If you have to say 'no', give your child a good reason and offer an alternative. Where possible talk with them about the rules and what you expect from them. Be clear.

Tip 2: Set Boundaries - Be consistent.

- Parents need to agree the rules. It will help the child if both parents take the same approach.
- When you say no, mean no. Do not give into the child's tantrums.
- If you make promises keep them.
- Rules should be simple and clear so the child understands exactly what is to be done or not done.

Tip 3: Reward and Notice Good Behaviour - Sometimes it is easy to ignore children when they are behaving well, and only notice them when they are misbehaving. Children love their parents' attention, and if they have to behave badly to get it, they will. Give them lots of praise when they are behaving well, rather than focusing on misbehaviour.

- Rewards do not have to be material things.
- Real praise and encouragement is the best reward as it can boost a child and build self-esteem and confidence.
- Try not to stress over the little things. If you are praising things they are doing well, and ignoring the small niggles, your child will learn that unacceptable behaviour no longer gets them the attention.
- Praise: As a general rule, try to give five times more praise than criticism.
- Avoid comparisons: All children are unique. Don't compare your child to other children.

4. Behavior Modification Procedure

Behavior modification techniques are being used since long to help parents manage problem behaviour in

children. These techniques are based on behavioural principles of learning which states that **all behaviors are learned behaviors, and can be changed or modified.**

Behavior modification uses the concept of reinforcement and punishment. **Reinforcement** is a process in which the consequences that happen after child's behavior increase the likelihood that he will do that behavior again. By giving your child reinforcers at home for good behavior we are trying to increase the likelihood that s/he will continue to show good behavior at home. Reinforcement can be positive or negative. Positive reinforcement includes providing the child with something pleasant or desirable, like praise, hug, or tangible rewards. Negative reinforcement involves allowing the child to escape an undesirable or aversive situation. **Punishment** is a process in which the consequences that happen after child's behavior decreases the likelihood that he will do that behavior again. A positive punishment involves giving aversive or unpleasant stimuli for problem behaviour, whereas a negative punishment involves removing access to a pleasant or desirable stimuli or situation.

To modify a particular behavior, we need to first define the behaviour in question in observable and measurable terms. Behavior refers to any action, reaction, or activity of an organism that can be observed and recorded. Behavior involves a person's actions (what people do or say). It is not a static characteristic of a person. Eg. He/she is angry. This does not tell us about the behavior. **He screamed at his mother, ran upstairs, and slammed the door to his room.** This is a behavior that can be labeled as **anger**.

Once we have clearly defined the behaviour, we need to measure the behaviour for its baseline. Behaviors can be measured in terms of its frequency, duration, or intensity. **Frequency** is the number of times the behavior occurs in an observation period. To measure the frequency of a behaviour, simply count each time that it occurs. **Duration** is the total amount of time occupied by the behavior from start to finish. Measure the duration of a behavior by timing it from its onset to its offset. The **Intensity** of a behaviour is the amount of force, energy, or exertion involved in it. Intensity often is recorded with a measurement instrument or by using a rating scale. For example, Parents might use a rating scale from 1 to 5 to measure the intensity of a child's tantrum.

The next step involves carrying out a **functional assessment** to understand why a child engages in a particular behaviour. Functional assessment is the process of gathering information about the antecedents and consequences that are functionally related to the occurrence of a problem behavior. Parents are asked to keep a track of antecedent, behaviour and, a consequence each time the problem behavior occurs. An Antecedent is what happened just before the behavior occurred. The Behavior is the exact behavior that parents have defined. The consequence is what happened immediately after the behavior. Doing a functional analysis of behaviour will help us to control the antecedents and consequences for the behaviour, thereby helping us modify the behaviour.

We also need to gather information on a list of potential reinforcers for the child that can be used in the process of behaviour modification. Reinforcers can be tangible items like a toy, something to eat; or a verbal praise; or access to an activity; or simply giving attention to the child.

After all the above mentioned information has been gathered, we now move on to apply specific behaviour modification techniques. Following are certain techniques that can be used to modify behaviours:

1. **Extinction** – involves eliminating the reinforcing consequence for a problem behavior thereby resulting in a decrease in the frequency of the behavior.
 - To use extinction, we first need to identify the reinforcer that maintains the problem behavior and then eliminate it (make sure it no longer follows the behavior). Do not assume that a particular reinforcer is maintaining a problem behavior. The same problem behavior exhibited by different people may be maintained by different reinforcers.
 - Make sure that it is safe to use the extinction procedure. It is important to determine whether extinction could result in harm to the child exhibiting the problem behavior or to other persons in the immediate environment.

- o The use of extinction often is accompanied by an extinction burst, in which the behavior increases in frequency, duration, or intensity, or novel behaviors or emotional responses occur. Parents need to be informed about this extinction burst and be prepared for it.
 - o Consistency needs to be maintained while implementing the extinction procedure in a sense that all people involved in the treatment must be consistent and eliminate the reinforcing consequence each time the problem behavior occurs.
 - o A behavior that is no longer reinforced will decrease in frequency and stop.
- ii. Token Economy – A token economy is reinforcement system in which conditioned reinforcers called tokens are delivered to people for desirable behaviors. The tokens are later exchanged for backup reinforcers. Each point received by child for desirable behavior is a token. A token is something delivered to a child immediately after a desirable behavior, accumulated by the child, and later exchanged for backup reinforcers. Backup reinforcers can be obtained only by paying for them with tokens, and tokens can be obtained only by exhibiting desirable behaviors.



5. Errorless Compliance Training for ODD

Behavior change brought about by means of punishment rarely generalizes to settings where the threat of punishment is not present. There is potential for punitive or power-assertive consequences that are intended to reduce problem behaviors to actually serve as reinforcers for aberrant responding. Some children may be deprived of adequate levels of stimulation, attention, and praise from their parents. Under such circumstances, youngsters may seek less positive forms of stimulation and attention (e.g., scolding, reprimands, and even physical struggles) and may use undesirable responses to initiate such interaction.

Errorless Compliance Training involves a graduated and success-focused approach. With this intervention, the environment is arranged to ensure the lowest possible probability of noncompliant responses during intervention.

The treatment process begins with an observational probability assessment of child compliance to parental requests to determine a hierarchy of child compliance. Requests are then divided into four probability levels, from requests that are highly likely to yield compliance (Level 1) to those that rarely do (Level 4). During the initial phase of treatment, parents are taught to deliver a high proportion of Level 1 requests and to immerse the child in praise and warm physical contact after each compliant response.

Lower probability requests (Levels 2, 3, and 4) are gradually and sequentially introduced at a slow enough rate to ensure continued high rates of compliance. By the end of treatment, the child is typically complying at a high rate even to low probability requests.

Thus, through gradual introduction of challenging requests made by parents, which are often the primary triggers for problem behavior, children are taught to tolerate difficult compliance situations that were previously associated with defiance.

Extinction: During Errorless Compliance Training, we ask parents to pay little attention to episodes of noncompliance because some behaviors may have been reinforced and maintained by parental attention in the form of scolding and angry retorts. In Errorless Compliance Training, the extinction component involves trying to ensure that noncompliance is not functional for accessing desirable social outcomes for the child.

What Is Errorless Compliance Training?

- Parents use the Errorless Compliance Training approach to teach their children to cooperate with their requests. With this approach, the parent focuses much more on child success and pays less attention to child failure.
- Parents start treatment by asking their child to complete tasks that they enjoy or are easy for them to do. By starting with such easy requests, parents greatly increase child compliance and opportunities to reward the child for cooperation.
- Parents praise and reward their children for compliance to these requests.
- After children have successfully completed many easy tasks requested by their parents for several days, tasks that are slightly more difficult are introduced. Task difficulty is introduced gradually to ensure that children continue to respond to requests with the same high rate of cooperation. Parents continue to praise and reward the children for compliance with these more challenging requests.
- By the end of treatment, children typically continue to comply with requests that they may have refused to cooperate with before treatment.

Anger Management

Anger is a normal emotion that everyone feels from time to time. Anger may be an appropriate response in some situations, the challenge is to help children stay safe and to keep others safe too. Anger is a secondary emotion that erupts due to an underlying emotion of maybe: frustration, embarrassment, hurt, feeling that something is unjust, fear etc. Managing anger is one of the biggest emotional issues that children face. Anger needs to be managed, rather than simply avoided. Suppressing anger within oneself doesn't work as it can bottle up and eventually burst out in the form of physical violence or verbal aggression. Children need to be taught that anger can be expressed in ways that are not hurtful to anyone including themselves.

Anger Coping Techniques:

1. *Be a model for children:-* Show them how you use appropriate ways to tell others you are angry and sort out problems.
2. *Discuss feelings:-* It helps children to learn that having angry feelings is normal and is something that can be talked about. For them to learn to manage anger effectively they need adult support and guidance. They need to know that anger is a normal human emotion and that there are acceptable ways of expressing it. They need to feel understood and supported rather than judged or blamed for feeling angry.
3. *Anticipate and prepare:-* Adults can help children manage their anger by identifying situations that often trigger angry responses and by being prepared to offer support. This may include diversion techniques and planning with an individual child/young person in advance how he or she can handle a

challenging situation.

4. *Use positive discipline*:- Providing specific praise when children manage their anger well supports their learning.
5. Deep breathing: When one is angry, their breath becomes heavier and faster. Deep breathing allows to slow down breath and calm oneself. Take a deep breath in through the nose, while counting to 5. Hold the breath for about 3 seconds. Breathe out through the mouth, while counting to 5. Repeat this step until the child feel calm.
6. Draw a picture about it or write down your feelings. This helps in appropriate venting of emotions without causing harm to anyone.
7. Distraction: Go for a walk, listen to music, do coloring, or engage in any activity that one likes.

Conclusion

As the chances of children with ADHD to develop behavior problems as they grow older are significantly high, it is important to train parents in managing such behavior efficiently before it gets worse. Parent training programs are based on behavioural principles and equip parent to deal with their child's behaviours on their own. It allows parents to be compassionate and understanding to their child. The management techniques in this chapter provide parents with skills to teach their children appropriate behaviors in different situations.

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Group Therapy in Attention Deficit Hyperactive Disorder (Adhd):

SESSIOND:

Physical Activity Interventions for ADHD

Dr Juby Raj AR

Project Associate, CDC

Introduction

Physical exercise has been found to have positive effects on general health and well-being, improving mood and quality of life, and reducing stress responses. While physical activity can refer to any bodily movement caused by skeletal muscles, with expenditure of energy, exercise is a planned, structured physical activity, intended for physical fitness. A growing body of literature suggests beneficial effects of exercise on symptoms of attention deficit hyperactivity disorder (ADHD). Improvements in neurobehavioral functions have been demonstrated, including reduced impulsivity and hyperactivity, improved attention, and enhanced performance on executive functioning tasks. Increased exercise levels have been found to be associated with alleviated ADHD symptoms in the general population.

Motor competence refers to the child's capacity to participate meaningfully in play, games, and activities and is a key enabler of child's physical activity. Motor competence in voluntary goal-oriented movement requires the use of limbs and skills in which both the movement and the outcome of action are emphasized. Developing motor competence in fundamental motor skills like moving through space (locomotion e.g., running, jumping), having control over their musculature in opposition to gravity (balance and stability e.g., balancing, twisting), and ability to make controlled and precise contact with objects in their environment (object manipulation e.g., grasping, handling, throwing, catching, tool use).[1,2]

Motor skills and coordination deficits in ADHD

Studies have shown that children with attention deficit hyperactivity disorder (ADHD) experience more deficits in both fine and gross motor skills, especially in tasks requiring coordination of complex movements, such as handwriting, than their non-ADHD counterparts. They have impaired fine and gross motor skills and appear excessively clumsy and exhibit excessive disproportionate level of aimless, excessive motor activity, restlessness, fidgeting. Inattentive symptoms relate mostly to motor coordination problems, though a relationship between hyperactive and impulsive symptoms and motor coordination problems has also been reported.

Developmental coordination disorder (DCD) has also been shown to co-exist in children and individuals with ADHD. [3–5] Kaiser et al. systematically reviewed 30 articles on motor skills of children with ADHD and 15 articles which analysed the influence of ADHD medication on motor skills and motor control. The review showed that children with ADHD inattentive subtype seem to have more impairment of fine motor

skills, slow reaction time, and online motor control during complex tasks. Also, when on medication, the ADHD children with mild motor deficits before medication tend to improve their motor skills to the normal range, whereas the ADHD children with severe motor deficits before medication show persistent motor skill impairment which might meet the diagnostic criteria of developmental coordination disorder (DCD) as a comorbid disorder.[6]

The prevalence of motor problems in children with ADHD ranges from 30% to 52%.[7,8] Pitcher et al assessed fine and gross motor ability of males with attention-deficit-hyperactivity disorder (ADHD) were compared with a group of control children using the Movement Assessment Battery for Children (MABC) and the Purdue Pegboard test. They found that 58% of children with predominantly inattentive ADHD subtype, 49% with ADHD combined subtype and 47% with ADHD hyperactivity and impulsiveness had motor problems.[9]

Fliers et al. found a low-to-very low level of motor development in 52% of children with ADHD. Based on clinical and epidemiological studies, they suggested that 30–50% of children with ADHD have specific motor-skill problems.[3,10]

Motor problems lead to difficulties in everyday life, including academic performance, sport, play and self-esteem. These deficits may have an intense effect on children's development, leading to difficulty with written communication, inhibited social interaction and poor performance in sports activities. Poor fine motor skills can make cognitive learning and performance more difficult because of the involvement of fine motor skills in cognitive activities.[11,12]

Neurophysiological Basis and Relevance

Motor deficits have been hypothesized as part of the basic symptomatology of ADHD, and also a manifestation of DCD, which has a high prevalence among children with ADHD.

Many of the differences found in the neural systems between ADHD and neurotypical comparisons are present in the areas responsible for motor control. Reductions in cerebral volume, cerebellum, prefrontal cortex and right caudate in individuals with ADHD, delayed or abnormal maturation of the prefrontal cortex, amygdala, accumbens, and hippocampus, abnormalities in fronto-striatal functioning-hypoactivity in the dopaminergic and noradrenergic systems have been implicated in the executive and non-executive dysfunction in ADHD. [13–15] Three mesocortical, mesolimbic and nigrostriatal pathways have been shown to be dysfunctional and consequently cause deficiencies in the cortical areas, resulting in ADHD symptoms.[16–18]

Sagvolden et al proposes a dynamic developmental theory of ADHD combined and hyperactivity-impulsivity subtypes based on the hypothesis that altered dopaminergic function plays a pivotal role by failing to modulate nondopaminergic (glutamate and GABA) signal transmission appropriately. A hypofunctioning mesolimbic dopamine branch creates altered reinforcement of behavior and deficient extinction of previously reinforced behavior. This leads to delay aversion, failure to "inhibit" responses ("disinhibition"), impulsiveness, deficient sustained attention, and development of hyperactivity in novel situations. A hypofunctioning mesocortical dopamine branch will cause attention response deficiencies (deficient orienting responses, impaired saccadic eye movements, poorer attention responses toward a target) and poor behavioral planning (executive dysfunction). A hypofunctioning nigrostriatal dopamine branch will cause impaired modulation of motor functions and deficient nondeclarative habit learning and memory. These impairments will give rise to apparent developmental delay, clumsiness, neurological "soft signs," and a "failure to inhibit" responses when quick reactions are required. The theory predicts that behavior and symptoms in ADHD result from the interplay between individual predispositions and the surroundings.[17,18]

The altered dopaminergic function and hypofunctioning nigrostriatal dopamine will lead to problems with gait, balance, laterality, gross and fine motor control.

Difficulties with motor inhibition may be associated with disturbances in the orbital prefrontal circuit

system, which also plays a central role in executive functions. A morphometric MRI study of right-handed ADHD boys and matched healthy controls by Berquin et al. suggests that cerebellar-prefrontal circuit dysfunction may underlie the motor control, inhibition and executive function deficits encountered in ADHD.[19] Impaired praxis and manual dexterity measures are associated with grey matter volume in the post-central gyrus in children with ASD and ADHD.[20]

Children with ADHD tend to score lower than their typically developing counterparts in areas of balance, stability, and object control. In a longitudinal neuro-imaging study by Mackie et al, 36 children with ADHD were compared with 36 matched healthy comparison subjects. They found volumetric abnormalities in pre-central and post-central gyri, the inferior parietal cortex and a nonprogressive loss of volume in the superior cerebellar vermis of subjects with ADHD. ADHD subjects with worse clinical outcome exhibit a downward trajectory in volumes of the right and left inferior-posterior cerebellar lobes, which become progressively smaller during adolescence relative to both Typically developing and ADHD with better outcomes.[21]

ADHD symptoms and balance deficits have been hypothesized to be related to persisting primitive reflexes, such as the Moro Reflex, Asymmetric Tonic Neck Reflex (ATNR), Symmetric Tonic Neck Reflex (STNR), tonic labyrinthine reflex and the Galant spinal reflex. ATNR, tonic labyrinthine and Galant spinal reflexes manifest in an irritation of the lumbar area, and frequent, visible movement of the lower and upper limbs, an inability to stand still, problems playing games or doing group activities. A 2021 study by Petr Bob et al. demonstrated that ADHD symptoms and balance deficits are strongly and specifically associated with persistent ATNR in girls and STNR in boys.[22]

Ability of self-organization in dynamic systems, that is, the body's ability to identify a stable pattern within the context of the body's characteristics, and environment is lower in ADHD populations.[17] Children with ADHD need a greater range of motion for the trial-and-error process of finding the right strategy to keep balance. Rosa Neto et al. studied the fine and global motricity, balance, body schema, and spatial and temporal organization of 50 ADHD and 150 typically developing controls. Results showed a deficit of nearly two years in the motor development of children with ADHD compared with the normative sample. [23] Task constraints, maturity, and environmental demands influence the selection of appropriate balance strategies- may limit the motor competence development in ADHD children. Inappropriate constraints put forward by adults, and perceived lower levels of motor competence than their peers also limit the opportunity and motivation of ADHD children to engage in physical skill development activities.

Potential of Physical Exercise interventions in ADHD

Physical exercise interventions potentially improve cognitive function and mental health through the neurobiological mechanism (changes in the structural and functioning composition of the brain such as stimulating brain-derived neurotrophic factor), the psychosocial mechanism (satisfying basic psychological needs such as through social interaction) and the behavioural mechanism (changes in associated behaviours through self-regulation and coping skills and improved sleep quality).[24,25]

Acute bouts of exercise-transient improvements, a positive mood shift, the release of endorphins, and an increase in cerebral blood flow, while chronic Physical exercise interventions produce physiological adaptation- brain structure and function, enhance neurotransmitter systems, upregulate BDNF, increase neurogenesis, and improve psychological well-being. [26,27]

Studies have reported that exercises augment the synthesis and releases of dopamine and other CA in the prefrontal cortex, nucleus accumbens, caudate nucleus, and basal ganglia.[28,29] Stimulant medications in ADHD act by increasing the availability of dopamine and norepinephrine in the prefrontal cortex resulting in reduction of symptoms and improvement of executive functioning in the majority of ADHD patients. In a similar way, exercise might compensate for dysregulated catecholamine levels in ADHD patients and thereby improve cognitive and behavioral functioning and can be an adjunct to ADHD treatment.

Subtype analysis in the children/adolescent group found significant improvement of ADHD inattention

symptoms. Although the results might be biased by the high heterogeneity, Various forms of physical activity interventions have been studied for ADHD, including structured exercise sessions, dance forms, walking, treadmill, yoga etc. A meta-analyses of nine before–after studies (232 participants) and 14 two-group control studies (162 participants/141 controls) on exercise interventions for ADHD, by Xie et al. showed significant improvements on all studied ADHD-related symptoms- inattention, hyperactivity/impulsivity, emotional problems, and behavioral problems. Meta-analyses for two-group control studies further confirmed that PA intervention significantly improved the inattentive symptom. [30] Stratified analysis based on the type of motor skills, showed that closed motor skills are beneficial for hyperactive/impulsive problems, while open motor skills are beneficial for attention problems. Openskill sports which are related to changing environment require more visual attention and fast, flexible decision making and execution, which makes open-skill sports more beneficial for inattentive symptom. Closed-skill sports in stable and high predictable external environments, proprioception sensory feedback are emphasised and are beneficial for hyperactive/impulsive problems. Subgroup analyses in unmedicated patients in the studies indicates that physical activity may be an effective stand-alone treatment.[30]

Dong Li et al. analyzed the effects of 10 different types of physical activity on children with ADHD through a network meta-analysis. They found that traditional aerobic exercise, aquatic exercise combination exercise, cognitive-motor training, and horsemanship were more effective in improving motor skills. Aquatic exercise was found to reduce attention problems and social problems, and improving cognitive flexibility. Compared to traditional aerobic exercise, aquatic exercise, acute aerobic exercise, and cognitive-motor training were more effective. Cognitive-motor training inhibition switching and Perceptual-motor was shown to improve working memory than other forms of physical activity interventions. Horsemanship was found to be the best physical activity intervention in terms of indicators of social problems.[31]

Yiling et al. systematically reviewed the evidence for the effects of physical activity interventions on executive function in children and adolescents with ADHD and studied the moderating effects of key variables of PA on executive function. The meta-analysis showed that physical activity interventions improved inhibitory control, working memory, and cognitive flexibility in children and adolescents with ADHD. Subgroup analysis revealed a moderating effect of intervention intensity, motor skill type, sessions of PA, and weekly exercise volume on executive function.[32]

Tsai et al. studied whether the effect of acute aerobic exercise on inhibitory control in children with attention-deficit/hyperactivity disorder (ADHD) is moderated by exercise intensity using flanker task with concurrent collection of electroencephalography (EEG) data after three different intensities of treadmill running. Results showed better inhibitory control following both low- and moderate-intensity exercises relative to vigorous aerobic exercise, which could be characterized by an optimal state of cortical arousal. [33]

A systematic review of 30 studies on exercise interventions in ADHD by Ng et al. found that mixed exercise programs had the largest effect. No adverse effects arising from physical exercise were reported in any of these studies.[34]

Assessment and follow up of children in a Physical exercise intervention programme

A comprehensive assessment of child diagnosed with ADHD for physical activity intervention should include

- Medical History- including severity of ADHD symptoms, current/past health conditions which might limit the intensity, type, and duration of physical activity the child can engage in
- Physical activity habits and patterns of the child
 - o Average duration and type of daily physical activity
 - o History and frequency of falls/injuries
 - o Specific sports/arts activities involving physical activity the child shows interest in

- o Average daily recreational screen time
- o Sleep habits- sleep duration, bedtime resistance, daytime sleepiness, other sleep problems
- Medical Examination- pallor, anthropometry, nutritional/musculoskeletal problems
- Assessment of motor competence and deficits
- Individual tests of balance, coordination

Plate tapping test (tests speed and coordination of limb movement)

Two yellow discs (20 cm diameter) are placed with their centers 60 cm apart on a table of adjustable height, in front of which the child is standing. A rectangle (30 x 20 cm), is placed equidistant between both discs. The non-preferred hand is placed on the rectangle. The subject moves the preferred hand back and forth between the discs over the hand in the middle as quickly as possible. This action is repeated for 25 full cycles (50 taps). The time taken to complete 25 cycles is recorded[35]

Single leg Stance test/ Timed unipedal stance test (tests static balance)

Performed with eyes open and arms folded/ or on the hips. The participant must stand unassisted on one leg and is timed in seconds from the time one foot is flexed off the flat floor to the time when it touches the ground or the standing leg or an arm uncrosses/ leaves the hips. Static balance norms by Condon and Cremin or Dhanani and Parmer may be used. [36,37] Alternatively, baseline and follow up performances can be assessed though improvements from baseline.

Flaming Balance test (static balance)

Stand on a beam. Keep balance by holding the assessor's hand (if required to start). While balancing on the preferred leg, the free leg is flexed at the knee and the foot of this leg held close to the buttocks.

Start the watch as the assessor lets go of the participant/subject. Pause the stopwatch each time the subject loses balance (either by falling off the beam or letting go of the foot being held). Resume over, again timing until they lose balance. Count the number of falls in 60 seconds of balancing.

Tandem Stance (static balance)

Stand with feet in a heel-to-toe position on straight line drawn on the floor, and arms across the chest or on hips, with eyes open. Time commenced when the subject places the dominant foot in front of the other foot on the straight line and time ends strictly when the subject either: (1) use his arms (i.e., uncrossed arms/ arm leaves hip), (2)displace any foot,(3) movement of the foot from original position/ stepping. [37]

Battery tools to assess motor competence

Movement Assessment battery for Children- 2nd edition (MABC-2)

The MABC-2 is a diagnostic tool for movement disorders in children and adolescents from 3-16 years of age. The battery has eight tasks that challenge static balance, dynamic balance, manual dexterity, and ball skills, each of which are adapted across three age ranges (3–6 years, 7–10 years, 11–16 years). Performance on each task is assessed primarily through task completion times (using a stopwatch) and/or task success. The MABC-2 also includes a questionnaire-based checklist (for teachers, parents, and therapists to provide feedback on the motor skills in natural environments in school, family, and community settings.[38–40]

Bruininks-Oseretsky Test of Motor Performance- 2nd edition (BOTTM-2) is an individually administered measure of fine and gross motor skills of children and youth from 4-21 years of age. It assesses motor performance, specifically in the areas of fine manual control, manual coordination, body coordination, and strength and agility. Both Complete form and short forms are available.[41]

Assessment of Sleep

Sleep duration and quality are important actors for emotional and behavioural improvement in ADHD children.[42–44] Although physical exercise and behavioural interventions can improve some sleep

problems, issues like Sleep disordered breathing, parasomnias etc may need otorhinolaryngological/ neurological/Psychological management, along with the interventions.

Children's Sleep Health Questionnaire (CSHQ)

The CSHQ is a 33-item parent-reported questionnaire reflecting on a child's sleep over the past month. Questions are scored on a 3-point Likert scale (Rarely, Sometimes, And Usually) with higher scores indicating worse sleep, with reverse scoring for six items (items 1, 2, 7, 9, 10, 28). The data produce 8 subscale scores: bedtime resistance (6 items), sleep duration (3 items), night waking (3 items), sleep onset delay (1 item), sleep anxiety (4 items), parasomnias (7 items), sleep disordered breathing (3 items), and daytime sleepiness (8 items). A total score on the CSHQ consists of the sum of 33 unique items. Internal consistency coefficients of the CSHQ are near (0.68) or above (0.78) acceptable standards for the community and clinical samples, respectively. A cut-point of 41 has 80% sensitivity in identifying children with sleep problems. [45,46]

Physical Exercise interventions in ADHD

General recommendations

A physical exercise programme for ADHD children should:

- Be Structured: ADHD children need structure and organization in activities because of their unique characteristics. Structured exercise programmes of at least 30-45 minutes duration are recommended.
- Include more than one type of physical activity to keep them engaged- along with exercise, games/ plays, zumba/dance routines etc.
- Select activities, and games based on the child's age, and interests, physical fitness
- Include exercises, games, and other physical activities to improve balance, and coordination also.
- Activities for Motor Skills Development can be incorporated as specific training programme in physical exercise training sessions
- Activities to improve postural control, and motor coordination can be included in games or other sessions also
- Activities to improve Static balance, Dynamic balance, Perceptual-motor training/ Coordination- progressively raise frequency, difficulty levels
- Set achievable goals for balance and coordination tasks for upcoming session for encouraging compliance
- Specific sport/ dance training can improve motor skills, executive functions, attention, social development

Physical Activity recommendations in home and community settings

- Encourage at least 60 minutes of Moderate-Vigorous Intensity Physical Activity (MVPA) per day – any sports or activities the child has interest and aptitude
- Limit recreational Screen time less than 2 hours per day
- For group sports and plays, patiently advise the child on the rules, and ensure monitoring, encouragement. If the child has difficulties in keeping up with peers, specific instruction and training, along with encouragement for even small improvements will help the child overcome perceived incompetence and encourage participation.
- Advise and ensure safety precautions
- Activities of daily living needs a structure and routine, especially the bed time and sleep hygiene measures.
- Classroom accommodations- Discuss the child issues with the teacher, and decide on measure for managing the child's requirements with minimum conflicts and class disruption. This will also

- For children with other medical conditions, physical activity only based on recommendations of the doctor

Activities to improve balance

- Single Leg stance for balance improvement:
- Standing unassisted on one leg on a flat surface, with arms folded for as long as the child can. At least 3-5 repetitions, of 1 minute duration, for each leg.
- Increase the difficulty level by modifying the sensory input (closed eyes), or surface area of base (balance beam, foam etc)
- Tandem stance for static balance:
- Stand with feet in a heel-to-toe position on straight line drawn on the floor, and arms across the chest, with eyes open.
- Increase the difficulty level by modifying the sensory input (closed eyes, head turn)
- Tandem walking- dynamic balance (Heel to toe Walking)
- Walk forward with feet in heel-t-toe position on a straight line, while maintaining balance. Reverse tandem walk for increasing difficulty level.
- Hopping – for dynamic balance
- Hopping on one leg- along straight line and maintain balance, for at least 5-10 steps.
- Increase difficulty- Zig-zag hopping using exercise ladder or pointers arranged in zig-zag pattern.

Games and sports to improve balance

- Hopscotch
- Games on balance board
- Activity ladder exercises
- Water tumbler race, lemon and spoon race etc.

Activities to improve coordination, and manipulation

- *Body Rotations*

Stand with feet apart at shoulder width, arms on hips or outstretched sideways. Rotate trunk to each side in an alternating manner.

- Arm circles:

Stand with feet apart at shoulder width, arms outstretched sideways at shoulder level, with palms facing down. Rotate arms clockwise and anti-clock wise. Increase difficulty by alternating backward leg steps, or leg kicks while continuing arm circles.

- Burpees
- Knee cross chops (without weights) , Jumping jacks, Ski jacks,

For Bilateral and same side coordination

• High knee chops- left

- 180 Jumps, Agility ladder exercises
- Ball activities- Drop and catch, Roll and kick, dribble

Use firm, bouncing balls and do not use hard balls. Use balls with progressively lesser diameters for increasing difficulty level.

Games and sports to improve coordination skills

- Hopscotch/ Game mat activities
- Playing marbles
- VBall games- Throw ball, basketball etc.
- Aquatic games and exercise

A Structured Physical Exercise Intervention model for ADHD

Group strength: 5-7 children, preferably homogenous age group (6-7 years, 8-9 years)

Duration: 30-45 minutes

- 5-8 minutes: warm up, stretches (1 or 2 routines)
- 5-10 minutes: Exercises with music- Zumba, Aerobics, Jogging, Hula-hoop etc.
- 10-20 minutes: Exercises to improve muscle strength, stability, coordination
- 10 minutes: Games (frog jumps, obstacle races, ball throwing/ catching, balancing games etc.)
- 5-8 minutes: stretching, cooling down

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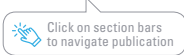
Parenting Support for Children with Developmental Delays and Disabilities



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for every child

PARENTING SUPPORT FOR CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES

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LIST OF ACRONYMS

- CRPD:** Convention on the rights of persons with disabilities
- ECD:** Early childhood development
- ECE:** Early childhood education
- ECI:** Early childhood intervention
- FGM:** Female genital mutilation
- IPV:** Intimate partner violence
- OPD:** Organizations of persons with disability
- MHPSS:** Mental health and psychosocial support
- UNICEF:** United Nations Children’s Fund
- UNICEF ECARO:** UNICEF Europe and Central Asia
- WHO:** World Health Organization

CONTENTS	ABOUT	INTRODUCTION	DATA ON CHILDREN WITH DISABILITIES	CHALLENGES PARENTS FACE	PARENTING SUPPORT INTERVENTIONS	LIFE-COURSE APPROACH	PARENTING SUPPORT STRATEGY	ENDNOTES
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ABOUT

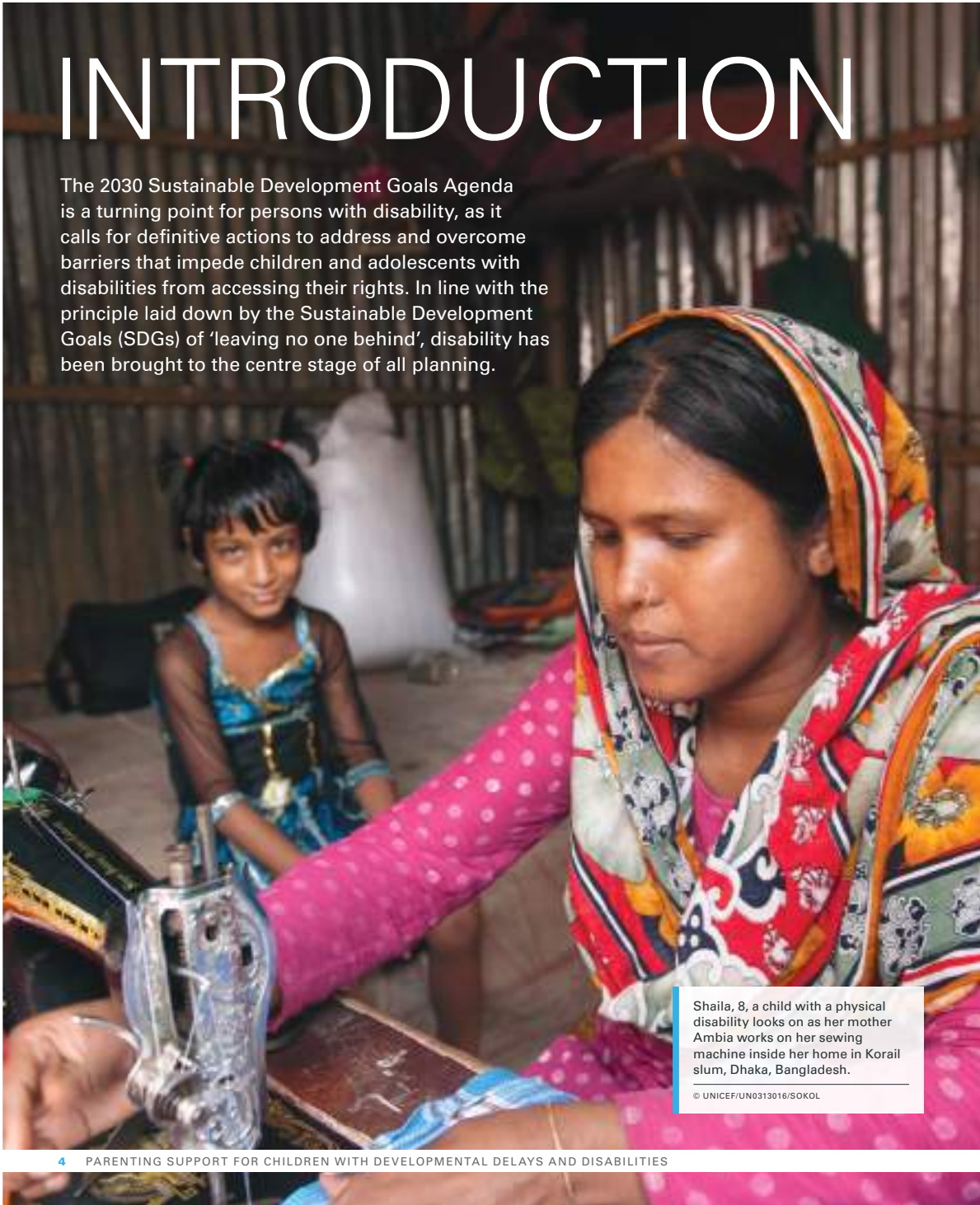
Guoguo is playing with his parents in the Aijia Village of Dianjun District, Yichang City, China.
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Parents and caregivers are the best providers of nurturing care. How well-versed they are in managing the complex needs of children with developmental disabilities and delays, and how readily they can access mainstream services such as health, nutrition, education, child protection and social protection, amongst others, will largely determine their journey of parenting. As the needs of each child with disability are unique as well as multifaceted, certain targeted interventions (like accessible and affordable trained professionals; and availability of assistive devices which make the child independent and make the parent relatively free) are also required.

The physical and mental health of the parents, their sense of personal effectiveness, financial comfort, and a community which embraces diversity will largely define and shape the parenting inputs and the development of a child with disabilities. This brief is about bringing to the attention of all state parties, policymakers, programme planners, implementers and communities parenting support strategies and interventions which can benefit parents and help them create better spaces for children with developmental delays and disabilities.

INTRODUCTION

The 2030 Sustainable Development Goals Agenda is a turning point for persons with disability, as it calls for definitive actions to address and overcome barriers that impede children and adolescents with disabilities from accessing their rights. In line with the principle laid down by the Sustainable Development Goals (SDGs) of 'leaving no one behind', disability has been brought to the centre stage of all planning.



Shaila, 8, a child with a physical disability looks on as her mother Ambia works on her sewing machine inside her home in Korail slum, Dhaka, Bangladesh.

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Five out of the 17 SDGs make a reference to persons with disabilities, with 11 explicit indicators covering aspects such as:

- inclusive education
- access to information, health care and rehabilitation, basic infrastructure and services
- skills development
- social security
- employment
- data disaggregation based on disability for various parameters.

The SDGs provide a powerful framework for communities and nations to move towards developing disability-inclusive practices. The 2030 SDG agenda is aligned with the Convention on the Rights of Persons with Disabilities (CRPD), which is to incorporate the disability perspective in all aspects of its realization, monitoring and evaluation. This sentiment is aptly reflected in CRPD adopting the slogan, “Nothing About Us Without Us”.¹

In spite of an enabling framework provided by SDGs, and many efforts made by nations, things don’t seem to have changed much for children with disabilities. According

to a recent report, it is estimated that, globally, there are nearly 240 million children with disabilities. The global estimate is based on a subset of 103 countries and covers more than 60 indicators of child well-being. It confirms what the world already knew; children with disabilities continue to face multiple challenges like poor access to education, proper nutrition, learning opportunities, participation and protection from abuse, violence and harmful practices (*See Figure 1*). These provide challenges that decelerate the chance for children with disabilities to realize their rights.²

Amongst all children and adolescents, those with disabilities are the most marginalized and excluded groups.⁷ In families, guilt, shame and fear are frequently associated with the birth of a child with a disability.

Children with disabilities are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development.⁸ Starting right from the struggle to survive, they experience widespread violations of their rights; a dearth of educational and economic opportunities; severe social, economic, cultural and civic disparities; negative attitudes and stigma; and lack of adequate policies and legislations for their protection.⁹

WHO ARE CHILDREN AND ADOLESCENTS WITH DISABILITIES? DEFINITION OF KEY CONCEPTS

The CRPD states that “**persons with disabilities** include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others”.³

The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) regards **disability** as neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors.⁴

Developmental delay refers to children who experience significant variation in the achievement of expected milestones for their actual or adjusted age.⁵ Delays can be temporary and the child’s development may catch up when the situation improves.

It is not just the medical conditions that lead to **development disabilities**. The complex interaction between a health condition or impairment and environmental and personal factors contributes to how disability is perceived, as well as how its impact is managed, which means that each child’s experience of disability is different.⁶

As a result of discrimination, children with disabilities have poor health and education outcomes; the barriers to engagement in civic life may be intensified for them, including access to employment; and they have low self-esteem and limited interaction with others.¹⁰ They are at higher risk of facing violence, exploitation, abuse, neglect and harmful practices.¹¹ Moreover, girls with disabilities are at a higher risk of experiencing sexual and physical violence compared to boys with disabilities. Other forms of violence frequently faced by them include community violence and peer violence, including bullying, and slurs that they face.¹²

In accordance with the biopsychosocial model of disability, it is now widely recognized that disability arises not just from a person’s impairments but rather the person’s interactions with an environment which presents barriers to leading a dignified and fulfilling life. All persons, including those with disabilities, deserve to live their lives with dignity.

The challenges faced by children and adolescents with disabilities are also the challenges of their families.



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Recognizing this, it is fundamental to have adequate mechanisms for these families to access support systems; to have equal access to universally available services for their children; and to have targeted services which address specific needs arising from the disability.

THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2006)

Preamble

“That persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”

Article 7

“In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration”

Article 16.2

“States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender and age-sensitive assistance and support for persons with disabilities and their families and caregivers”

Article 23.2

“Provide those health services [...] early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities”

Article 26.3

“States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation”

Article 28.2(c)

“To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care”

DATA ON CHILDREN WITH DISABILITIES

The availability of data on children with disabilities has been a long-standing challenge due to the limitations of narrow definitions and the lack of a standardized methodology for data-collection.¹³ When absent from official statistics, children and adults with disabilities remain politically and socially 'invisible'.¹⁴ As a smaller number gets reflected in the data, this also results in lower budgetary allocations for children with disabilities.

Fahiem Abrahams, 37, plays with his son, Fawad (in red), 4, and son Mika-eel (in black), 3, at their home in Bonteheuwel, Western Cape, South Africa. Fawad, who lives with autism, communicates primarily through musical intonation rather than words.

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Further, country-level data available on disability do not always allow comparisons between those with disabilities and those without. Also, the data collected are not always disaggregated, and therefore may not often give information on the disadvantages faced by women with disabilities, children with disabilities, older people with disabilities and so on. In several countries even when data on disability are collected, they are not published.¹⁵ Additionally, global experts have called for accurate, culturally relevant and robust data.¹⁶

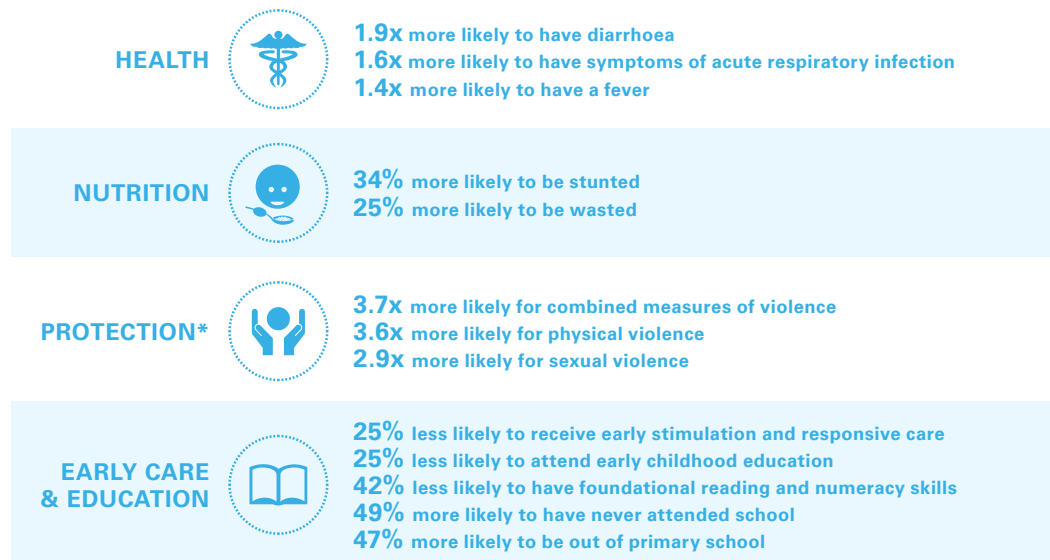
In addressing the need for robust data on children with disabilities, of particular relevance is the Washington Group/ UNICEF Module on Child Functioning.¹⁷ The measures were specially designed to be internationally comparable and to allow the SDGs to be disaggregated by disability.¹⁸

A recent global publication is *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*, published by UNICEF in 2021, employed the Washington Group CFM to collect data.¹⁹ The publication provided evidence that children with disabilities face more negative health and nutrition outcomes, receive less responsive care from parents, have worse learning outcomes and face much greater violence and abuse, as is reflected in the following data (See Figure 1).

Discrimination based on gender is a critical issue in and of itself, but the effect is compounded when a girl or woman has a disability. Globally, 68 per cent of girls and 30 per cent of boys with developmental or intellectual disabilities are likely to experience sexual abuse before their eighteenth birthday.²¹ Compared to boys, girls with disabilities are more

FIGURE 1: Data on children with disabilities²⁰

Global estimates show there are 240 million children with disabilities (2–17 years). Compared to children without disabilities, children with disabilities are:



Source: United Nations Children's Fund, *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*, UNICEF, New York, 2021; *Liverpool John Moores University, and World Health Organization, *Violence Against Children with Disabilities*, WHO, n.d., United Nations Children's Fund cited in *The State of the World's Children: Children with disabilities*, UNICEF, New York, May 2013

likely to be excluded from family interactions and activities, and less likely to receive health care or assistive devices. While boys with disabilities are expected to get a job and live independently, families have lower expectations of girls.²² Girls with disabilities are also less likely to receive vocational training, get educated or be employed, compared to boys with disabilities, or girls without disabilities.²³

The discrimination experienced by children with disabilities worsens in times of calamities, conflicts and pandemics. Save the Children conducted a large-scale study based on a representative sample of 17,565 parents or caregivers and 8,069 children (aged 11–17).

Participant groups were drawn from 37 countries. The hidden impact of Covid-19 on children and families with disabilities was studied and the major findings were:²⁴

- 44 per cent of children without disabilities and 55 per cent children with disabilities were playing less.
- A higher percentage of children with disabilities reported an increase in negative feelings (86 per cent), showed signs commonly associated with distress (69 per cent) and violence at home (43 per cent) when compared with reports from children without disabilities (83 per cent, 47 per cent and 15 per cent, respectively)
- 1 in 3 caregivers of children with disabilities reported that the children did not have access to any learning materials.



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CASE STUDY 1.

JORDAN: UNICEF’S INCLUSIVE EDUCATION WORKSHOPS²⁵

To support children with disabilities in Jordan during the coronavirus pandemic, UNICEF provided disability-inclusive workshops in camps and host communities on Mathematics, Arabic and perceptual and sensory skills. This was accompanied by videos for parents to use with their children for speech and occupational therapy during the lockdown.

Support facilitated by the Ministry of Education was given through community volunteers on WhatsApp called ‘shadow teachers’. Special permission was

obtained by UNICEF to allow these teachers to continue monthly home visits in the camps.

Close to 1,000 children with disabilities in the camps used these services. Transparent face masks were used to allow lipreading for better communication without compromising safety.

UNICEF also provided pre-loaded tablets to 80 families in the Azraq camp. These tablets contained learning resources and facilitated the development of educational and digital skills when schools were shut.

CHALLENGES PARENTS FACE

Parents and caregivers include mothers and fathers (biological as well as step parents and adoptive parents), siblings, grandparents and other relatives involved in caregiving. Parents provide nurturing care to the child in an emotionally supportive environment with opportunities to play, interact, communicate, explore and learn, all in a safe and secure space.



Maria Alexandrova, her mother, Zornitsa Bosilkova, and her best friend, Vanessa Georgieva, walk in front of the Tower of the Meshchiite downtown Vratsa, Bulgaria. Maria, 17 years old, living with cerebral palsy, is an advocate for other adolescents with disabilities in Bulgaria.

© UNICEF/UN0338723/NABRDALIK VI

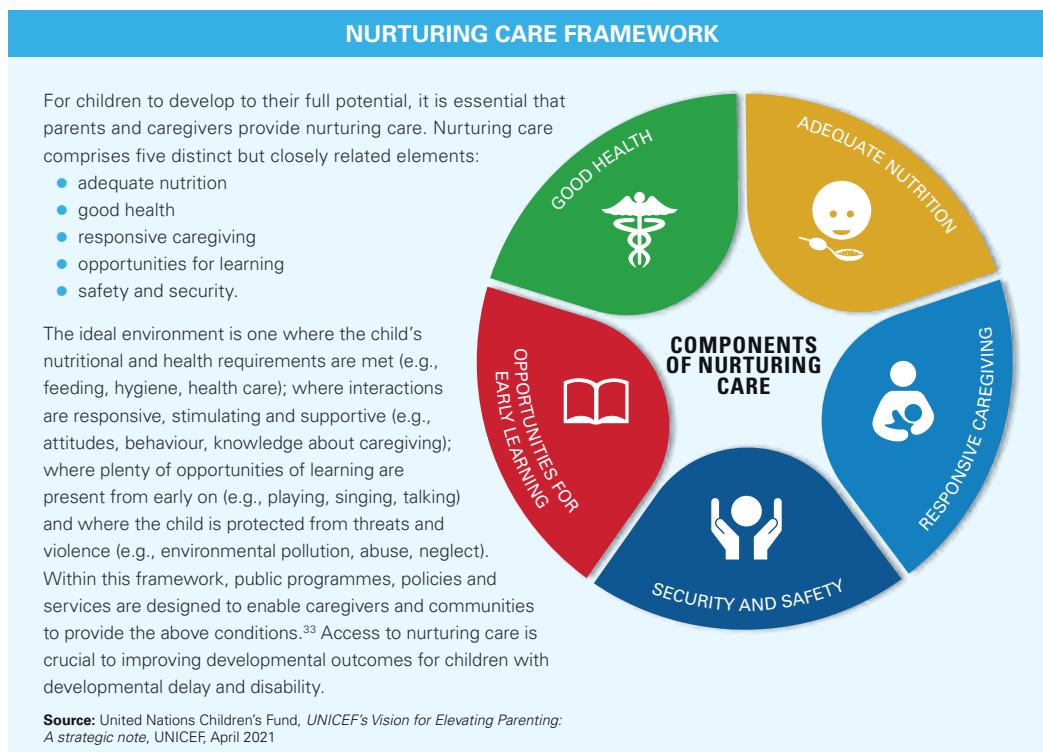
Parents help build the architecture of their children’s brains through responsive interactions, hence laying the foundation for physical health, lifelong learning, executive functions and psychosocial well-being. ‘Parenting’ refers to the “interactions, behaviours, emotions, knowledge, beliefs, attitudes and practices associated with the provision of nurturing care”.²⁶ The quality of parenting practices is the key to good development outcomes.

Parenting is a challenging job, and the challenges mount when it comes to a child with disability. Challenges experienced by parents of children with disabilities include:

- excessive workload demands which reduce their free time and lower their quality of life²⁷
- lack of money due to job loss and added expenses of assistive devices, transport and medical care²⁸
- mental health issues like stress, anxiety and depression (at times ‘chronic’ depression)²⁹

- feelings of stigma, discrimination and isolation, with some facing a negative narrative on disability in communities.³⁰
- low social support and low connection to parent networks or organizations of people with disability
- inadequate information about services available for children with disabilities.³¹ They spend a lot of time in trying to find the availability of and access to services.

While it is important that parents should be supported with information on best practice, it is, at the same time, equally important to appreciate that parents too have needs (e.g., mental health, financial, social) that can’t be ignored. Parents need support and care so that they are able to provide the best possible care for their child with a disability, appreciating that they are creators of safe and balanced environments for their families.³²



PARENTING SUPPORT INTERVENTIONS



The aim of parenting support interventions is to strengthen parenting capacities so that they can provide the best care for their child with developmental delays and disabilities. The interventions also include care of the parents' personal and mental health and can be key accelerators for navigating towards what is best for the child with disability.

Nesaruddin Babu, 18, enjoys time talking to his mother at their home in Daulatpur, Khulna in Bangladesh. Despite his disability, he is able to generate income for his family.

© UNICEF/UNI154368/KIRON

UNICEF’s vision includes integrated, multilevel programming which moves beyond approaching parents as passive recipients of information or education. Instead, it views parents and caregivers as actively engaged in co-constructing support for their children as well as for themselves.³⁴ Parents and caregivers are seen as partners in programme design implementation and service provision. This shift may be particularly important for parents in strengthening their own knowledge and becoming more empowered.³⁵ This is especially relevant for parents of children with disabilities. Programmes build on the strengths of the parents, are culturally responsive and move away from adopting a deficit approach. Inclusivity is a key principle and nurturing care is supported for all children, explicitly including children with disabilities.³⁶

Parenting support includes structured interventions with the primary focus on parents co-constructing and learning new skills that address parental knowledge and acting on attitudes, beliefs and practices. The interventions have the greater goal of improving parent-child interactions and the overall quality of nurturing care that a child receives. As children mature into adolescence, parenting relationships evolve. Parents require new, developmentally appropriate skills and strategies to meet their children’s needs. Therefore, parenting support programmes should also include interventions for the emotional well-being of the parents.³⁷

Parenting support builds on the principle of ensuring that inequities are addressed from the outset so that no child is left behind. Parents of children with developmental delays and disabilities need incremental levels of support, and families require more individualized and intensive services to improve the development of their children.³⁸

Benefits of family-friendly policies, including leave for care of children with disabilities; breastfeeding support; inclusive, accessible, quality childcare; child benefits; pensions for caregivers; and early detection and intervention. This should be a part of parenting support interventions for families of children with disabilities.

Despite social norms becoming more progressive, most of the responsibility for childcare still falls on women. The imbalance in energy and time expended is significant when caring for children with disabilities and has an equally significant impact on the well-being and health of female caregivers.³⁹ Although mothers continue to be the primary caregivers, it would be worthwhile to include fathers in parenting support programs as well. Recognizing that disability impacts girls more, parenting support interventions also need to be gender responsive.

GENDER RESPONSIVE PARENTING

Parenting that applies key principles such as gender equality and inclusion, and that promotes positive gender norms and socialization, in order to transform imbalanced power structures in families (and future generations) is known as **gender-responsive parenting**.

Examples would include ensuring girls and boys are provided with

equal and adequate nutritional and health services. Another is ensuring the equitable availability and distribution of resources and opportunities for all children of all genders and abilities, e.g., digital devices for remote learning at home.

Ending gender-related harmful practices at home are also part of this kind of parenting. These

practices include gender-based domestic violence, but also gender-bias such as telling boys that they cannot cry and making girls (but not boys) take on caregiving and domestic tasks at home. As children move to adolescence, restrictions on female mobility or the stigmatizing of menstruation as ‘impure’ or ‘taboo’ are also some gender-biased discriminatory practices.⁴⁰

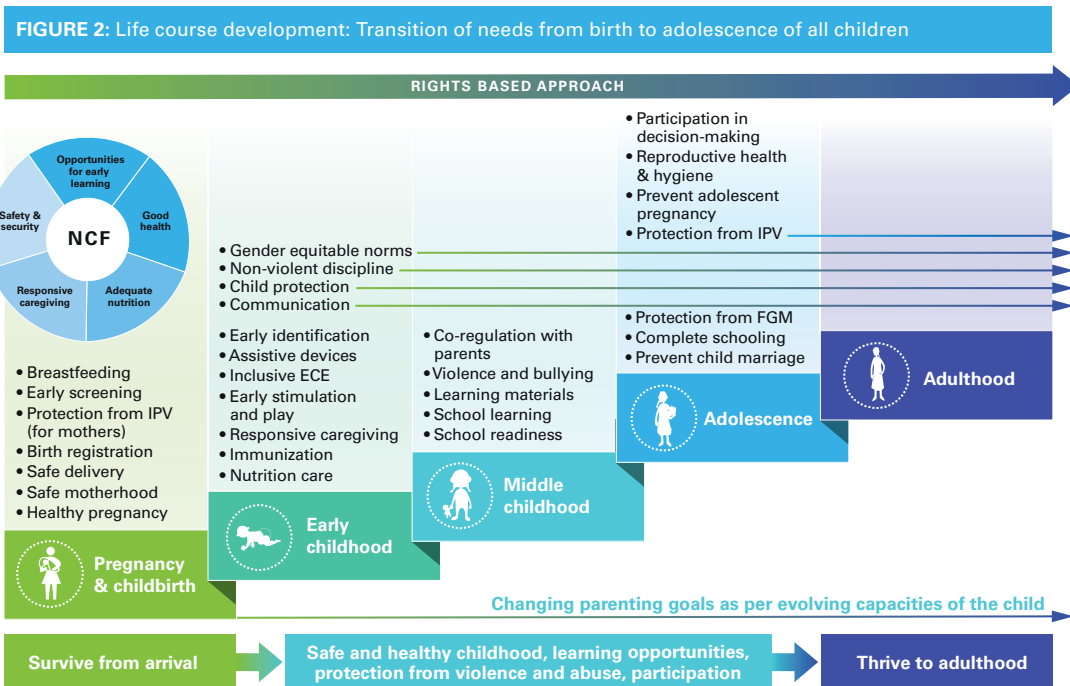
THE LIFE-COURSE APPROACH

A life-course approach acknowledges that most life stages or transitions are social constructs that are neither finite nor irreversible.

It recognizes that all stages of a person's life are intricately linked with each other as well as the lives of other people in society and with past and future generations of their families. It is increasingly used in the analysis of epidemiological and health trends.

Ljiliana Randjelovic holds her two-year-old foster daughter, Natalija Dinic, at their home in the city of Niš. Natasha was born with Down's Syndrome and a heart problem in a place without support or counselling for parents of disabled children.

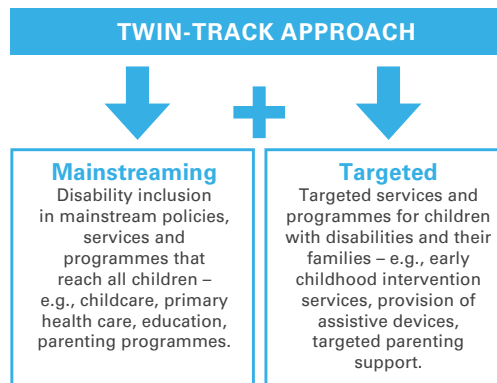
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This figure reiterates the importance of enriched environments for overcoming developmental delays and disabilities. This approach advocates continued support across the life course, matched to a child's needs at each development stage.

The life course approach helps to bring out needs and challenges of each stage, while the proposed twin-track approach of UNICEF and World Health Organization (WHO) is a blended approach. It proposes that families make routine contacts with mainstream health, nutrition, education, child protection, social welfare and other services to address needs of children with disabilities.

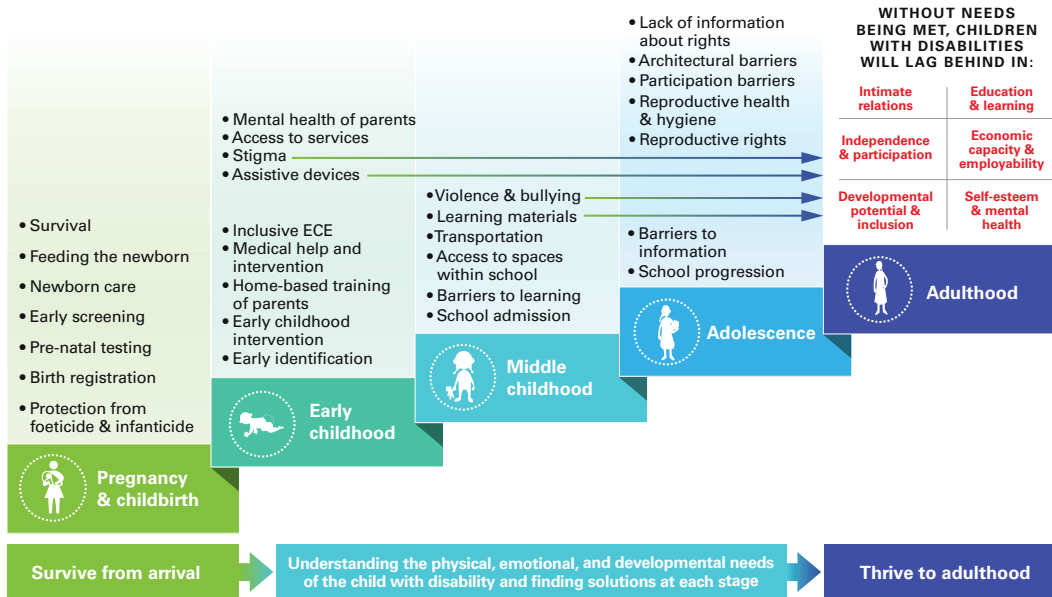
There should be an effort to make these routine services disability-sensitive and disability-inclusive, providing the required support throughout the life course in all key developmental areas. Simultaneously, these services can be complemented by specific targeted interventions like early detection and early intervention (see Case Study 2),⁴¹ inclusive education; the provision of assistive devices; respite care; and targeted parenting support for the families



Source: United Nations Children's Fund, *UNICEF's Vision for Elevating Parenting: A strategic note*, UNICEF, April 2021

with children with developmental delays and disabilities, among others.⁴² The twin-track approach can be adopted to address challenges faced by children across the life course challenges faced by children with disabilities and

FIGURE 3: Life-course challenges in the development of children with disabilities (targeted concerns)



to find targeted responses to those challenges. Figure 2 depicts the life course challenges which are common for all children, while Figure 3 portrays the challenges

more specific to children with disabilities. Twin-track interventions (mainstream and targeted) can be woven around these challenges.



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CASE STUDY 2.

UGANDA: ABAANA EARLY INTERVENTION PROGRAMME⁴¹

The ABAaNA early intervention programme studied early neuro-developmental outcomes which arise after neonatal encephalopathy in Uganda.

The ABAaNA programme was adapted for children aged 0–2 years, and aimed to improve parenting skills and knowledge with a participatory and empowering approach.

The ABAaNA programme was peer-led in group settings at the community level. Each group consisted of 6–10 families and training was provided through modules on understanding disability, mobility, training, feeding, communication, positioning and carrying the child, play and local community experiences.

Each module session lasted 2–3 hours, with time included for facilitated discussion, and was delivered every 1–2 weeks. The programme’s core themes included:

- promoting the human rights of children with disabilities

- endorsing their participation and inclusion within community and family
- optimizing their potential for development, health and quality of life
- promoting the empowerment of caregivers through peer support and information-sharing
- understanding the experience of the child and family, including addressing stigma.

Families enrolled in the course were encouraged to problem-solve together, collectively reflect and share experiences with each other. Group sessions were facilitated by ‘expert parents’ who also had children with neurodevelopmental impairment, and had undergone training. The delivery of the full programme was intended to take six months, and included a minimum of one home visit by an expert parent facilitator. Outcomes of interest were feasibility, acceptability, the quality of life of the child and the quality of life of the family. When piloted in an urban area in 2015–2016 among 28 families, there was a 25 per cent improvement in the quality of life scores for the families after the intervention.



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The SDGs indicate that people with disabilities are among the most marginalized and vulnerable population groups. The reports collected by international organizations reveal that disability itself is one of the main reasons why people with disabilities are lagging behind.⁴³



PARENTING SUPPORT STRATEGY

Anna Rosa Aniva stands with her son, Tercio Cangela, 4, in his wheelchair provided by UNICEF at their home in Beira, Mozambique.

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CONTENTS	ABOUT	INTRODUCTION	DATA ON CHILDREN WITH DISABILITIES	CHALLENGES PARENTS FACE	PARENTING SUPPORT INTERVENTIONS	LIFE-COURSE APPROACH	PARENTING SUPPORT STRATEGY	ENDNOTES
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Children and adolescents with disability can face rejection, ridicule, a lack of opportunities to learn, play, access education and many essential services, and are mostly the lowest priority in the planning of most nations. Families regularly feel the brunt of widely-held misconceptions and stereotyped beliefs. Parents and the wider family play a

vital role in caring for children with disabilities. Parents are critical pillars for building human capital in the first two decades of life.

Given below are some proposals for disability-inclusive parenting support strategies.

TABLE 1: Disability-inclusive parenting support strategies

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>1 Strengthen parents' knowledge and skills to provide nurturing care and to respond to life-course challenges of children with disabilities</p>	<ul style="list-style-type: none"> • Nurturing care promotes the development of children with disability. Hence, it is very important to assess with parents the life-course challenges faced by a child with disabilities and to plan, co-construct and consult with them to build their knowledge and capacities to care for their child with disabilities (see Case Study 3).⁴⁴ • As parents are the first point of contact with the child, they may identify signs of a disability (see Figure 4), way before anyone else, such as: <ul style="list-style-type: none"> • a lack of startle response to loud sounds at birth • no eye contact with caregiver while feeding • an infant's babbling decreasing, rather than increasing between the age of 6–12 months • delayed milestones of, e.g., sitting or walking. • If parents ask for support, health workers should be sensitive to, and respectful of, their concerns. • Responsive parenting (e.g., playing with the child) which is child-centred and respectful of a child's dignity, needs to be promoted, as do positive gender norms and socialisation. • Non-violent discipline also needs to be encouraged, with an emphasis on the importance of safe spaces for children with developmental delays and disabilities. • Parenting also needs to be promoted across the life course, as per the evolving capacities and specific needs of children (such as parents having access to counselling for appropriate feeding practices). As children grow up, parents need to collaborate with them to co-regulate and co-construct important decisions, like making decisions on appropriate independence for the adolescent child, or in defining sexual limits. As children with disabilities continuously face stigma, discrimination and abuse, co-create parenting strategies in consultation with the child, so as to build self-esteem. The programmes can also be made culturally sensitive and coherent by involving parents in making decisions right from the early stages of the programmes' design ideation, right up to its implementation. This way, a programme will take into account the disability needs of the children and will be tailored to the needs of the community it has been developed to serve. • Leverage and invest in programmes that involve fathers and other members in caregiving activities.

CASE STUDY 3.

GHANA: GETTING TO KNOW CEREBRAL PALSY⁴⁴

This programme was aimed at empowering families via voluntary participation at community level.

Caregivers were invited to be part of support groups which provided training through modules on ‘Getting to know Cerebral Palsy’.

Seventy-five caregivers from eight districts in Ghana were invited to join support groups of between eight and ten people. Each group met for an average of four hours a month studying modules covering a wide range of subjects, including communication, feeding, positioning and carrying, assistive devices and resources, play, everyday activities, evaluating your child, running a parent support group and disability in your local community.

These sessions were followed by short home visits and engagement with other family members. Training was voluntary and based on the principles of adult learning theory. The objective was to provide peer support and promote problem-solving and critical thinking. It included improving the care and support that could be provided to the child by the caregiver,

enhancing the understanding of their rights and sharing their learning with other caregivers.

Thirteen facilitators went through a week-long master training and were paired to impart training to each support group. Each pair comprised a primary health worker and a physiotherapist or physiotherapist’s assistant.

Attendance was quite high, with 92 per cent of all families attending all training sessions. At baseline, it was observed that common themes included low levels of knowledge, high levels of stigma, including self-stigma, high levels of emotional and physical exhaustion and difficult relationships within the family with social exclusion of the child and caregiver.

Two months after the intervention, caregivers reported an improved sense of well-being. This was based on an enhanced understanding of their child’s condition, a positive shift in attitude towards their child, more hopeful feelings and, owing to the group support, a decreased sense of alienation.

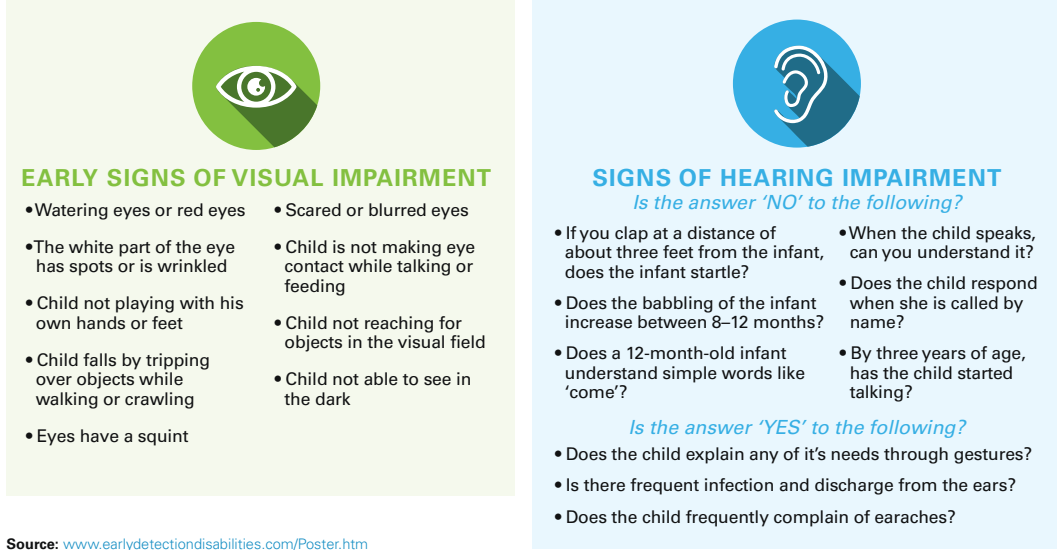
TABLE 1: Disability-inclusive parenting support strategies (continued)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>2 Link parents and caregivers to mental health and psychosocial support services</p>	<ul style="list-style-type: none"> Facilitate access to mental health and psychosocial support (MHPSS) services and programmes (such as counselling). Enhance access to platforms, organizations or support groups which facilitate conversation, messaging, knowledge exchange and collaboration on parenting of children and adolescents with disabilities. Leverage existing programmes to provide support in cases of intimate partner violence.

TABLE 1: Disability-inclusive parenting support strategies (continued)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>3 Strengthen health systems and access to disability-inclusive health services</p>	<ul style="list-style-type: none"> ● Strengthen services and programmes for mothers and child care to prevent disabilities. Make available affordable immunization and essential medicines for promotive health care. Ensure equitable access to health systems. Strengthen nutritional screening to prevent undernutrition and micronutrient deficiencies. ● Capacity building of community health workers and Early Childhood Development (ECD) workers to acquire simple skills for early detection of disabilities and developmental delays. This would also bridge the resource gap of trained service providers for disability needs, especially in the context of low- and middle-income countries (LMICs). For example, the DIA (Detection-Inclusion-Ability) Training Module implemented in India followed the strategy of preparing a simplified module on early detection of disabilities (locomotor, visual, hearing and intellectual) and trained 120 community workers using the Module. Trained workers using a centre-based approach as well as home visits screened 13,000 children (birth to 6 years) and detected 921 (7.08 per cent) children with disabilities. These children were referred for early intervention. The results showed that suitably trained workers can serve as an essential bridge between children with disabilities and government services, creating a more integrated and coordinated system.⁴⁵ Countries can develop, test and roll out modules that can be integrated into health worker training packages. ● Implement a policy of mandatory national annual screening for disabilities in ALL children by trained community workers. Use opportunities when children come at key entry points for detection like primary health centres, creches and preschools (see Case Study 4).⁴⁶ It is important to note that children who don't have access to health services, or who are not attending preschool, are less likely to be identified early. Home visits for identification would be required in such cases (see Figure 5). ● Offer clear referral pathways so that early detection can be followed by early intervention. For example, community-based initiatives, such as Village Health Nutrition Day, provide first-contact primary health care that is crucial in identifying disabilities and providing immediate intervention and referral to specialized services. This is particularly important for children with disabilities and their families living in hard-to-reach areas.⁴⁷ ● Service delivery of interventions should include centre-based and home-based care. For example, community workers can make home visits to share strategies for the proper positioning of a child with cerebral palsy, using locally available material. ● Early medical intervention services to minimize disabilities should be readily available in hospitals. ● Countries should have a 'model of community-based services', where a repository of affordable and accessible disability support professionals (such as speech therapists and occupational therapists) are available. ● Where digital access or geographic access is a challenge, provide remote delivery of disability-inclusive health, nutrition and education services through traditional methods like home visits, community radios, etc. ● Rehabilitation units can be set up to innovate assistive devices and find affordable solutions for improving functionality of children with disability.

FIGURE 4: Early signs of visual and hearing disability⁴⁸



CASE STUDY 4.

LATIN AMERICAN AND CARIBBEAN COUNTRIES: CARE FOR CHILD DEVELOPMENT⁴⁶

Childcare and family support services were identified as entry points for addressing families affected by the Zika virus when it started spreading in Latin America and the Caribbean in 2016.

Care for Child Development (CCD) was used in eight countries over three years as part of early childhood interventions by promoting family inclusion, strengthening responsive caregiving practices and helping families in addressing the developmental and long-term health issues of the Zika syndrome and other congenital disorders.

CCD is aligned with nurturing care as it aims at strengthening the capacity of caregivers and families to engage in communication and play with children. It motivates caregivers to be sensitive and respond positively to children's signals, promotes interaction between children and their caregivers and learning opportunities and focuses on children's potential rather than children's limitations.

In the case of Peru, CCD materials were adapted to the Peruvian context, including the language and images used. Coordination between ECD workers and specialized child disability professionals was encouraged for the better delivery of services. The training included a module on disability identification, early care and practical sessions with children with disabilities.

In Peru, CCD has made a difference for 1,000 children and their families. Improvements were seen in health services as well as in early education. For example, previous educational interventions focused on activities led by teachers on how to interact with children, with parents as observers. However, after CCD was adopted, children interacted actively with their caregivers, with teachers contributing in a more supportive capacity.

FIGURE 5: Key entry points and referrals

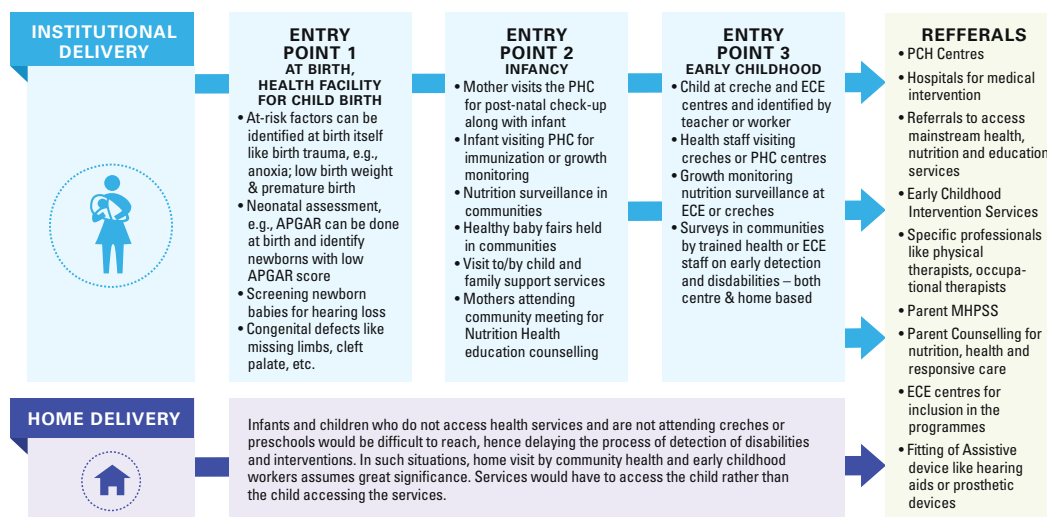


TABLE 1: Disability-inclusive parenting support strategies (continued)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>4 Enhance access to quality inclusive education</p>	<ul style="list-style-type: none"> Promote inclusive education and make, as a right, education accessible for ALL children at all levels. Support and build the capacity of teachers, starting from early childhood education, to adapt to the learning needs and learning styles of children with developmental delays and disabilities (e.g., teaching the concept of a circle to a visually impaired child by using the sense of touch and 3D teaching aids). Adopt child-friendly, developmentally appropriate teaching-learning practices, adapting materials, using flexible curricula and spaces as per universal design for learning while maintaining safe learning environments, catering to a wide variety of learning styles, learning needs and personal preferences.⁴⁹ Ensure transport access to learning centres at all life-course stages. Remove the barriers hampering children with a disability from attending school. Provide access to teaching-learning materials and innovative technology for supporting the education of children with developmental delays and disabilities (see Case Study 5).⁵⁰ A study assessed the impact of technology-enhanced storytelling (TES) designed to support parent-child interaction and vocabulary in preschool children. The TES involved the use of a tablet for real-time auditory, visual and textual prompts in story narration. It generated active child involvement and stimulated parent-child interaction. The use of prompts was associated with higher quality parent-child interaction while narrating stories.⁵¹

TABLE 1: Disability-inclusive parenting support strategies (*continued*)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>4 Enhance access to quality inclusive education (<i>continued</i>)</p>	<ul style="list-style-type: none"> • Enable access to education in remote areas through digital and traditional delivery platforms. As part of ensuring that children with disabilities can access affordable textbooks in all contexts, UNICEF and its partners have launched the initiative <i>Accessible Digital Textbooks for All</i>. This adapts the principles of Universal Design for Learning, where the barriers to learning are assumed to be in the environment, not the student. The initiative enables textbooks to be given to a child with a vision disability, hearing disability or an intellectual, developmental or learning disability. It sets the standards for features like sign language, narration, interactivity and audio description of images.⁵²

CASE STUDY 5.

MONTENEGRO: FOR EVERY CHILD A VOICE⁵⁰

UNICEF Europe and Central Asia (ECARO) and UNICEF Montenegro, in cooperation with the Ministry of Education and the Bureau of Education Services, has implemented this programme to ensure that children with communication impairments don't miss out on essential early childhood learning opportunities.

It is widely recognized that barriers to communication-related disabilities arise from not knowing how to use assistive technology with children, and a lack of appropriate and economical assistive technology solutions available in regional languages.

The For Every Child A Voice programme has found a way to combat this using an assistive technology for augmentative and alternative communication called C-Board, which:

- facilitates interaction
- helps overcome speech impairments
- develops language
- allows children to participate in social and learning activities.

This application allows children to communicate through symbols and enables text conversion to speech. It is also open-source, compatible with offline mode and available in more than 30 languages. It can be accessed online on tablets and smartphones by parents and children, and professional help is available in learning how to use it. It also has the added advantage that, in settings where access to technology is a problem, since the symbols are pictorial, they can be printed and used as paper resources.

The use of C-Board was intended as a routine-based intervention where carers and professionals are trained in the use of assistive technology and integrated as communicators in the child's schooling and home environment. User interviews have indicated that the app has also been useful in strengthening family bonds and enabling better communication. It has also led to improvements in competency, self-esteem and adaptability for the children.

TABLE 1: Disability-inclusive parenting support strategies (continued)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>5 Integrate disability-inclusive support in national systems and develop linkages</p>	<ul style="list-style-type: none"> ● Strengthen referral pathways and multisectoral service delivery by developing new partnerships and coordination mechanisms with ECI programmes and other early childhood services for example: <ul style="list-style-type: none"> ● health, e.g., provision of essential medicines and assistive devices ● nutrition, e.g., nutrition surveillance ● education, e.g., digital technology in schools for children with communication conditions ● social protection, e.g., budgeting for free wheelchairs ● child protection, e.g., sensitizing child protection officer that compared to other children; the child with disability is more vulnerable to violence and mal-treatment.⁵³ ● Encourage and support community-based rehabilitation programmes as these show the best outcomes in supporting families, as well as engaging communities. Often, this is the first support reaching families, especially in LMICs (see Case Study 6).⁵⁴ ● De-institutionalize care services for children with disabilities by establishing systems of alternative care and support to families, including respite care. This would mitigate the risk of burn-out in parents. ● Adopting and developing Family Friendly policies such as: <ul style="list-style-type: none"> ● disability scholarships ● transport allowances ● medical insurance ● allowances for families looking after people with disabilities ● financing disability-related expenses through health insurance. ● Participation of parents in community engagement, social accountability mechanisms and design and the delivery of policies and services, aimed at helping children with disabilities and their families. ● Provide workplace support to parents of children with development disabilities and delays. ● Engage with organisations of persons with disabilities (OPDs), including those that support family members of children with disabilities. ● Negotiate with families to ensure financial literacy and access to any available grants for financial augmentation and to support higher expenses due to disability-related costs. Build linkages with existing programmes to support the economic strengthening of families.

CASE STUDY 6.

INDIA: COMMUNITY-BASED REHABILITATION PROGRAMME⁵⁴

In Karnataka, India, the Association of People with a Disability provides services including community-based rehabilitation (CBR) for children with cerebral palsy and their caregivers.

The rehabilitation programme involves home-based therapy sessions and parental training. These are aimed at improving the knowledge of parents on cerebral palsy, using therapy to handle their children, and making them aware about the rights of people with disabilities. In addition to rehabilitation, the programme promotes the use of assistive devices. Parent training helps mitigate the serious challenge of lack of accessible professionals in rural areas.

The study looks at the effects of the CBR programme on 100 parents of children with cerebral palsy. Their health, knowledge, social life, empowerment and home modification have been studied.

After completing the programme most parents reported a positive change in health. This included reports of reduced discomfort, reduced physical stress (e.g., handling, feeding, transfer, etc.), decreased anxiety and frustration and sufficient sleep at night. Most also said that, after the training, they:

- were comfortable taking care of their child

- could perform activities of daily living for their child
- had knowledge about cerebral palsy
- knew how to handle their children in proper ways
- had experienced a change in lifestyle.

The CBR programme also positively impacted the parents' social lives. Most of them found it easier to participate in social activities outside their home, such as attending religious and social functions, marriages and family gatherings. They got the time they needed for their own interests and needs, they did not feel neglected by their community and their family's attitude was more positive. On aspects of empowerment, most parents reported their awareness of the rights of people with disabilities (such as concessions, disability cards and specific facilities made available by the government) and being able to speak about themselves and their rights. As for the use of assistive devices, while there were no major changes found in toilet and home modifications, the use of wheelchairs, special chairs and orthotics improved children's mobility and positioning and reduced the physical burden on the parents.

CASE STUDY 7.

MALAYSIA: @KITACONNECT⁵⁵

In the wake of the COVID-19 lockdown @KitaConnect is a disability-inclusive digital channel and was developed in 2020 by UNICEF Malaysia, the Childline Foundation and StudyHub Asia in response to the concerns and experiences of Malaysian adolescents and young people (including those with physical, learning, psychosocial, hearing and/or visual disabilities). This segment of the population had to rapidly adapt to online schooling, using the internet to learn how to protect themselves when seeking social interaction and connection online. The transition was particularly challenging for those with disabilities, as digital platforms were often inaccessible to them and caregivers were not equipped to provide digital learning assistance.

Based on RapidPro technology, @KitaConnect was designed as a dedicated virtual space to inform, connect, support and inspire action by and for

young people. From the outset, the digital channel was made accessible and inclusive with options for closed captioning and subtitles, and was able to support sign language interpretation and language translation. The platform also strived to connect those with disabilities and those without disabilities by offering, for instance, sign language lessons for those with and without hearing impairments. Plans for the wider representation of young people's disability community involved including youth leaders from the special olympics in peer-to-peer trainings on topics of general interest, and building capacity for disability-inclusive content.

As of December 2021, the platform engaged 615,000 young people, including five per cent with disabilities, through youth chats, skills-building workshops and online @KitaConnect community and livestreaming platforms.

TABLE 1: Disability-inclusive parenting support strategies (continued)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>6 Improve access to information and services</p>	<ul style="list-style-type: none"> • Promote the use of digital platforms for parent training and give access to information on parenting children with disabilities, online resources and digital apps. Prepare a repository of professionals, the lists of which can be displayed on digital platforms. • Use social networks and digital mediums to connect with other parents, and seek help for MHPSS (see Case Study 7).⁵⁵ • Parents without access to technology need to be reached through alternative, community-based mechanisms such as home visiting, mobile platforms, radio, television and social work support – and they must also be reached in times of crisis.

TABLE 1: Disability-inclusive parenting support strategies (continued)

MAIN APPROACHES	KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES
<p>7 Make policies and laws and strengthen redressal systems</p>	<ul style="list-style-type: none"> • In line with CRPD, each country must have laws with a rights-based approach for children and people with disabilities. • Each country should have national systems for redressal when the rights of children with disabilities have been violated. As an example, the Association of Youth with Disabilities in Montenegro, supported by UNICEF, provided legal and psychological support to 250 families of children with disabilities.⁵⁶ • Each country should have disability-inclusive policies covering areas such as health and education. The impact of policies can be gauged by the example of the 'Zero Reject' policy in Malaysia, which contributed to the school enrolment of over 20,000 children with disabilities.⁵⁷
<p>8 Enhance and improve data on children with disabilities</p>	<ul style="list-style-type: none"> • Countries need to strengthen data on children with disabilities; a first step would be registering their births. • In national census taking, nations need to enumerate accurately the total number of children with disabilities. • Disaggregated data on sex, age and disability need to be made available. Disaggregated data must also be collected on survival (e.g., the mortality rate for infants and children under five with disabilities), nutrition, health, access to services (e.g., how many visit health centres), education (e.g., enrolment and attendance), violence and participation (e.g., data on barrier-free cities and universal design in built spaces). • Maintaining registers and records of children with disabilities makes them visible and improves participation. UNICEF has been providing support to the Government of Myanmar in the registration and certification of people/children with disabilities. This has led to the registration of approximately 60,247 children with disabilities and 123,434 people with disabilities.⁵⁸
<p>9 Increase awareness generation</p>	<ul style="list-style-type: none"> • Increase awareness about CRPD and the rights of people and children with disabilities. • Mobilize global awareness on the importance of providing parenting support as a key priority within countries. • Raise community awareness about disability to reduce stigma and discrimination and make communities inclusive. Use C4D strategies, which could be a strong enabler for creating mass awareness. Involve faith-based leaders and local leaders to sensitize communities on disabilities.

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