Special Issue on Developmental Pediatrics

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The virtue of human existence is attributable to the power of thought, feelings, personality, social relationships and productive motor skills. The whole process of acquisition of this complex interplay is developmental neurology. The three basic domains of development are physical, cognitive and psychosocial. But these domains interact in various ways. Human development is holistic and not in separate parts.

The establishment of well-equipped neonatal nurseries and advances in perinatal care have contributed to a great extent towards survival of many high risk newborns. But mere survival is not the ultimate goal. Offering a good quality of life is equally important. Early identification and stimulation of at-risk neonates is crucial in this process. It is important for both growing brain and body. The purpose of intervention is to reduce detrimental stimuli and to provide appropriate opportunities for development.

Early detection of developmental delay is based on some commonly used techniques like taking appropriate history including developmental, relevant clinical examination and use of some screening tool for assessment of developmental milestones. Before putting the baby for intervention the assessment should be done by any of the standardized scale available. It is also important to set up a proper neurodevelopmental centre as the children with special needs need the services of several professionals. If the various needs of these children are addressed under one roof then it is of great benefit to the children and their parents too. Their parents need a lot of support and motivation to bring up these children.

It is the collective responsibility of the obstetricians, neonatologists, developmental pediatricians, special educators, various therapists and parents to nurture these delicate children for their fruitful future. This special issue on Developmental Pediatrics released on the occasion of VI GDBPCON, Cuttack is dedicated to those children with special needs.

Jaydeep Choudhury
Editor of this Issue & Executive Editor

About the Editor of this Issue

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Providing Early Stimulation: Helps Children Grow

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It was first believed that the nervous system was relatively rigid and it would change just a little during the first stages of maturity. This concept now differs because of the influence of two variables: age and use of the neurons. The human brain is made up of cells (neurons). These cells form networks of connections. Every time a brain is stimulated in an adequate way new neuronal connections are being made. The more connections, the more neurons integrated; this determines intelligence, social and emotional skills.

In order to have an adequate development, the brain should be intact. This is the reason that all the efforts to increase intelligence should consider the brain capacities. All human beings are born with less than a third of adult brain capacity. After being born, the cortex and all the central nervous systems are developed rapidly, as a consequence of the environment and experiences. The intense interaction with the environment is a basic element that conditions the development of the brain.

The complexity of the nervous system interactions and the elevated number of interconnections existing between the nerve cells have made scientific researchers accept that its development depends on epigenetic factors that activate and modulate the genetic information present in neuron cells during growing. About 75% of the nervous system maturity is genetically programmed. The rest depends on experiences that is why providing an enriched environment, makes it possible to promote a better biopsychological-social development of children between the ages of 0 and 6 years. During this stage it is possible to modify neurons structurally and functionally depending on its use or disuse.

Experiences of stimulation are based on knowledge of the development of the nervous system. Valuable research has shown that stimuli such as stroking the fetus through the belly, soft and melodious sounds or sound of the human voice, especially the mother’s, as well as light and vibrations are pleasurable to the baby. Once babies develop hearing in the fifth month, music is excellent for aural stimulation and to soothe the baby. Immediately after birth, a baby distinguishes the mother’s voice and show preferences for sounds heard while it was still in the womb. Music heard while in the womb seems to give babies a feeling of confidence and relaxation. However, mothers can give their babies the emotional benefits of music even before hearing develops at five months. Postnatal stimulation in the form of massages and exercises has also shown to enrich the development of these babies.

However, the baby can learn to relate these stimuli to their meanings only if they are presented in an organized way, otherwise, they will probably forget or ignore them. We know that when the experiences occur in a pattern, they are organized in the baby’s brain more efficiently. Prenatal stimulated babies
tend to exhibit enhanced visual, auditory, and motor development. They also show superior learning capacity and higher IQs. Prenatal stimulation is a process that encourages learning in unborn babies optimizing mental and sensory development.

If the extraordinarily receptive brain of the child lacks the stimulation for which it is primed during the first three years, the possibility for various types of learning may be substantially reduced. During key developmental periods, some parts of a child's brain can nearly double in size in a year. Infant stimulation programs\(^1\) are organized programs of enrichment designed to provide developmentally appropriate activities to babies and toddlers who have or who are at risk for a variety of conditions that may interfere with their ability ultimately to have a full and productive life. Among these conditions are:

(i) The sequelae of poverty, nutritional, sensory, and emotional deprivation, family instability,

(ii) Developmental disability.

The first type are children in whom environmental factors are the major events leading to concern for mental development. This so-called cultural-socially deprived group is felt by many to constitute the majority of the borderline and mildly retarded children. They are by far the largest group of handicapped in our school systems.

The second type are the biologically impaired, \(\text{i.e.}\) children with brain damage, sensory deficits, or physical impairments; they are a very heterogeneous group. In this group a multi dimensional interactive model can deal with the complexities involved in early child development; hence now the term early intervention\(^2\) is appropriately used.

There are now a number of well-documented follow-up studies to show that early preschool stimulation programs for the infant from a low socioeconomic environment have both short-term and long-term benefits, providing that support systems are maintained during the school years. Thailand\(^3\) for example has a child development program where a community volunteer, usually a woman who has raised children is given short introductory training, and is assigned 5 families who are expecting new infants. She makes a home visit shortly after the birth of the infant, assesses the home and evaluates the mother's capacity to care for and to stimulate her infant adequately. The volunteer instructs the mother in a variety of early infant-stimulation techniques, including talking, touching, holding, playing, and using appropriate toys. In villages where the program has been implemented, developmental characteristics (such as IQ) of children were better than in comparison villages. They even weighed more with a reduction in second-degree malnutrition. Similarly, the Roving Caregivers Programme\(^4\) run by the Rural Family Support Organization (RuFamSo), a Clarendon-based NGO and UNICEF partner is a child development and parenting education programme provided through a home-visiting service. The Rovers reach rural children, many of whom are in families which cannot afford day care or do not understand the importance of providing proper care and stimulation for early childhood development. Rovers go from home to home to work with these young children and parents, introducing them to developmentally appropriate child-care practices. Each Rover is assigned to about 30 families and receives training in child development. They provide colorful and
interesting toys and learning material for the children in the form of manipulative cushions with zips and buttons to develop eye-hand coordination, bottle stoppers and shells in egg boxes for classification games, balls and hoops for motor development, “feely bags,” and picture cards for sensory and language skills.

Premature infants in neonatal intensive care units are being cuddled, patted, stroked with vibrators, and rocked in water beds and motorized hammocks. They are exposed to flashing lights, dangling birds and toys, and piped-in heartbeat sounds and music. Data\(^6\) suggest that tactile/kinesthetic stimulation popularly referred as massage therapy may be a cost effective way of facilitating growth and behavioral organization even in very small preterm neonates. Critical findings from 3 studies\(^7\) indicate a 21% to 47% greater weight gain for the massage therapy versus the standard care control group. Other findings of interest include greater bone mineralization, earlier hospital discharge, and more optimal behavioral and motor responses for the massage therapy group. These findings and a meta-analysis of 19 studies\(^8\) indicate that 72% of infants receiving massage therapy did better than controls, support the view that massage therapy improves the clinical and developmental course of preterm infants. Research\(^9\) in the neonatal intensive care unit has focused on uses of music to reduce stress, to promote homeostasis and weight gain, to reinforce non-nutritive sucking, to enhance developmental maturation, and to shorten length of hospitalization. Music benefits documented for full term newborns may also apply to the premature infant, i.e., lullabies promote language development; familiar music is recognized, reinforcing, and comforting; and infants orient to and avidly attend to music more than other auditory stimuli. Preterm neonates provided with pacifiers for non-nutritive sucking during tube feeding started bottle-feeding three days earlier, averaged a greater weight gain per day, and were discharged eight days earlier.\(^9\)

In recent years, there has been an exponential proliferation of developmental stimulation programs for environmentally deprived and neurologically handicapped children. In India the CDC Thriruvanadapuram model\(^2\) of early intervention as developed at the Child Development Centre has evolved itself into a practical mother oriented stimulation and therapy model, amalgamating experiences of pioneers in the field to problems of working with at-risk babies. Their aims of early stimulation include:

(i) Stimulating the child through normal development
(ii) Preventing developmental delay, both mental and physical
(iii) Prevention of asymmetries and abnormalities
(iv) Detection of transient neurological abnormalities and minimization of them becoming persistent abnormalities

Nowadays infants and preschoolers with neurologic disorders roll on beach balls in special “infant classrooms,” on “therapeutic playgrounds,” and in “creative play centers.” Older children with learning disabilities practice walking on balance beams to improve their gross motor skills and learning abilities. Sensory integration therapy “enhances the organization of brain mechanisms and neural integration.” Vestibular impairment is treated by providing “a bombardment of stimulation through the...
many different vestibular receptors activating synapses and increasing the number of impulses converging on neurons."

Without intending to promise normal brain development, personnel in many of these programs convey to parents the message that stimulation and intervention will, in effect, grow new brain cells.

Introduction
With the advancement of perinatal and neonatal care the survival of the premature and extremely low birth weight babies are gradually increasing constituting a new group of babies, the high risk neonates. During routine follow up these babies may have some problem in acquisition of expected milestones of development. The delay in development can be in the domain of motor, cognitive, adaptive and language. Recently it has become the emerging concern for the pediatrician to detect the developmental delay at earliest possible time so that the babies may enjoy the full potential of development by the early intervention services at the expected age.

The early detection of developmental delay is based on some commonly used techniques such as reviewing the parents regarding the developmental history, relevant clinical examination, and use of some screening tool for assessment of developmental milestones.

Previously the scope of using the screening tool by the pediatrician was very restricted probably due to lack of knowledge on infant development and also due to lack of ecological validity of the scales.

Aim of Developmental Screening
(i) Early detection of the abnormality will help to formulate developmental remediation at earliest.
(ii) Early intervention in various aspect will help the baby to achieve the full potential of development in due course of time.

Assessment of Developmental Milestone
(i) Gross motor – Neck and body control, rolling, sitting, standing, walking.
(ii) Fine motor – Dressing, writing, playing instruments, and other coordinated action of fingers.
(iii) Personal social – Interaction with the surroundings, relationship with the family and peers.
(iv) Language – Spoken language and gestures for communications.

Criteria for Developmental Screening Test
(i) It should be simple, brief, less time consuming and culturally acceptable.
(ii) It should be designed in such a way that it identifies the children who may need detailed assessment by standardized tool later.
(iii) May identify the group of children requiring comprehensive evaluation by neurological examination, imaging, chromosomal and metabolic study.
(iv) It can be used in community screening for delay by the Anganwadi workers, primary school teachers, etc.
(v) Should have adequate sensitivity, more than 0.65, and specificity.
(vi) Should be standardized with adequate validity and reliability in larger population.

(vii) The screening tool may not detect the minor abnormalities of development.

For detection of minor abnormalities or for confirmation of the cases found to be abnormal in screening the detailed assessment should be done by any of the standardized scale available by trained professionals before putting the baby for intervention.

Over the past century some remarkable research has been done in the field of developmental diagnosis. Arnold Gessel had started his studies in Yale University on the development of infants as early as in 1920. At about the same time Nancy Bayley started her work in Berkely which continued over 36 long years for three generations of study on development before being standardized on 1400 children and published as Bayley Scales of Infant Development (BSID) in the year 1969.

The scales include Motor, Mental and Behavior Rating Scale. The motor and mental scale assess the child’s current level of gross motor, fine motor, cognitive, language and personal social development; and behaviour rating scale the behaviour of the child during the testing session.

The motor scale includes items to assess the movements associated with rolling, sitting, crawling, creeping, standing, walking, running; fine motor evaluation involves prehension, adaptive use of writing implements, and hand movements.

The mental scale conceptualizes the items on cognizance like persuit of living object, exploring them into meaningful manipulation, memory, habituation, problem solving, vocalization, social skills and imitative behavior.

As a diagnostic tool the BSID remains most useful worldwide for complete developmental assessment of the baby as the motor and mental functioning are evaluated simultaneously but independently. Initially the developmental scales were designed to identify the children who were functioning delayed in achieving developmental milestone but by administering the scale a clinician can get lots of information to compare the child with the same age peers.

Based on the Bayley Scale of Infant Development (BSID) the adaptations are made to make it culturally acceptable and over the years with greatest dedication and perseverance the Indian versions are validated successfully to be used as developmental screening tool for our children.

**Baroda Developmental Screening Test for Infants (BDSTI)**

This scale is based on Baroda norms on BSID Research form 1961, validated in the city of Baroda in 1970.

Dr P Phatak selected 54 items from Bayley Scale of Infant Development Research Form 1961 to be used as a screening test for survey.

It is used widely in India as a screening tool for assessment of infant development.

It includes 22 motor and 32 mental items validated against BSID Baroda norms.

The test can be done from 0 to 30 months. Items are arranged as 97% pass age placement. They are grouped age wise monthly till 12 months, 3 monthly till 18 months, and 6 monthly till 30 months.

Like Bayley scale it is also a point scale and total scores of motor and mental items are calculated as total scores.
The raw scores are converted to motor and mental developmental index. If a child fails items according to the chronological age is selected for detailed study. The sensitivity of the tool is 0.66 to 0.93 and specificity is 0.77 to 0.94. (BDSTI vs BSID full scale)

**Advantages:**
(i) Easier to use
(ii) Acceptable in Indian population.
(iii) Provides developmental age, developmental quotient for assessment.

**Trivandrum Developmental Screening Chart**
A simple and easily administrable test for developmental assessment validated at Trivandrum Child Development Centre for hospital as well as community settings.

17 items are selected from Baroda norms denoting motor, mental, hearing and visual function.

Each item is represented as a horizontal line which represents 3% to 97% of children passing the item of Baroda norm.

This test can be administered up to 24 months of age.

A vertical line is drawn at the chronological age of the child to be tested. The age in months are written in horizontal axis below the item chart. If a child fails to achieve any item that falls to the left hand side of the vertical line drawn the child is considered to have developmental delay.

Any delay has to be assessed in detail by other standardized tool.

Sensitivity is 0.67 and specificity is 0.79.

**Advantages:**
(i) It can be used in busy office practice to screen for delayed development.
(ii) It takes only 5-7 minutes for administration.
(iii) No special tool or special training is required so can be used for community screening.

**Developmental Assessment Scale for Indian Infant (DASII)**
A revision of 1970 Baroda norms from birth to 30 months based on BSID research form 1961.

Dr (Mrs) Pramila Phatak has done an extensive study at Baroda, India starting from 1963 based on the Bayley Scale of Infant Development.

More than 30 years she had dedicated to standardize the scale using longitudinally in 4100 case records in Indian settings, using some indigenous materials.

She had selected 67 motor and 163 mental items modifying in culturally accepted way from original Bayley scale.

The test can be performed from 0-30 months of age.

Like Bayley Scale it is also a point scale and each item for which the child under testing credited is scored 1. The total motor and mental performances scores the child obtains are calculated by adding up the total items passed or credited on the respective scales.

The total 230 items are evaluated simultaneously and independently to assess the developmental ages.

The percentages of infants passing each item in each age groups (months) were calculated and intercepted for ages where 50%, 3% and 97% of infants would have passed each items.

For each item 50% placement age is considered as equivalent motor and mental age.
The raw score in motor and mental scale are converted in motor and mental developmental quotient (Equivalent IQ) respectively by using a formula of chronological age and developmental age.

Developmental quotient (motor) = Motor developmental age / Chronological age x 100.

Developmental quotient (mental) = Mental developmental age / Chronological age x 100.

Developmental quotient more than 85 is considered normal.

The items in both motor and mental scale are subdivided into several cluster to specifically identify the areas of weakness or less functioning while doing the test for formulating definite intervention programme.

So this scale can be used for detailed assessment in particular field of development of the babies detected as delayed functioning in one of the screening tool.

**Disadvantages:**

(i) It needs special training for doing the scale and handling the child under testing, require special set of furniture and standardized test kit and manual.

(ii) Child’s full cooperation is needed for administering the test.

(iii) On an average it requires 30-40 minutes to complete the test items may be prolonged depending upon the mood of the child.

(iv) Mother’s apprehension and interference may cause hinderence in testing.

(v) All the developmental scales needs age correction for preterms.

(vi) Needs thorough knowledge of infant development.

(vii) Developmental quotient reflects the child’s functioning on the testing period, there may be little consistency of DQ in infancy with the IQ in later part of life. DQ is assessed for developmental remediation by early intervention.

**Indian Adaptation of Vineland Social Maturity Scale (Malin, 1992)**

This has been widely used scale in India for age range of 0-15 years.

It measures the child’s adaptive behavior, and skills in communication, self help general, self help eating, social relation, occupation, locomotion and self direction.

The scales yield a social age which can be converted into social quotient score.

**Indian adaptation of Stanford Binet Test (Kulshreshtha’s test) and Revised Weschler’s Intelligence Scales (WISC R) adapted by Bhat.**

These two tests are commonly used in India for testing of IQ.

Stanford Binet relies upon mainly on verbal items.

It is used in the age group of 2-23 years.

The WISC R has separate verbal and performance IQ. It is long generally requires two settings but assess the child’s IQ in complete manner.

Used in the age group of 6-17 years.

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Principles of Developmental Assessment

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Development is defined as the growth of perceptual, emotional, intellectual, and behavioral capabilities and functioning during childhood. Developmental assessment is an important part of evaluation of the child as developmental problems are comparatively far more common than many other chronic medical problems with a significant impact on the quality of life. The World Health Organization (WHO) has estimated that 10% of the world’s population has some or the other form of disability. Other studies across India also give a similar estimate, i.e., 8 to 10% of children having some delay in one or the other domains of development. Prevalence of developmental delay ranges from 3.5% to 10% of the general population in various studies carried out all across the world.

Objectives of Developmental Assessment
(i) To detect or exclude abnormalities.
(ii) To make a differential diagnosis between different parameters in developmental levels.
(iii) To make an etiological diagnosis.
(iv) To measure the severity of a functional deficit.

Principles of Development
The basic laws of human development are as follows:
(i) Development is a continuous process from conception to maturity.
(ii) The sequence of development is the same in all children but the rate of development varies from child to child.
(iii) Development involves maturation which is closely related to myelination of the CNS.
(iv) Motor development takes place in a cephalocaudal and proximo-distal direction.
(v) Development proceeds from generalized mass activity to specific individual responses.
(vi) Certain primitive reflexes have to be lost before the corresponding voluntary movement is acquired.
(vii) There is a psychological growth seen as an increase in function and ability.
(viii) Each developmental phase has a past and a future and an assessment of the present phase allows a prediction of the next one.

Developmental Assessment
A comprehensive developmental assessment will include a study of the following development parameters such as:
(i) Motor development – gross and fine manipulation, balance and movement.
(ii) Personal social development.
(iii) Adaptive (or nonverbal) development.
(iv) Communication and language development.
Learning skills.

Hearing and vision assessment.

The basic principles of development have to be well understood and a thorough knowledge of normal variations and abnormal is essential before attempting any developmental assessment. It prepares the examiner to be aware of the development level of the child depending on age and guides the examiner through the evaluation.

A thorough history including the prenatal, perinatal and post-natal factors which profoundly affect the development of the child should be noted. A complete examination including physical examination, anthropometric parameters, assessment of vision and hearing and other factors which affect development should be undertaken. As development takes place in different domains, a complete developmental assessment should cover all the areas of development adequately, i.e., motor, cognitive, psychosocial etc. The evaluation of both verbal and non-verbal skills gives a complete picture of the developmental status of the child.

Developmental assessment tools:

Developmental assessment tools available are mainly of 2 types: screening tools and diagnostic tools.

Screening tools – Screening tools are usually quick observational tools or pre-test questionnaires which provide preliminary evidence of lag in any domain of development. It is easy to administer, usable by paramedical staff and inexpensive. It usually includes quick questionnaires for parents/healthcare givers etc, and covers areas like language development, cognitive delays, behavioral and psychiatric problems etc. The Trivandrum Developmental Scale for Children (TDSC), Gessell's Motor Milestones, pre-test questionnaire of Denver Development Screening Test (DDST), Parental Evaluation of Developmental Status (PEDS), Early Language Milestones (ELM), Attention Deficit Hyperactivity Disorder (ADHD) Checklist, Behavioral Checklist etc are examples of screening tools. However, screening tests have certain limitations such as over-diagnosis, failure to follow up and may lead to high anxiety in parents.

Diagnostic tools – The diagnostic tools are used for the detailed evaluation of the child and usually have a good predictive value. These tools are useful in evaluation of the severity of the problem and can be used for planning interventional procedures in the specific areas of delay. Developmental assessment tools that are standardized for a particular population have a better predictive value. Bayley Scale and its Indian Adaptation DASII (Development Assessment Scale for Indian Infants), Kamat Binet test of Intelligence (KBI), Wechsler's Intelligence Scale for Children (WISC-III), Diagnostic Test for Learning Disability (DTLD), DDST etc are examples of diagnostic tools. Various assessment tools that may be required to carry out the assessment are specific for the domains they are designated to test and should be used judiciously in combinations so as to arrive at a complete picture of the child and give a detailed diagnosis of the lags in specific areas or a global delay.

The serial assessments can give a fair prediction of longterm prognosis and also the impact of any interventional strategies employed. A complete evaluation should give the information to plan out intervention to help the child in the areas of delay. A detailed evaluation with proper understanding and
counseling of the parents plays an important role to motivate them and accept the problems and long-term therapies.

**Procedure of developmental assessment:**

Developmental assessment should be carried out by professionals with expertise and patience. Developmental assessment should be carried out in a separate room which is well lit and quiet, with no distractions of people or other sounds. The room should be colorful and interesting to the child. Minimal furniture should be present in the room.

During initial history taking, the child becomes comfortable in the presence of parents and a few simple play items such as dolls, bricks, puzzles etc should be laid to allow free play. The entire assessment session should be well planned and structured by the examiner. The child’s relationship and interaction with the examiner and care-giver is very important as the child will give the best response and show highest skills in the form of spontaneous play and well-controlled motivated interactions in presence of care-givers. The aim of the assessment should be to get as accurate an observation as possible and allow the child to do his best. The assessment may be carried out in multiple sittings as required. Rapport building and gaining the trust of the child is the first block. Similarly, making the child sit and holding his attention for a short span also requires expertise and patience. The assessment system should be flexible and a particular sequence as in an adult cannot be followed. Avoid undressing the child or undress only as much as required. Various parameters of development are tested by combining the test of vision, hearing, neurological and developmental assessment. Also, the care-givers could be instructed to elicit certain responses from the child during the evaluation process.

During the first year of life, neurodevelopmental approach is the best as during this period, though there is a lot of development at different domains it is closely related to the development and maturation of the central nervous system. The tests that are used are Dubowitz scoring for gestational assessment, Amiel-Tyson Angles for passive tones, Brazelton Scales, detailed neurological examination, examination of hearing and vision by appropriate tests. For cognition, tests such as Bayley Scales (DASII), Denver Development Screening Test – II (DDST-II), Vineland Social Maturity Scale (VSMS), etc may give reasonable information.

For older children, along with the motor development, language development becomes the major area to be assessed. Various stages of language development and comprehension need to be tested with the appropriate tests. Also, many non-verbal tests such as puzzles, peg-boats, form-boats etc give a clue about the adaptive development. In older children, the approach towards the test and examiner and behavior during the testing gives us important information about their social development. Perceptive skills and learning skills need to be tested in still older children. The tests used for evaluation of perceptive and learning skills are Aston’s Index, Woodcock Johnson Test of Achievement and Cognitive Abilities – III, Schonell’s Attainment Test, Wide-Range Achievement Test (WRAT), Diagnostic Test for Reading Disability (DTRD), Test of Written Language (TOWL) etc.

**Developmental Diagnosis**

A comprehensive developmental assess-
ment should be able to answer some very fundamental questions about the normalcy of development, whether delay is present or development is abnormal or distorted. Similarly it also gives us information about the parameters that are affected and details about the child’s weaknesses and strengths.

The inference should not be drawn by one particular test or score as the overall score in a particular test may not give us a correct picture until the different components or sub-tests are analyzed. The conclusion of developmental assessment should be based on a complete detailed history, risk factors, family history, medical and neurological examination and developmental assessment appropriate for the particular age.

The major systems to be considered while making a developmental diagnosis are motor development including fine and gross motor skills, cognitive development including language and adaptive functions and perceptual functions. A child with cerebral palsy will show gross problems and delays in motor and perceptual functions but may have normal cognitive functions. Similarly, a child with dyslexia may show mild problems in fine motor coordination with normal intelligence and significant perceptual problems. A child with autism will have normal motor development, mild problems in adaptive function but severe delays in language areas and severe problems in perception.

Advantages of developmental assessment:
Developmental assessment helps us to know the development of the child in relation to his age and compare his performance to the other children of his age. Serial assessments give us information about the rate of development in different areas. It also gives us information about the neurological condition being static or progressive in view of gains or losses of skills that occur over a period of time.

Drawbacks of developmental assessment:
Developmental assessment does not pinpoint the cause of the delay as most delays may be multifactorial in origin or have no identifiable cause. The biggest dilemma of developmental assessment is that even at the end of the evaluation the differentiation between normal and abnormal is difficult. Especially in younger infants in the first few weeks of life, it is very difficult to differentiate the normal and abnormal neurological signs. After assessment of smaller babies or infants, accurate prediction of future intelligence and functions cannot be accurately predicted. The possibility of any other future problems cannot be ascertained. Also, the effect of environmental factors cannot be assessed so early. A few of the tests do not have age-appropriate norms for a given population. This also hampers its predictability. The interpretation of the test can also be hampered by other environmental factors such as cultural issues, parenting styles etc, which play a very important role in the psycho-social development of the child.

As development is a continuous process, serial follow-up and assessment are very important to assess the different phases of development and the impact of any interventions. The serial assessments should preferably be done by the same examiner at two separate intervals. The follow-up assessments help to determine the impact of intervention on the child. The child should be reviewed every three to six months and...
the plan of action should be suitably altered based on the latest assessment.


Common Causes of Developmental Delay

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Advances in perinatal care and establishment of well-equipped neonatal nurseries have contributed to a great extent for survival of many newborns who would otherwise have succumbed in their early days. But the ultimate goal is not just survival, but offering a good quality of life to the neonates. Early recognition of infants at risk for developmental disability is important as it provides the opportunity for early referral for interventional services and diagnosis.¹

Whom to Screen?
Ideally all infants and children should be screened for developmental delay.¹ But such a policy may not be practical. It requires a lot of qualified and capable manpower for effectively screening the newborn. Further it will be time consuming. So it is neither feasible nor cost-effective in our country. Hence screening should be done in selected high-risk infants.¹

What Can Go Wrong?
Insult to the newborn may be due to problems at various stages of development.²
1. Inherent fetal problem – Genetic factors.
2. Problems in pregnancy and during delivery.
3. Problems during neonatal period.

Categories of Risk Factors for Developmental Delay
Developmental deficits occur among babies with four categories of risk.³
1. Genetic and metabolic disorder – The experience from the developed countries has shown that the incidence of severe mental retardation and cerebral palsy have not come down despite the best possible perinatal care. But there is a substantial reduction of mild to moderate cases of developmental delay, possibly due to detection and prevention of genetic factors. In countries like India, there are poor facilities for genetic screening, detection and counselling. So when a young mother presents with a baby with Down syndrome, the baby needs immediate attention.
2. Environmental risk – Home environment is a very important factor in child development but many children are not born in an ideal home environment.
3. Biological risk – Birth weight is perhaps the single most important factor which influences the outcome of a birth in terms of survival, growth and development. The consequences of low birth weight are reflected in high mortality, poor physical growth, impairment of cognitive function and intellectual development and even later adulthood diseases such as diabetes and coronary artery disease. If a child is to be born with full growth potential it will be obligatory to ensure that he is born with a normal weight at birth.⁴ Apart from this, prematurity, birth asphyxia, neonatal hyperbilirubinemia, hypoglycaemia, neonatal convulsion and intrauterine
infection are considered to be risk factors for poor development.

4. **No apparent risk** – Developmental delay is often observed in babies born without any apparent risk factor. On the other hand many babies born with several risk factors develop normally.

**High-risk Infant**

(i) Birth weight less than 1250 grams
(ii) Gestation 30 weeks or less
(iii) Intraventricular hemorrhage
(iv) Asphyxia
(v) Severe neurological problems
(vi) Bronchopulmonary dysplasia that requires oxygen supplementation
(vii) Complex congenital heart disease
(viii) Abnormal neurological examination at discharge
(ix) Significant feeding problems
(x) Intracranial pathology, congenital or acquired like periventricular leukomalacia
(xi) Diaphragmatic hernia
(xii) Persistent pulmonary hypertension
(xiii) Significant circulatory failure
(xiv) TORCH infection
(xv) Persistent prolonged hypoglycaemia
(xvi) Multiple/major congenital anomalies and genetic disorders.

**Moderate-risk Infant**

(i) Birth weight between 1250 and 1500 grams
(ii) Prolonged ventilation
(iii) Surgical anomalies
(iv) Metabolic disorders.

Along with these screening can also be done in children whose parents express concerns for the child’s development and in whom teachers and physicians suspect problems.

**Prenatal Diagnosis**

Prenatal diagnosis employs a variety of techniques to determine the health and condition of the fetus. Congenital anomalies account for 20-25% of perinatal deaths.

**Indication for prenatal diagnosis:**

(i) Women aged more than 35 years
(ii) Raised maternal serum α-fetoprotein
(iii) Family history of neural tube defects
(iv) Family history of chromosomal disorder
(v) Carriers of X-linked recessive diseases who want termination

**Some diseases that can be diagnosed prenatally:**

(i) Polycystic disease
(ii) G6PD deficiency
(iii) Muscular dystrophy
(iv) Hemophilia
(v) Down syndrome
(vi) Some metabolic disorders

**Prenatal diagnosis is helpful for the following:**

(i) Managing the remaining weeks of pregnancy
(ii) Determining the outcome of pregnancy
(iii) Planning for possible complications during delivery
(iv) Deciding whether to continue pregnancy.
(v) Finding conditions that may affect future pregnancy.

Sub-optimal perinatal care is the most
important modifiable determinant of neurodevelopmental outcome.  


4. Assessment and intervention in developmental neurology. Institute of Distance Education, University of Kerala; Child development Centre, Thiruvananthapuram. 2007.

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An Endeavour of IAP Growth, Development and Behavioral Pediatrics Chapter

A Subspeciality Book on

**Behavioral Pediatrics**

**Chapters on**:  
Approach to Behavioral Pediatrics  
Behavior Disorder in Children and Adolescent  
Habit and Tic Disorders  
Developmental Disorders:  
- Attention Deficit Hyperactive Disorders  
- Pervasive Developmental Disorders (Autism)  
- Mental Retardation  
- Learning Disorders  
- Communication Disorders  

Somatization Disorders  
Children with Chronic and Terminal Illness  
Emotional Disorders

**To be released during PEDICON 2008, Bhubaneswar**
We are all aware that a baby’s first experience is emotional – the birth’s cry. From the moment a baby is born he/she starts to express emotion. At birth a baby’s first cognitive task is to attend to objects for sorting out familiar and unfamiliar perceptions. During this time, infants’ emotional states are simple such as distress contentment and interest. But within a few months, babies starts showing sadness, happiness and also starts solving problems through emotional skills. He /she starts coping with the inevitable struggles of life, learns to accept changes calmly and embrace new ideas and resources. The full range of emotional development – means sadness to happiness to a state of anger – all starts taking place. The baby starts learning to deal with his/ her emotions appropriately.

Newborn
Let’s start with the state of a newborn. Kagan has found that a newborn has a natural perceptual bias toward curved lines, red colour and movements. When an object shows all these features, the infant becomes especially attentive. Kagan believes that an infant attends to his mother’s face for a long time as the features of the face, which is curved; has a movement; and has red lips, are according to the infant’s perceptual bias. In two to four months, evidence of happiness appears in a baby’s “social smile.” They turn extremely curious, meets frustration with crying, kicking, biting1-4.

Four Months
The infant’s attention will begin changing by four months because the brain by now has changed. The infant becomes interested in things that are a little different from what he knows and enters a different world with a temperamental bias. This affects the child’s way of responding emotionally. Although there are a large variety of temperaments in infants, it can be roughly divided into High Reactive children (very sensitive to novelty) and Low Reactive children (for whom novelty does not affect behavior). While High Reactive children are biased to become shy, timid, quiet and fearful, Low Reactive children are biased towards sociability and fearlessness. In four to nine months the basic emotions, which include fear, excitement, anger, disgust, surprise, joy and sadness, emerge.

Nine Months
Neuroscientists have found that by nine months the frontal lobes of the brain (the regions that, in part, allow for retrieval of the past) get connected with the limbic system (the emotional centers of the brain) and the baby can now remember his/ her immediate past, which creates a separation anxiety (cries when someone familiar leaves), common to a nine month old around the world. Another feature seen in babies at this age is recognition fear of strangers and fear of change. The child is now able to retrieve a set of familiar faces from memory and compare a new face with the familiar ones.
Two Years

Just before a child's second birthday, a remarkable human trait begins to appear – concern about what others think. In around 18 months of age, a child begins to show the first signs of understanding right and wrong. Three abilities are key to development of the Superego. First, the child wonders, “what will my mother or father think if I soil my clothes, hit my brother, etc.” Second, the child becomes aware of his intentions, his name, and his degree of enjoyment of an event. Finally, the child develops language skills that enable him/her to categorize the world into groups, strata, and opposites. For example a ball is a toy, which is an objects to play with. Food is something you eat but not something you are supposed to play with, even though it is just as interesting to throw as a ball. Also self-conscious emotions develop, such as guilt, embarrassment and pride.

Five to Seven Years

This is the time when a child can relate his/her responsibility to the social context. A child is given to the school at this age and although feels boring, he/she sits in the classroom assuming the importance of learning. Even unwillingly a child can pick up his/her toys and does so with an understanding that his/her mother likes the house to be kept neat. He/ She can by now well understand that a person or something cannot be ugly and pretty, working and rested, big and small at the same time. This sort of understanding enables the child to understand inconsistencies in languages too.

Another interesting thing is that the child at this age develops a guilt consciousness because he/she become aware of the fact that there are standards of conduct. If a two- three-year-old girl breaks a glass, she may be fearful or anxious because of the mistake. But she does not realize that the action could have been prevented. By five- six years of age, a child recognizes that violating the standard does not need to occur and the child becomes vulnerable to guilt. However, the different aspects of a child develop side by side. The rate of development varies with the condition of upbringing, such as physical, social, intellectual stimulation, language model, exposure to environmental influences (socio cultural & socio economic) behavioral models etc. But it is useful to know the age milestones of emotional development to identify children who are at risk for anxiety disorders.

Influences of Parents in Childhood Development

The different aspects of a child develop side by side. The rate of development however varies with the condition of upbringing, such as physical, social, intellectual stimulation, language model, exposure to environmental influences (socio cultural and socio economic) behavioral models etc. Let’s see how significant person’s behavior affects the childhood emotional development.

1. Parents/older children quarreling violently in front of the child will cause the child to develop fear, anxiety, even hatred for parents. Conflict and imbalance in the parental relationship, conflicting demands on the child, rivalry for the Child’s affection, jealousy focused on the child may lead to conflict, anxiety and neurotic symptoms in the child.

2. Overanxious, jealous, fearful, uncontrolled (in anger) parents encourage the child to develop similar
habits.
3. Training by threats and physical punishment produces fearfull aggressive, inhibited behavior leading to maladjustment and problems of controlling the child.
4. If the behavior of guardian is dictated by temporary moods and self-interest rather than a consistent method of training, mental development will be severely affected.
5. Leaving the child in charge of a series of untrained domestic employee is harm full, as :
   (a) They are often not suited for the role of educator and model.
   (b) The child cannot form a lasting emotional bonding with anyone.
   (c) Confusion and conflict may arise as result of changing and differing values of employees and family members.
6. Conflicting instructions and attitudes by parents and grand parents or other adults having to do with the child's upbringing are harmful and result in confusion of values and emotional conflicts in the child.
7. Parent's acceptance of the child or lack of it is vital factor in healthy development.
   (a) Some children are unwanted by their parents. A child made to feel unwanted cannot develop in a healthy normal manner.
   (b) Sometimes sex of the child is unwanted. Sometimes parents try to overcome their frustration by bringing up a girl as a boy and vice versa. This creates identification problem.
   (c) Some parents prefer one child and another. This gives rise to suffering and frustration in the neglected child, also sibling rivalry, even hatred for getting the parents attention.
8. Parents must recognize individual differences among their children and accept them. One child should not be compared favorably or unfavorably with another. Parents own wishes as they how they wanted their child to turn out should not come in the way of accepting it lovingly as it happens to be (slow learner, handicapped, aspiration different from those of the parents etc).
9. Excessive/overprotective love is destructive, ie, doing every thing for the child makes him helpless, dependent, selfish, and demanding and usually in the end resentful against his/her parents.
10. Excessive pressure for good performance in school is very harmful.

Tips of Parenting
1. Be playful and encourage social games by engaging in face-to-face nonverbal imitative interactions with the baby, encouraging him to imitate expressions such as raising his eyebrows, sticking out his tongue, mirroring voice tone, coughing.
2. Tune in to the baby's cues as to when and how much stimulation he needs. If the baby suddenly seems uninterested in interaction, provide some quiet time. This helps the baby learn how to regulate his emotional state by soothing himself.
3. Help the child feel secure by expressing your understanding of her thoughts and feelings. As she acquires more words, teach her to label feelings. Remember
to be involved in the three main parts of communication:

(i) Demonstration – show things and say things by changing the tone and pace of speech.

(ii) Imitation – copy what your child says and does

(iii) Animation – smile, play, and react with pleasure

4. Provide experiences that will help the baby to learn that making sounds and responding to the sounds that others make is pleasurable and results in a response and social interaction from others.

5. Listen to the baby’s coos and babbles and don’t interrupt. In this way she’ll learn that what she has to say is important.

6. Make a series of sounds in one breath, such as “ba-ba-ba.” Encourage the baby if he imitates you. In this way he’ll learn about connected speech.

7. Provide comfort – If you respond quickly and sensitively to your baby’s cry or discomfort then he will feel his needs are being and valued and he will develop security.

8. If you provide soft, lullaby music when feeding your baby, (breast or bottle) and let grasp your finger then he will enjoy new sounds that are as comforting as speech and Practice grasping more will make him feel more and more confident with his ability.

9. Feed your baby whenever he is hungry then he will develop trust, that his needs will be met.

10. Be purposeful in guiding your child’s emotional life. Focus intentionally on his emotional needs. These needs are just as important as his cognitive, physical and spiritual needs. Let children know that they are responsible for any feeling they experience. Likewise, they are not responsible for others’ feelings. Avoid blaming children for how you feel.

11. Build a strong bond by spending quality time with your child. Experts agree that parents who interact regularly with their children beginning in infancy develop stronger bonds.

12. Stay emotionally in tune. Connect with your child on an emotional level. Attempt to understand what she is feeling. When she is happy, be happy for her; when she is sad, cry with her.

13. Encourage your child to verbalize his/her needs, ask your child’s opinions often. After reading a story to your child, ask his/her opinion of events or characters in the story. Discuss real life situations – ask your child’s opinion about what should be done in those situations.

14. Model healthy emotional relation. Your children will mimic the way you handle emotions and the way you relate to others. By managing your own emotions in a positive way, your children will learn to do so as well.

15. Teach children how to handle negative emotions. Doing this well does not come naturally. Children need to be taught how to handle “defeat”, develop “tease tolerance” deal with “conflict or anger” in a healthy way. Let children settle their own disputes between siblings and friends alike. Children who are taught these skills early are better able to handle negative feelings as adults.
16. When you feel good about your child, mention it to him. Children remember positive statements parents say to them. They store them up and “replay” these statements to themselves. Practice giving your child words of encouragement throughout each day. 

17. Use descriptive praise to let your child know when they are doing something well. Don’t be afraid to give praise often even in front of family or friends. Also, use praise to point out positive character traits. For instance, “I like the way you stick with things you do even when it seems hard to do.”

18. Teach your child to practice making positive self-statements. Self-talk is very important in everything we do. Psychologists have found that negative self-talk is behind depression and anxiety. What we think determines how we feel and how we feel determines how we behave. Therefore, it is important to teach children to be positive about how they “talk to themselves.” Some examples of useful self-talk are: “I can get this problem, if I just keep trying.” Your child can become an expert at this by listening to positive statements which will help him to develop positive self-esteem.

19. Avoid criticism that takes the form of ridicule or shame. Sometimes it is necessary to criticize a child’s actions, but when the criticism is directed to the child as a person it can easily deteriorate into ridicule or shame which leads to develop low self-esteem. It is important to learn to use “I statements” rather than “You statements” when giving criticism. For instance say, “I would like you to keep your clothes in the proper place in your drawers not lying all over your room;” rather than saying “Why are you such a lazy slob?”

20. Teach children to change their demands to preferences. Encourage your children to ask assertively for what they want pointing out that there is no guarantee that they will get it. Reinforce them for asking and avoid anticipating their desires.

21. Teach your child about decision-making and to recognize when he has made a good decision. Many time Children make decisions but often are not aware of that. Parents can help children in improving their ability to consciously make wise decisions by helping the child:

(i) To clarify how he sees, hear, and feels about the problem that is creating the need for a decision.

(ii) Brainstorm the possible solutions by pointing out the fact and by suggesting alternatives if the child has none.

(iii) Allow the child to choose one of the solutions only after fully considering the consequences. The best solution will be one that solves the problem and simultaneously makes the child feel good about himself.

(iv) Later join the child in evaluating the results of that particular solution. Did it work out well? Or did it fail? If so, why? Reviewing the tactics will equip the child to make a better decision the next time around.

So in the development of a child’s psychology or emotional state, parent’s
behavior forms an important element. Most of the experience that a child gathers is from his/ her parents. Better the parents behave, better a child develops.

5. URL : http://www.medem.com/search/article_display.cfm?path=\TANQUERAY\M_ContentItem&mstr=M_ContentItem/ZZZ7GO1P8FC.html&soc=AAP&srch_typ=NAV_SERCH. Accessed on 1 August 2007.
Organizing a Neurodevelopmental Centre – Basic Steps

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Introduction
Why do we need a neurodevelopmental centre? It is something similar to a hospital OPD, where there are several departments under one roof. Children with special needs need the services of several professionals. Having all the services under one roof enables efficient management of the child. Life is a lot easier for the parents, different needs of the child are addressed at the same time, and there is better co-ordination among the professionals themselves.

Overview of Organizational Aspects
There are various areas to consider when setting up a neurodevelopmental centre.
1. Identifying the child population.
2. Designing the clinic itself.
3. Obtaining the correct equipment.
4. Getting the right personnel.
5. Deciding on the format of the clinic.
6. Successful implementation of the clinic.
7. Recording information.

Identifying the Child Population
Whom do we see at the neurodevelopmental centre? It can be a worried parent bringing in their child. It can also be a worried doctor or other professional (eg, school teacher) who can refer a child for assessment. Children may present with the following problems:
(i) Global developmental delay.
(ii) Isolated motor delay.
(iii) Isolated speech delay.
(iv) Hyperactivity.
(v) Behavior problems.
(vi) Academic underachievement.

Designing the Clinic
It is always nice to have large space but more often than not we have to make do with small space and makeshift rooms. Many people have started work in a single room and have slowly expanded in phases. Here is an outline of a moderate layout. The centre should ideally have the following areas:
(i) Waiting area with a reception desk – keep it clean, airy, and simple. Decorations should be minimum and with easily washable and non-breakable materials.
(ii) Consulting rooms – two consulting rooms can be shared amongst the different professionals.
(iii) Physiotherapy/occupational therapy area (~12’ x 14’)
(iv) Speech therapy area, ideally sound proof (~10’ x 12’)
(v) Special educator area (~10’ x 14’)
(vi) Toilet with disabled facility
(vii) Feeding / nappy changing area
Please do not forget disabled access to all areas.

Obtaining the Correct Equipment
As Mowgli once said some of the ‘bare’ necessities needed are:
Stethoscope, ophthalmoscope, auroscope, torch, tape measure, weighing scales (baby and toddler), baby mat, growth charts.

Selection of toys for assessment should include – soft toys, balls, cars, animals, picture book, pencil, paper, bricks (preferably 1” sides), small beads and thread.

Purchasing a formal developmental assessment tool like DDST or DASI is ideal and helps in the long run.

To provide basic services, the following equipments will be needed for PT/OT/speech therapy and Early Intervention (IE). These include mat, plinth, therapy balls, bolster balance board, stool, stool with wheels, colorful toys, sensory devices like toys with light music, rattles etc. The EI room should have a total floor mattress, mirror, cut out table, adaptive chair, toilet with adjustable seat, toys and feeding tools like adaptive spoon, adaptive plate holder, adaptive glass etc. These lists can be exhaustive and has to be requirement based.

Hearing and vision will have to be assessed on each child. This can be done by having your own audiologist and optometrist or by appropriate referrals to a separate centre.

Getting the Right Personnel

Several professionals are vital for the effective functioning of the center. These include a Developmental Pediatrician, Pediatric Neurologist, Pediatric Psychiatrist, Pediatric Psychologist, Physiotherapist, Occupational Therapist, Speech Therapist and a Special Educator. The people who form the backbone of the center are the Receptionist, an OPD Nurse and a Helper to keep the place clean at all times. If possible inclusion of a Social Worker helps in counseling and liaison work for the parents. A large center will need an administrator as well. In smaller centers one of the professionals usually looks after the administrative work.

From time to time you may invite other professionals for special sessions.

Deciding on the Format of the Clinic

Each professional works independently and have their stipulated clinic timings. The pediatrician, neurologist and psychiatrist see the patients for assessment, diagnosis and follow up. The psychologist, physiotherapist, occupational therapist, speech therapist and special educator see patients for assessment and therapy. The parents should be invited to sit through the therapy sessions so that they may carry on the good work at home. The receptionist has to co-ordinate the interdisciplinary movement of the child.

Ideally all children coming to the center should be seen at least once by the Developmental Pediatrician who can make the necessary referrals. Subsequent follow-ups can be decided by individual professionals themselves. All attempts should be made to reduce the total number of visits to the center.

The professionals should come together at least once a month (multidisciplinary meeting) to discuss the progress of individual patients. Parents should be invited to join the discussion on their child so that their concerns and views may be taken into account.

Depending on the need of the population you may run several special clinics, eg, feeding clinic, sleep clinic, child guidance clinic, constipation clinic, Down syndrome clinic, Genetic counseling etc.
Successful Implementation of the Clinic

Before it starts, it is absolutely vital that you inform the receptionist how you want it to run. Believe it or not a good receptionist can make all the difference. They are the first contact the parents have as they walk through the front door. Get it wrong, and you may have angry and impatient parents glaring at you, who may never come back.

It is important for the parents to also understand the format of the clinic, and this will perhaps make them more tolerable of unavoidable delays. Try and keep written information in the waiting area for parents.

Try and maintain an appointment system. Inform parents that they should come prepared with enough supply of food, water and change of clothes, nappy etc. Sometimes getting the favorite toy of the child helps. They should cancel the appointment if the child suddenly falls ill, say has fever or a cold. Parents always try to get everything done in one day. It has to be explained that children often get tired of seeing several professionals and refuse to perform. Hence they cannot be assessed properly. Thus one has to be realistic about the length and number of appointments. However some consideration has to be made for outstation parents.

Non attendees can be frustrating, as that appointment could have been offered to someone else. One way of minimizing this is to have parents reconfirm their appointment twenty four hours in advance. Something like what airlines do with their passengers. You may have a list of parents who are willing to attend at a very short notice.

In essence one has to be extremely flexible and accommodating.

Recording Information

This may seem the most tedious part but is in fact the most crucial aspect. Records should include the number of patients seen, their background information, and details of their assessment including diagnosis. It is important to maintain baseline records so that future changes in the child’s development may be compared.

It is also important to use the information for audit, the only way to improve and monitor standard of care.

Last but not the least it helps monitoring of financial transactions.

There are various ways of recording information. There are commercially available software programs for this purpose. Computerization does make data retrieval a lot less painful and time consuming. You can also print out the information which may be used as a written record. This method needs to be supplemented by hand held records.

Parent Held Records have been found to be a very effective mode of communication amongst professionals. The parents are given a file on their first visit which includes all information, including growth charts, assessments, consultations and referrals. It can also hold useful information like Medical Planner, Immunization Record, Appointment Schedule, Current Medication List and Emergency Plan with Contact numbers. The different professionals can communicate through this record.

Conclusion

Setting up a neurodevelopmental center must be done with careful planning. Seeking the correct advice from the correct people is vital. Try and visit some such centers to form visual impressions.
Children are constantly changing dynamic individuals, which is why they are so interesting to observe. Observation of them forms the basis of any form of neurodevelopmental clinic.

Acknowledgement
In preparation of this article, I took help from The Organization of Child Health Surveillance in General Practice by Dr M H Tseung.

All members of Indian Academy of Pediatrics can be a life member of IAP Chapter on Growth, Development and Behavioral Pediatrics. We request the members of IAP in various States to kindly be a member of this chapter by filling the following form and deposit it in the address of the secretary with a DD of Rs.550/- in favour of “IAP Chapter on Growth and Development” payable at Kolkata.

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9. Fax No. :……………………………..10. Email :…………………………………………………………

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Cash…………………………………………………..

Date : Signature

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Vol 3 No 2 September 2007