

Consensus Statement of the IAP - Neurodevelopmental Chapter On Neurodevelopmental Disorders Habilitation Process: Strategic Plan for Prevention, Early Detection and Early Intervention

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ABSTRACT

Justification: Neurodevelopmental disorders, as per DSM-V, are described as a group of conditions with onset in the development period of childhood. There is a need to distinguish the process of habilitation and rehabilitation, especially in a developing country like India, and define the roles of all stakeholders to reduce the burden of neurodevelopmental disorders.

Process: Subject experts and members of Indian Academy of Pediatrics (IAP) Chapter of Neurodevelopmental Pediatrics, who reviewed the literature on the topic, developed key questions and prepared the first draft on guidelines. The guidelines were then discussed by the whole group through online meetings, and the contentious issues were discussed until a general consensus was arrived at. Following this, the final guidelines were drafted by the writing group and approved by all contributors.

Objectives: These guidelines aim 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 development nurse counselor.

Statement: There is a need for nationwide studies with representative sampling on epidemiology of babies with early NDD in the first 1000 days in India. 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. Preconception counseling 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; Risk stratification of NICU graduates, Newborn Screening; Counseling parents; Screening for developmental delay by trained professionals using simple validated Indian screening tools at 4, 8, 12, 18 and 24 months; Holistic assessment of 10 NDDs at child developmental clinics (CDCs) / district early intervention centre (DEICs) by multidisciplinary team members; Confirmation of diagnosis by developmental pediatrician/developmental neurologist/child psychiatrist using clinical/diagnostic tools; Providing parent guided low intensity multimodal therapies before 3 years age as a center-based or home-based or community-based rehabilitation; Developmental pediatrician to seek guidance of pediatric neurologist, geneticist, child psychiatrist, physiatrist, and other specialists, when necessary; and Need to promote ongoing academic programs in clinical child development for capacity building of community based therapies, are the chief recommendations.

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Bio-psychosocial development is a dynamic inter-relationship between genetic, brain, cognitive, emotional and behavioral processes most active during the early developmental phase; any significant and persistent disruption to this dynamic process through environmental and biological risk, in the first 1000 days of life (F-1000-D) can lead to neurodevelopmental disorders and consequent disability [1]. Habilitation process through series of early intervention for high-risk babies has been recommended in the revised status of the convention on the rights of persons with disabilities [2] and has been promoted by the National Health Mission (NHM) [3]. Habilitation process by its primary, secondary and tertiary preventive approaches, from the care of high-risk conception and pregnancy to the first two years of life, minimizes the risk outcomes much before the rehabilitation process. Whereas, habilitation is the process of prevention of impairment (e.g., birth asphyxia) going on to disability, rehabilitation prevents disability going on to handicap [4]. While both processes are needed in the Indian subcontinent in an organized manner, the lack of habilitation process results in a systematic error in the delivery of very early services for babies at high risk in rural and urban India [5,6].

This Consensus Statement of the Indian Academy of Pediatrics Chapter of Neurodevelopmental Pediatrics (IAP NDP) will emphasize on the habilitation process as a very early developmental services model. The statement will discuss the epidemiology of at risk of developing neurodevelopmental disorders (NDD) and early NDD; the delivery model with a modified district early intervention centre (DEIC); the evidence-based practice in the habilitation process; and, the projected effectiveness in the context of IAP and National Health Program in India.

This statement has to be taken as a way to practice and enhance the envisaged models of Rashtriya Bal Swasthya Karyakram (RBSK), especially the district early intervention centre model, during the first thousand days of the life of a baby at risk. The recommendation of this consensus statement should be understood in close conjunction with consensus guidelines on the diagnosis and management of global development delay [7]. We have made efforts to harmonize the two related dimensions of global development delay and habilitation, so as to synergize the clinical care in delays and early disabilities.

PROCESS

Conceptualization and topic selection: There have been well evidenced consensus statements/guidelines/practice parameters from the various official organizations that focus on the prevention of NDD and rehabilitation of children with NDD in India. There is a need to provide the

practitioners with a consensus statement for the habilitation process that is specific to first thousand days of the life of a baby but with overarching effect on many of documents available. This IAP-NDP chapter guidelines will conceptualize habilitation from three perspectives: *i*) early stimulation vs intervention, *ii*) habilitation vs rehabilitation, and *iii*) first 1000 days (prevention of delay and active therapy for identified delay).

Literature review: We performed a systematic literature review of systematic reviews, meta-analysis and randomized control trials, for a ten year period (January, 2013-September, 2022), in the PUBMED, SCOPUS and Cochrane Library using the terms: (“neurodevelopmental disorders”[MeSH Terms] OR (“neurodevelopmental”[All Fields] and “disorders” [All Fields]) OR “neurodevelopmental disorders”[All Fields]) and (“India” [MeSH Terms] OR “India” [All Fields] OR “India’s”[All Fields] OR “India’s”[All Fields])) and ((meta-analysis [Filter] OR randomized controlled trial [Filter] OR review [Filter]) and (2013:2022[pdat])) and retrieved 258 studies (k = 258). Finally, we extracted details on: (1) epidemiology of NDD in India (k = 485), (2) disability resources available in India (k = 105), (3) prevention (k = 187), (4) early diagnosis (k = 159), (5) early intervention (k = 102), (6) ways of harmonizing this Consensus Statement and RBSK model, especially the District Early Intervention Centre Model (DEIC) (k = 8). In addition to all this data, the literature was hand-searched for appropriate studies not published online before the mentioned ten-year period, which included conference presentations as well.

Building the Consensus: There were two work groups, composed of general pediatricians, pediatricians with special interest in NDD, child and adolescent psychiatrists, occupational therapist, developmental therapist and specialist nurses. Their age ranged from 21 to 65 years and experience in NDD varied between 2-32 years. Modified delphi technique was used to arrive at the consensus and draft the recommendations among the experts by the facilitator (MKC) (**Fig. 1**). The facilitator and various experts of the IAP-NDP Chapter met as two workgroups; one group met online (during pandemic) and another group met in-person later in Kochi, Kerala, India. The facilitator co-ordinated both the work groups and finally drafted the recommendations with a panel consisting of selected experts. Consensus was defined as ‘agreement’ if $\geq 75\%$ of the members of the workgroups had concordance and ‘disagreement’ if $< 25\%$ of members had concordance, and included in the subsequent round.

Building the evidence base: The inclusion of studies to provide evidence for consensus was based on Guidelines of the Oxford Centre for Evidence-Based Medicine

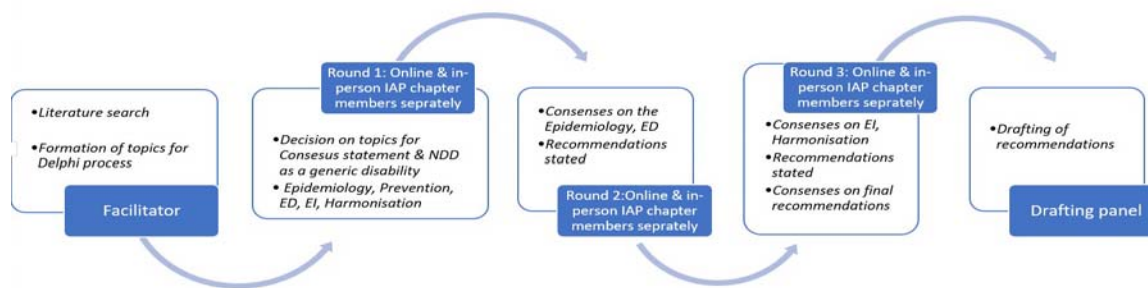


Fig. 1 The modified Delphi technique used for developing the consensus statement.

(Levels of Evidence, March 2009) by the multidisciplinary experts. The conversion of the evidence to recommendation was done following the GRADE protocol and drafted by the drafting panel.

Drafting the recommendation: The consensus statement was drafted and reported based on the ACCORD (Accurate Consensus Reporting Document) reporting standards [8]. If appropriate studies were not available from India, recommendations from other official organizations in India or international organizations were adopted.

CONSENSUS STATEMENT

A. The Epidemiology of At Risk of NDD

This section reviews the epidemiology of various risks in babies, mothers or family context and poverty at various stages of their first thousand days of life. Research studies have identified advanced maternal age (27-106% risk), maternal antepartum bleeding (81% risk), maternal pre-natal medication use (46% risk), first order pregnancy (61% risk) [9], meconium aspiration (RR: 7.34), feeding difficulties (RR: 3.35) [10] as risk factors for NDDs in the antenatal and early neonatal period. Prematurity and low birth weight being important determinants of adverse neurodevelopmental outcomes, the risk factors identified include socio-economic status (AR: 41.4%), non-pregnant maternal weight (AR: 22.9%), maternal height (AR: 29.5%), severe anemia (AR: 34.5%) [11], pregnancy induced hypertension (OR: 4.09), maternal short stature (OR: 2.34) [12]. However, the epidemiology of the early stages of NDD, especially during the F-1000-D, is not available in India at Level I evidence. Secondly, as with the epidemiological studies in other countries in Asia, specific learning disability (SLD) is the most prevalent NDD in India as well. The normative data on the basic language, writing, and mathematical needs further validation in the context of SLD.

Recommendation I

There is a need for nationwide studies with representative sampling on epidemiology of babies with early NDD in the first thousand days in India.

Recommendation II

Specific learning disability (SLD) has been documented as the most common NDD in India after six years, and special efforts should be made to establish the epidemiology of infants and toddlers at risk for SLD, where ever measures are available.

B. Evidence-Based Practice in the Habilitation Process

The risk identification during pre-natal (conception and pregnancy) and perinatal period .

Research studies have suggested the following for risk identification during the prenatal and perinatal period; *i*) assisted conception (8.3% for birth defect) [13], *ii*) genetic tests like chromosomal aberrations (19-20%), monogenic disorders (1-25%), errors of metabolism (3-4%), *iii*) intrauterine infections (3-4%), *iv*) toxins (1%), *v*) HIE using modified Levene/Sarnat's score (14-31%) [14], *vi*) malnutrition [15], *vii*) pathological family functioning [16], *viii*) maternal TORCH infection [17], *ix*) neonatal hypoglycemia [18], *x*) significant neonatal jaundice [19], *xi*) tools like Hammersmith Neonatal Neurological Examination [20], Brazelton Neonatal Assessment Scale [21], perinatal risk factor stratification tool [22], Prechtl general movement assessment [23], *xii*) abnormal cranial ultrasound [24], and *xiii*) mother baby bonding assessment [25].

We used the following process of assigning a risk status to babies. The selection of a measure for identification of any form of risk in the F-1000-D was based on an acceptable clinical yield rate over multiple studies or

single well conducted study that established the diagnostic accuracy of at least a sensitivity of 70% and specificity of 80% [26]. **Table I** details the risk identification and tools for early detection during infancy and childhood.

C. Delivery Models for Habilitation Services in India

The service delivery models for habilitation process (HP) has not been specifically developed for India to provide the evidence-based screening and interventions discussed in the previous two sections. For an ideal HP services delivery model for baby at risk, in India, it should focus on a triadic approach, namely: *i*) focusing holistically on the various domains of the baby even if the risk is noted in only a domain, following an Individual Habilitation Plan (IHP); *ii*) Individualized family service plan (IFSP) which includes counseling and training in IHP, supporting the family to overcome the anxiety and grief about the risk factors and to have a watchful monitoring of the baby's development; *iii*) finally, linking the family with national and state programs for social and financial security with an individual social and financial security scheme (ISFS).

1. Review of delivery systems for habilitation process in India

A review of the available systems demonstrated that the Rashtriya Bal Swasthya Karyakram (RBSK) is the best fit for providing the Habilitation Services (HS) in India within the existing policies, programs and resources allocated at the national level (RBSK, 2013) with the addition of the 5th D- discernable risk factors. See **Table II**. However, for enhancing this ambitious and expanding initiative of the Government of India, seamless service provision between DEIC and the proposed Block Early Intervention Centers (BEIC), empowering the latter is required, with provision of social and financial security to the babies and families at risk [27] enabling access to habilitation services.

2. Enhanced Rashtriya Bal Swasthya Karyakram Model for Service Delivery of Habilitation Process With Block Early Intervention Centre (BEIC).

The rationale for developing the Enhanced Rashtriya Bal Swasthya Karyakram Model has been that self-referred, Community EIC and SNCU babies screened have been exponentially increasing ever since the provision of RBSK services (from 3,71,59,012 in 2014-2015 to 10,04,10,009 in 2019-2020) and more babies required transdisciplinary intervention during the same time (83,327 in 2014-2015 to 1,70,651 in 2019-2020). However, as part of the capacity building mandate of the RBSK, the post of a multipurpose developmental therapist has not been included, except as a pilot project in Kerala.

Currently there are about 342 operational DEICs at the national level and there are 766 DEICs required to make it a pan-India program, which might happen in a phased manner. The approach to negate this widening gap has to be two-pronged, to facilitate the capacity building, to share the 4Ds/5Ds burden between DEIC and BEIC as well as to upgrade the functioning of BEIC in districts with paucity of health care-resources. It can be approximated that to make the DEICs functional in every district, around 800 developmental therapists (DTs) will be required at a minimum. In order to provide DTs at block levels in BEICs, the number required will be much more. Until the time the state universities take up the onus of creating graduate programs in Developmental Therapy, this gap in manpower can be met by short-term training of available manpower resources like Anganwadi Workers at CDCs/DEICs. Further details on the infrastructure, human-resources for health and services provided at the DEIC can be obtained from the website https://nhm.gov.in/images/pdf/programmes/RBSK/Operational_Guidelines/Operational-Guidelines-DEIC-RBSK.pdf

3. Comparison of DEIC and BEIC for sharing of the 4Ds/5Ds: See **Web Table I**.

4. The organogram for the enhanced RBSK model for service delivery of habilitation process with BEIC (**Fig. 2**)

5. Advantages of the RBSK Model for Service Delivery of Habilitation Process with BEIC.

The early child development services, which includes the F-1000-D, has already materials that are being used during pregnancy and the first two years of life. It includes a booklet 'journey of first thousand days'; an android App 'Ayushman Bhava'; call centers that provide individualized counseling related to queries; the LaQshya program that promotes mother-friendly labour and a redesigned developed illustrative Mother and Child Protection Card to assists in developmental monitoring [28,29]. The screens and intervention available in the early child development services of RBSK can add to the evidence-based screening measures and interventions discussed earlier.

E. Preventive management in conception, pregnancy and perinatal period (PCPP)

Pre-conceptional counseling: Research studies as documented in previous section concludes that the single most important modifiable risk factor for neurodevelopmental outcome is Low birth weight baby, and the modifiable antenatal factors for LBW babies include *i*) Pre-pregnancy maternal weight, height *ii*) maternal nutrition *iii*) maternal infections. Hence, the preparation for prevention has to start much earlier with introduction of the concept of 'Pre-

Table I Early Detection of neurodevelopmental Disabilities During Infancy and Childhood

<i>Risk situation and study</i>	<i>Measure for risk</i>	<i>Accuracy</i>	<i>Age covered</i>
Preterm infant, 2020 [64]	Hammersmith infant neurological examination	Sn: 96%; Sp: 93%	At 12 mo corrected age (CP vs no CP)
Neonatal neuro abnormality, 2005 [65]	Amiel Tison neurological assessment	Sn: 92%; Sp: 46%	0-12 mo
Motor delay, 2014 [66]	CDC grading for head holding, sitting and standing	Unknown	0-12 mo
Developmental delay, 2014 [67]	Bayley infant neurodevelopmental screen	Sn: 75-86%; Sp: 75-86%	3-24 mo
Developmental delay, 2014 [68]	Developmental observation card	Unknown	0-1 y
Developmental delay, 2013 [69]	Trivandrum developmental screening chart vs DDST	Sn: 84.6%; Sp: 90.8% NPV: 99.23%	0-6 y
Speech & Language Delay, 2016 [70]	Language evaluation scale Trivandrum vs REELS	Sn: 81%; Sp: 68%, NPV: 98%	0-6 y
Developmental delay, 2014 [71]	Denver developmental screening tool	Sn: 56-83%; Sp: 43-80%	0-6 y
Developmental delay, 2014 [72]	PEDS vs DPII and VSMS	Sn: 74-89; Sp: 70-80	0-8 y
Developmental delay, 2011 [73]	Ages and stages questionnaire vs DASII	Sn: 83%; Sp: 75.4%	1-66 mo/3-66 mo
Developmental delay, 1991 [74]	Baroda developmental screening tool	Sn: 66%; Sp: 77%	0-30 mo
Developmental delay, 2017 [75]	New Delhi-developmental screening questionnaire	Sn: 100%; Sp: 87%	9 mo and 18 mo
Developmental delay Pearson Clinicals [76]	Bayley scale of infant development-IV	Accuracy 82% for developmental delay	16 d- 42 mo
Developmental delay, 1997 [77]	Developmental assessment scale for Indian infants	Unknown	0-2 y
Developmental delay, 2007 [78]	Comm DEAL Developmental Assessment	Unknown	0-6 y
NDD, 2013 [79]	INCLen- neurodevelopment screening tool	Test-retest reliability: 0.8 Inter-rater reliability: 0.8	6-12 y
ASD, 2014 [80]	INCLen ASD vs DSM-IV-TR	Sn: 98%; Sp: 95%	2-9 y
ADHD, 2014 [81]	INCLen ADHD vs Conners's parent rating scale	Sn: 87.7%; Sp: 97.2%	6-9 y
NMI, 2014 [82]	INCLen NMI vs clinical assessment by experts	Sn: 75.4%; Sp: 86.8%	2-9 y
NMI, 2017 [83]	AIIMS modified INCLen NMI vs expert clinical assessment	Sn: 90.4%; Sp: 95.5%	2-9 y
Epilepsy, 2014 [84]	INDT-EPI vs expert clinical assessment	Sn: 85.8%; Sp: 95.3%	2-9 y
Epilepsy, 2017 [85]	AIIMS modified INDT-EPI vs expert clinical assessment	Sn: 91.5% Sp: 88.6%	1 mo-18 y
ASD, 2019 [86]	AIIMS modified INDT-ASD against DSM-V	Sn: 98.4%; Sp: 91.7%	3-15 y
ADHD, 2020 [87]	AIIMS modified INDT-ADHD against DSMV	Sn: 100%; Sp: 90%	6-18 y
ASD, 2017 [88]	Childhood Autism Rating Scale - 2	Sn: 81.5%; Sp: 78.6%	2-6 y
	Indian scale for assessment of Autism	Sn: 93.3%; Sp: 97.4%	3-20 y
	Autism diagnostic interview - revised	Sn: 92%; Sp: 89%	Mental age > 2 y
ASD, 2023 [89]	Trivandrum autism behavioural checklist against CARS-2-ST	Sn: 96.29%; Sp: 81.57%	2-6 y
ADHD, 2016 [90]	NICHQ- Vanderbilt ADHD rating scale	Sn: 80%; Sp: 75%	6-12 y
SLD, 2017 [91]	NIMHANS SLD battery	Test retest reliability: 0.53	5-12 y
Cognition, 2021 [92]	Weschler's intelligence scale for children-IV	Internal consistency: 0.97 Test-retest: 0.93	6-16 y
Home and family pathology, 2009 [93]	Home screening questionnaire against HOME inventory	Sn: 83%; Sp: 82%	
Multiple disabilities Unknown	RBSK Tool- community based rehabilitation	Unknown	0-6 y

PEDS: Parental Evaluation of Developmental Status; DP-II: Developmental Profile-II; VSMS: Vineland Social Maturity Scale; DDST: Denver Developmental Screening Tool; REELS: Receptive Expressive Emergent Language Scale; DASII: Developmental Assessment of Indian Infants; CARS-2- ST: Childhood Autism Rating Scale- 2nd edition, standard version rating; Sn: Sensitivity; Sp: Specificity; PPV: Positive predictive value; NPV: Negative predictive value.

Table II Review of the Available Systems For the Habilitation Process

<i>Scheme; Launch year</i>	<i>Beneficiaries</i>	<i>Benefits</i>	<i>Habilitation/Rehabilitation Process</i>
Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA); 2016	Pregnant women in 2nd and 3rd trimester	Health check-up, tests and required treatment on 9th of every month in all government hospitals across the country.	Habilitation process
Janani Suraksha Yojana	All pregnant women Below Poverty Line	Safe motherhood	Habilitation process
Navjaat Shishu Suraksha Karyakram (NSSK); 2009	Newborns	Basic newborn care, resuscitation, prevention of Hypothermia & Infection, early initiation of breast feeding	Habilitation process
Janani Shishu Suraksha Karyam (JSSK); 2011	Pregnant women & sick infants	Mother and baby treated within 48 hours. Medications, consumables, diagnostics, blood if required, free diet for 3 days during normal delivery/7 days for Cesarean. Similar entitlements for sick infants upto 1-year.	Habilitation process
Rashtriya Bal Swasthya Karyakram (RBSK); 2013	0-6 y (new-borns to young children)	Addressing the defects at birth, diseases, deficiencies & development delays, spanning 32 common health conditions	Habilitation & Rehabilitation process
Rashtriya Kishor Swasthya Karyakram (RKSK); 2014	10-19 y adolescents	Sexual & reproductive health, nutrition, injuries & violence, non-communicable diseases, mental health & substance misuse	Rehabilitation process

conception Counseling' aimed to reduce the risk of adverse health effects to the woman, fetus and neonate by addressing modifiable risk factors and by providing education about healthy pregnancy. The components would be as follows; *i)* Additional nutrition to pre-pubertal girls *ii)* Family life and life skill education for adolescents *iii)* Immunizations – Rubella, Hepatitis-B, HPV during early adolescence *iv)* Preconception folic acid intake *v)* Address body image/cosmetic concerns/ dental care. *vi)* Check-up – medical, ultrasound scan of abdomen and breast if indicated. *vii)* Screening for menstrual problems, Polycystic Ovary Disease, genito-urinary infections. *viii)* Screening for anxiety, depression, suicidal ideation *ix)* Newly-wed counseling – sexuality skills, understanding needs of self and partner and *x)* Self counseling for developing coping skills [30].

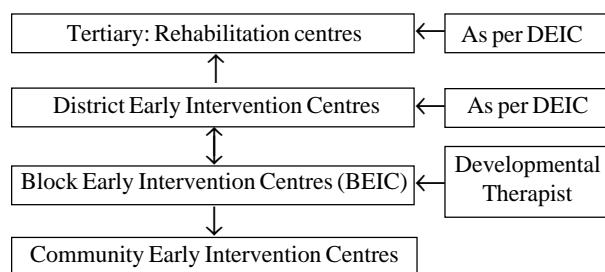


Fig. 2 The organogram for habilitation process based on the Enhanced Rashtriya Bal Swasthya Karyakram model of Block Early Intervention Centers (BEIC).

Joyful pregnancy: maternal stress and effect on baby: A systematic review and meta-analytical study suggests that prenatal stress may be associated with increased risk for ASD (pooled OR = 1.64) and ADHD (pooled OR = 1.72) [31]. Research studies also suggest that prenatal maternal stress maybe related to negative affect, surgency and self-regulatory capacities in the child [32]. UNICEF's vision for elevating parenting therefore includes promotion of parental mental health, emotional and social well-being, stress management and coping skills during pregnancy and early childhood as a part of the Nurturing Care Framework [33].

Recommendation III

Preconception counseling focusing on pre-pubertal girls' nutrition, family life education for adolescents and premarital and newly wed counseling for above 18 years, as part of focusing on first 1000 days (270+365+365 days).

E. Implementing best practices in the labor room and NICU to minimize brain injury

A large multi-center study conducted in 6 LMICs using WHO Essential Newborn Care Course found that after training, the rate of moderately or severely abnormal neurologic examinations at 7 days decreased from 8.0% before the intervention to 6.4% after ($P=0.01$), even though there was no significant reduction in neonatal and perinatal mortality [34]. A study conducted in 14 teaching

hospitals in India also found that after training of personnel in NRP, there was a significant shift towards more rational resuscitation practices [35]. Apart from training of NICU staff in resuscitation and essential neonatal care, practices in the NICU should also include *i*) provision of optimal perinatal care, optimal nutrition and developmentally supportive care practices *ii*) optimized intensive care practices *iii*) promoting readiness of healthcare facilities *iv*) supporting the family and *v*) quality initiatives [36].

F. Early stimulation

As per WHO-ECD-Nurturing Care framework, early stimulation can be considered to be an integral part of Responsive care giving and promoting early learning [37]. Early stimulation refers to doing simple everyday activities with the baby, like talking, singing, reading and playing [38]. The CDC model early stimulation was developed based on the objective of stimulating the child through normal development channels, prevention of developmental delay, prevention of asymmetries and abnormalities, detection of transient tone abnormalities and minimization of persistent tone abnormalities. The module involves four major sensory modalities; *i*) visual stimulation *ii*) auditory stimulation *iii*) tactile stimulation *iv*) vestibular-kinesthetic stimulation [39].

The present guidelines are based on a seminal randomized controlled study involving 900 special care nursery graduates with “CDC model early stimulation” which showed significantly higher Bayley scores at one- and two-year of postnatal age compared to controls. The summary of the results showed that; *i*) as compared to 84.2 Bayley index (average of Mental Development Index and Psychomotor Development 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 two years showed that the most significant factor that decided better outcomes was provision of early stimulation [40].

Recommendation IV

Promote efforts to organize systematic training programs in Newborn Resuscitation Program, Lactation management, developmental follow-up and early stimulation for SNCU/NICU graduates.

G. Very early risk stratification

A systematic review to predict adverse neonatal outcomes thorough antenatal risk scoring systems in India concluded that due to the low quality of such systems available in

India, efforts should be directed towards development of the same using current evidence available [41]. As per the available practices and evidence (**Table II**), the neonatal risk stratification model and follow up protocol proposed by NNF and adopted by IAP as the part of consensus guideline in Early Childhood Development (ECD) would be extremely useful in planning for further interventions [42].

H. Early detection (ED)

Early detection of the 4Ds are an integral component of the Habilitation process and the steps for early detection and referral pathway are as follows:

Stage 1: Identification of concerns, acknowledge, listen and act.

Stage 2: General development monitoring at 4, 8, 12, 18, 24 and 30 months and medical assessment including checking hearing, vision, thyroid status.

Stage 3: Developmental screening using validated Indian tools in the first two years and at school entry and confirmation by a developmental pediatrician. Additionally screening for autism should be done at 18-24 months and again, at 3 years of age as per the existing IAP consensus guidelines on ASD [43].

Stage 4: Referral for specific assessments by a multi-disciplinary team at DEIC/CDC as indicated by the disability suspected.

Stage 5: Discussion and intervention planning: Clear summary to parents, discuss assessment outcomes, counsel and follow up for comorbidity and growth and general health.

I. Relevant policies

Newborn Hearing Screening: As per IAP Guidelines, the first hearing screening should be conducted before the neonate's discharge from the hospital - if it 'fails', then it should be repeated after four weeks, or at first immunization visit. If it 'fails' again, then Auditory Brainstem Response (ABR) audiometry should be conducted. All babies with abnormal ABR should undergo detailed evaluation, hearing aid fitting and auditory rehabilitation, before six months of age [44,45].

Nurturing Care for Early Childhood Development: IAP-Task force recommended focusing on five essential components viz., *i*) good health, *ii*) adequate nutrition, *iii*) promotion of early childhood learning, *iv*) responsive caregiving, *v*) safety and security. UG/PG students also need to be exposed to hands-on-training at anganwadis, crèches, and in domestic setting [46].

Early Childhood Development: IAP consensus statement on Early Childhood Development suggest that interventions for ECD should begin from conception to adolescence, prioritized in first 3 years, inclusive and equitable for all, especially for high risk, vulnerable and marginalized families [47]. IAP Commitment to Nurturing Care for Early Childhood Development under National President 2021, is reflected in an exhaustive supplement that will go to over 30,000 members of the Academy and create awareness on the current status of national preparedness for implementing NC-ECD in India [48]. NNF commitment to Early Detection of Developmental Delay in India under National President 2021, is reflected in the DETECT training program successfully completed in all states of India and Nepal (NNF Today. Sep 2021; 2:9).

Recommendation V

Risk stratification of NICU graduates, newborn screening for congenital hypothyroidism and phenylketonuria and hearing screening, counseling parents for early stimulation and surveillance in the first two years as part of focusing on first 1000 days.

Recommendation VI

Screening for delays by trained AWWs/developmental nurse counsellors/developmental therapists/PHC doctors at CEIC/BEIC, using simple validated Indian screening tools at 4, 8, 12, 18 and 24 months.

Recommendation VII

Holistic assessment of 10 NDDs at CDCs/DEICs by multidisciplinary team members (developmental therapist/development nurse counsellor, physiotherapist, occupational therapist, speech therapists, clinical psychologist) with developmental pediatrician/pediatrician as team leader.

Recommendation VIII

Confirmation of diagnosis by developmental pediatrician/developmental neurologist/child psychiatrist using clinical/diagnostic tools at CDC/DEIC.

J. Early Intervention

Home-based intervention programs with parents as therapists have significant impact on outcome related to early childhood development [49]. The home environment of the child also needs to be assessed by the simple screening tool Home Screening Questionnaire (HSQ) that has been validated against the gold standard 'Home Observation for the Measurement of Environment (HOME)' inventory [50].

Optimal use of locally available Intervention Packages

It is important to have locally developed and validated screening tools and intervention packages. Randomized control studies have shown reasonable effectiveness and published for wider use [51]. Intervention tools can be indigenous and suited to the population being included. MKC's Trivandrum Developmental Screening and Intervention Package is one such example, where the Developmental Therapist-Pediatrician team introduces it to the mother at the center level using simple scientific and specific interventions to address delays/disabilities and the mother continues to do it at home and the child is monitored periodically at the center.

Individualized Care Plan (Bio-Psycho-Social model)

The steps are the following;

- i) Initial SWOC (Strength-Weakness-Opportunities-Challenges) analysis on the family resources for supporting the child.
- ii) Develop the Bio-Psycho-Social model for the child, the parents and the family/community in close proximity of the child.
- iii) Plan intervention for each domain at each level targeting all three components of this model.
- iv) Anticipatory guidance for development is to be provided to parents in order to promote optimal developmental outcomes [52].

The WHO-ICF (World Health Organization - International Classification of Functioning, Disability and Health) model can also be an extremely useful tool to formulate the Individualized Care Plan, taking into account not only the physical impairments of the child, but also the child's activities, participation, his environmental facilitators and barriers and his personal specificities [53]. Some intervention packages that may be used are listed in **Box I**.

Home-based vs Centre-based therapy: A program evaluation by Dixon et al in 2017 had concluded that participants made more significant progress in centre-based locations than home-based locations [54]. However, considering the skewed provider-recipient ratio in India, a low-intensity home-based approach utilizing the parent as the core therapist, assisted by the DT and allied therapists would be an effective approach, as demonstrated in a CDC, Kerala study in 2014 [55].

Family inclusiveness without stigma: Long-term parenting of children who have developmental disorders or mental

Box I Some Intervention Packages That May Be Used for Habilitation

1. CDC model early stimulation for at-risk babies [21].
2. CDC Grading based therapy for head holding, sitting and standing [36].
3. Developmental intervention package for babies < 1800g [37].
4. TDSC Items based therapy package among low birth weight babies [37].
5. Early Language intervention (0-3 y) for speech and language delay [38].
6. Clinic based, low intensity, early intervention for children with ASD [39].
7. Home based early intervention for Autism Spectrum Disorder [40].
8. NIMS Spectrum-CDRC Model Intervention for ASD [41].
9. Developmental diagnosis and use of home intervention package [42].
10. Organization of Clinical Child Development Services [44].
11. Child Development Aide (CDA) program [45].
12. Early intervention services to children with developmental delay [46].
13. Community Disability Intervention Program (<https://www.ubuntu-hub.org/>)
14. The ABAaNA early intervention programme.
15. Learning through Everyday Activities with Parents (LEAP-CP) [47].
16. Evidence-Based Interventions for Autism Spectrum Disorders [48].
17. Early Intervention and Prevention of Students with Specific Learning Disabilities [49].
18. Early Identification and Interventions for Children At - risk for Learning Disabilities [50].
19. Psychosocial Interventions for Students with ADHD [51].
20. Socio Communication Play and Educational Program Educating Parents on Direct and Interactive Teaching Techniques (SCoPEEDITT) [52].

health problems may place the parents at increased risk for poor physical and mental health [56]. Educating the family regarding the availability of various habilitation programs, social services and also to make sensible insurance policy decisions if available, are important especially in LMIC countries. Guidelines for Parents developed by IAP can be an extremely useful resource in this regard and can be provided to families of children diagnosed with delays and NDDs.

Apart from all these, already existing marital discord may worsen the socio-psychological family resource for caring a disabled child, especially so an autistic child. A practical way would be to use a Partner-Relationship

Assessment Tool [57] that may highlight dissatisfaction in any of the domains of; *i) Reality ii) Sexuality iii) Fantasy iv) Support v) Attitude vi) Personality vii) Conflict resolution*. Family therapy is designed to help people within the family make sense of difficult situations, and help them work together to develop new ways of thinking about and managing these difficulties. Making a family plan at an early stage can avert various stressors especially among young eager parents [58].

Integrating and Coordinating Multidisciplinary Services: Families of children with NDDs, autism spectrum disorder (ASD) in particular, face long and complex process in navigating diagnosis and acquiring services for their children. The myriad presentations and severities of these conditions also means that a one-size-fits-all approach is not successful for all children. A transdisciplinary approach with the developmental pediatrician as the team leader, enables coordinated and coherent linkages between disciplines. Providing interdisciplinary education is essential to produce healthcare providers with the knowledge and skills required to optimally collaborate in working environments [59].

Recommendation IX

Provide parent guided low intensity multimodal therapies before 3 years as a centre-based or home-based or community-based rehabilitation services supported by a Developmental Pediatrician/ Psychiatrist.

Setting-up of transition programs to school: The transition from early intervention programs to inclusive school settings and finally to college and to adult life represents a range of social challenges for children with developmental disabilities. Transitioning is an important and inevitable part of a child's life. Involvement and inclusiveness is another equally important domain necessary for a child to develop successfully. In a study in Australia, the challenges noted by parents included the school's lack of preparation for their child's particular developmental needs, especially in terms of the physical environment, while teachers reported challenges in meeting the needs of these children within the context and resources of the classroom [60]. The habilitation package therefore, should also include assessment of school readiness of children and pre-determined plans facilitating the smooth transition of children to schools.

K. Projected Effectiveness in the Context of IAP and NHP in India

Development of human resource to meet burden of at-risk, delay and NDDs in India

A good developmental surveillance program will depend

upon *i*) the degree of risk of developmental delay or discernable risk (example prevalence of low birth weight babies); *ii*) the burden of developmental delays in the community (2.5% in less than 3 years) [61] and *iii*) the burden of NDDs (9.2% in less than 6 years) [62]. The schedule of screening and follow up monitoring will differ according to level of risk, for eg. high-risk NICU graduates Vs low-risk post-natal babies [63]. To provide appropriate clinical habilitation service to this huge number of children, it is essential to concentrate on capacity building of manpower, building a team of developmental therapists (DT) or developmental nurse counselors (DNCs), well supported by developmental pediatricians wherever available.

Developmental Pediatricians and Developmental Nurse Counselor Team

Developmental Pediatrician (DP): In order to meet the need for qualified well trained developmental pediatricians, the IAP Neurodevelopmental Chapter initiated one year full-time Fellowship in Developmental and Behavioral Pediatrics at 15 accredited centres in India and each one of them is setting-up developmental pediatric units. This is in addition to the PG Diploma in Developmental Neurology Program of University of Kerala, conducted at CDC Kerala from 2004.

Developmental Therapists and Developmental Nurse Counselor (DNC): Developmental Therapists comprise a special team of graduates with two year full-time theoretical and practical training in clinical child development, certified by Government of Kerala. Kerala University of Health Sciences has already initiated the graduate program in Development Therapy. IAP Neurodevelopmental Chapter initiated one-year full-time Fellowship in Developmental Nurse Counselor Program for B.Sc. nursing graduates at NIMS-Spectrum-Child Development Research Centre, to be expanded to other accredited centers soon. The fellows in DNC and DTs are equipped to assist the pediatrician in the following roles; *i*) neurodevelopmental follow-up and early stimulation for NICU/SNCU graduates *ii*) early intervention for delays *iii*) assessment and intervention for 10 NDDs and *iv*) as a counsellor for parents of children with neurodevelopmental disorders/disabilities.

Allied therapists: The DT, being a multidisciplinary therapist, can be the nodal point of assessment and management in a BEIC. However, in a tertiary care centre, DEIC or CDC, a transdisciplinary assessment and management team is necessary, comprising the speech therapist, occupational therapist, physiotherapist, behavioral therapist with the pediatrician as the team leader and reference point.

Allied specialist medical professionals in the Habilitation Team

Role of pediatric neurologist: The developmental pediatrician should seek consultation from the pediatric neurologist in the following situations: *i*) Diagnostic dilemma *ii*) Features of neuroregression, neurometabolic or neurodegenerative disorders and global developmental delay, *iii*) Atypical regression in ASD and Attention-Deficit/Hyperactivity Disorder (ADHD), and *iv*) Pharmacological management.

Role of clinical geneticist: Services of a clinical geneticist available within the district or neighboring town or city should be sought in cases with *i*) dysmorphic features *ii*) global development delay *iii*) significant family history of genetic disorders and *iv*) on advice of pediatric neurologist.

Role of child psychologist: The child psychologist in the Habilitation team should play the following roles; *i*) Psychoeducational and behavioral assessment of the child *ii*) Provision of behavioral therapies, family therapies and counselling *iii*) Provision of remedial education along with the special educator and pre-school consultant

Role of child psychiatrist: The child psychiatrist should be consulted in case of *i*) management of maladaptive behaviors and aggression in children with NDDs *ii*) depression, anxiety and other psychiatric disorders *iii*) if psychotherapy is indicated.

Recommendation X

Developmental pediatrician to seek guidance when necessary of pediatric neurologist, geneticist, child psychiatrist, physiatrist, and other specialists, for special investigations and medications judiciously. Team leader to keep record of periodic follow-up assessment and feedback on emerging developmental status and the same to be shared with parents at regular intervals.

Recommendation XI

Need to promote ongoing academic programs in clinical child development which may be at graduate or post graduate level, or any other certificate program by NGOs or the Government under RBSK, for capacity building of community-based therapies.

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SUMMARY: SPECIFIC RECOMMENDATIONS

I There is a need for nationwide studies with representative sampling on epidemiology of babies with early NDD in the First 1000 days in India.

II SLD documented as the most common NDD in India after 6 years, and special efforts should be made to establish the epidemiology of infants and toddlers at risk for SLD, where ever measures are available.

III Preconception counseling focusing on pre-pubertal girls' nutrition, family life education for adolescents and premarital & newlywed counseling for above 18 years, as part of focusing on first 1000 days (270+365+365 days)

IV Promote efforts to organize systematic training programs in Newborn Resuscitation Program, Lactation management, developmental follow-up and early stimulation for SNCU/ NICU graduates.

V Risk stratification of NICU graduates, Newborn Screening for congenital hypothyroidism and phenylketonuria and hearing screening, counselling parents for early stimulation and surveillance in the first two years as part of focusing on first 1000 days.

VI Screening for delays by trained AWWs /developmental nurse counselors/developmental therapists/ PHC doctors at CEIC/BEIC, using simple validated Indian screening tools at 4, 8, 12, 18 and 24 months.

VII Holistic assessment of 10 NDDs at CDCs/DEICs by multidisciplinary team members (developmental therapist/ development nurse counselor, physiotherapist, occupational therapist, speech therapists, clinical psychologist) with developmental pediatrician/pediatrician as team leader.

VIII Confirmation of diagnosis by developmental pediatrician/developmental neurologist/child psychiatrist using clinical/diagnostic tools at CDC/ DEIC.

IX Provide parent guided low intensity multimodal therapies before 3 years as a center-based or home-based or community-based rehabilitation services supported by a Developmental Pediatrician/ Psychiatrist.

X Developmental pediatrician to seek guidance, when necessary, of pediatric neurologist, geneticist, child psychiatrist, physiatrist, and other specialists, for special investigations and medications judiciously. Team leader to keep record of periodic follow-up assessment and feedback on emerging developmental status and the same to be shared with parents at regular intervals.

XI Need to promote ongoing academic programs in clinical child development namely PG diploma in Developmental Neurology (Kerala University), Fellowship in Developmental Pediatrics and Developmental Nurse Counsellor (IAP – NDP chapter) and B.Sc in Developmental Therapy (approved by Kerala University of Health Sciences) or any other certificate program by NGOs or the Government under RBSK, for capacity building of community based therapies.

Additional recommendations for Service Delivery of Habilitation Package:

XII Rashtriya Bal Swasthya Karyakram (RBSK) is the identified model for the Habilitation Services with an enhanced approach and collateral referral channels to other existing National Schemes, especially with the Pradhan Mantri Surakshit Matritva Abhiyan, Janani Shishu Suraksha Karyakram, Rashtriya Kishore Swasthya Karyakram to provide the full spectrum of care.

XIII Expanding beneficiaries of Rashtriya Bal Swasthya Karyakram (RBSK) and the fully functional District Early Intervention Centre (DIEC) available in 238 DIECs/766 (as on August 2022); it necessitates to enhance the RBSK by empowering the Block Early Intervention Centers (BEIC) to provide the clinical services sans medical services and certification.

NDD: neurodevelopmental delay; SLD: specific learning disability; SNCU: special neonatal care unit; NICU: neonatal intensive care unit; AWW: anganwadi worker; PHC: primary health care; CEIC: national ethics committee for clinical research; BEIC: Block Early Intervention Centres.

Web Table I District Early Intervention Center (DEIC) Vs Block Early Intervention Centres (BEIC)

<i>Components</i>	<i>District Early Intervention Center</i>	<i>Block Early Intervention Centres</i>
Ministry of support	Ministry of Health and Family Welfare (MOHFW)	Ministry of Health and Family Welfare/Women and Child Development
Mandate	Envisaged at the district level for 4D service provision & capacity building of staff posted at these centers	Definitive identification of at risk and early 4Ds and single allied health personal for transdisciplinary service provision
Infrastructure	4000-5000 Sq.ft building with dedicated, standardized assessment & intervention rooms.	Not envisaged, needs planning
Human resources for health	Permanent and visiting medical and allied health specialist.	Developmental therapists (with multitasking skill): screening services, early stimulation and helping mother to be therapists
Service approach	Interdisciplinary	Transdisciplinary
Services provided	Cores service: Medical services, preventive health and immunization, general women and child services: nutritional and related to feeding of babies, neurological assessment, physiotherapy, occupational therapy, psychological services, cognitive development including play and socialization, testing for speech and language as well as vision and hearing Supplementary services: Certification	Cores service: General women and child services: nutritional and related to feeding of babies, neurological assessment, physiotherapy, occupational therapy, psychological services, cognitive development including play and socialization, testing for speech and language as well as vision and hearing Supplementary services: None
Outcome, documentation, referral & review	The 'DEIC Register' maintains the records of all outcomes. Monthly reports are captured through a chain comprising of DEIC manager, District Nodal Officer	The 'BEIC Register' maintains the records of all outcomes. Monthly reports are electronically/ manually sent through a chain comprising of BEIC manager to DEIC manager.