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## Screening, identification, early intervention, prevention and referral

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### Abstract

Screening and Identification of Disabilities Screening is a procedure that identifies a person who needs further assessment for diagnosis of a disability. Alternatively said, screening helps in 'suspecting' disability in a person. A screening procedure does not 'confirm' disability, but helps in short listing for detailed assessment. Screening is assessing a whole population in order to identify those individuals for whom some intervention in development would be beneficial. For example 'Newborn Hearing Screening' is mandatory in most countries. The 1-3-6 protocol emphasised in the Position Statement of the Joint Committee on Infant Hearing (JCIH, 2007) recommends that all newborns be screened for hearing loss by one month of age, appropriate amplification be provided by three months of age and early intervention needs to commence not later than six months of age. Though this is yet to become mandatory in India, there have been initiatives to create awareness and undertake early screening on the part of National Institutes and some NGOs.

**Keywords:** Screening, Identification, further assessment, suspecting, protocol emphasized, awareness

### Introduction

Identification is an outcome of screening. It is a process by which children with disabilities are identified for further assessment. Here, two types of screening can be distinguished, immediate screening to identify an existing need, and predictive screening intended to identify (and so prevent) a future need. Seven points to be kept in mind prior to screening. Educators have frequently expressed concern about young children who are exposed to known environmental risk factors associated with the development of chronic behavior problems (e.g., poverty, domestic violence, child maltreatment). Nevertheless, a societal commitment to address these environmental risk factors by identifying young children who are at risk for or are demonstrating chronic problem behaviors and to provide effective prevention and early intervention services has not been forthcoming. Although researchers have developed a number of effective early identification, prevention, and early intervention strategies, several significant barriers to the widespread implementation of those practices remain. The authors discuss these issues as they affect children who have emotional or behavioral disorders. They argue for societal action to change current policies and practices for young children.

- Frequency of the condition being screened for
- Seriousness of the condition
- Availability of effective treatment
- Timing of screening
- Reliability of Screening method and tool
- Value of early detection
- Cost effectiveness.

### Screening

A quick checklist or survey about a child's development to see if further evaluation is needed.

### Developmental Screening

The major goal of developmental screening is to reduce the time that elapses before any intervention begins. If the screening is to be effective, it must be accurate, comprehensive and cost-effective. Screening can occur through a variety of methods. They can include parent interviews, observations of the child, or the use of a specific instrument or checklist.

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### Medical screening

Prevention is better than cure. For preventing the mother and the child from various infections and diseases which may lead to impairment and disabilities; medical screening should be available for pregnant mothers, as well as for the new born child and growing children.

#### A. Pre-natal procedures Blood tests in the mothers which includes

- (a) Hemoglobin levels (Hb%) to detect anemia,
- (b) Blood glucose levels to detect diabetes,
- (c) Blood VDRL to detect syphilis,
- (d) Blood group and Rh typing for blood group incompatibilities,
- (e) Blood antibody tries to detect specific infections,
- (f) Alpha foeto-proteins to detect neural tube defects in the foetus.

#### Ultrasonography

During pregnancy helps in identifying many types of foetal pathology can be identified during the II trimester of pregnancy by means of ultrasound technique. Some of them are neural tube defects, hydrocephaly, microcephaly etc. Intra uterine growth retardation (IUGR) can also be detected through such measurements as foetalbiparietal diameter, crown rump length and transverse abdominal diameter.

Amniocentesis is a process which involves drawing of amniotic fluid through per abdominal route. The fluid is then subjected to biochemical and cellular tests. Amniocentesis is indicated in suspect cases of foetal chromosomal aberrations, congenital metabolic errors and open neural tube defects and severe Rh incompatibility. Thus amniocentesis is a technique for early identification and primary prevention.

Foetoscopy is carried out during II trimester of pregnancy through trans-abdominal route. By using fiber optic device, the foetus is visualized for its external features and for collecting samples of blood and tissues from the foetus. The procedure helps in diagnosing certain physical anomalies, metabolic disorders or biochemical abnormalities.

#### Chorionic villous sampling means

Biopsy of chorionic villi is performed either trans-abdominally or per-vaginally. The sample is then subjected to karyotyping and enzyme determination. There are hazards involved in this procedure in inexperienced hands

#### B. Neonatal and Postnatal procedures

After the birth and during first 3 months, several procedures can be performed to detect the conditions that lead to disability such as Apgar Scoring, Urine screening for metabolic errors – Apgar has devised a method of scoring of new born which is of practical value. At one minute after delivery it is an index of asphyxia and the need for assisted ventilation.

#### Biochemical tests in neonatal screening

Blood and urine examinations are conducted in the neonatal period for identifying metabolic disorders. It is not done as a routine examination but in all suspected cases and with previous history of mental retardation in the family. Cretinism is another condition which can be diagnosed in the neonatal period and necessary treatment given. Computed Tomography (CT) of the brain defines

intracranial anatomy by visualizing structures of different radio densities. The technique consists of acquisition of attenuation data from different views within a single cross sectional plane which are computed to present recognizable image. There are many abnormalities which can be detected by CT scan of the CNS such as anoxia of tissue, intracranial hemorrhage, hydrocephalous and congenital anomalies like agenesis of corpus callosum (ACC), etc.

MRI (Magnetic Resonance Imaging) is a new imaging technique used for display of brain anatomy. It uses radio frequency radiation in the presence of a magnetic field along with computation of data. It appears to be a superior procedure to many present techniques. Multidisciplinary team consisting of experts conducts the camp to confirm disability/make further referral for detailed assessment as the case may be. Thus screening helps in identifying large number of persons with suspected disability within a limited time period.

#### Behavioral screening

World Health Organization (WHO) has over the past 25 years been developing a simple methodology for screening and identification of children at risk of disability. It relies on the two-phase Ten Question Screening Instrument (TQSI), recently adjusted to include an eleventh question in the so-called TQSI plus. The first stage is carried out by community workers, and seeks to identify children whose mothers answer positively to one of the eleven questions below. A short questionnaire in the Yes/No format was developed to identify children with disabilities in community-based settings

Identification of possible disabilities (very common types) One can use the following simple signs to identify possible disability:

#### Visual impairment

- Complaint of frequent eye pain, itchiness, or discomfort
- Constantly reading close to face
- Attempts to brush away a blur
- Excessive rubbing of eyes
- Head-tilt or head turn when looking at something
- Excessive blinking
- Undue sensitivity to light
- Clumsiness in reaching
- Difficulty in reading letters on black board
- Using finger as a line marker while reading

#### Hearing impairment

- Fails to respond to loud sounds
- Fails to respond to soft sounds
- Turns head to locate from where sound comes
- Shows no interest or less interest in playing with noise making toys like rattle etc
- Fails to develop language unlike same age child
- Fails to understand simple verbal commands

#### Intellectual disability

- Fails to develop milestones unlike same age child
- Unable to complete given task
- May show impulsive behaviour such as throwing material, pushing peers, shouting etc.
- Fails to give attention and may lack eye contact
- May not give verbal response
- Difficulty in studies.

### **Role of stake holders in screening and identification of disabilities**

Access to healthcare, clean water, sanitation and female education-all significant determinants of child survival-are weak in many places in India. More importantly, access to the relevant interventions is largely unequal which drives unequal survival chances. Thus policies are unable to reach the poorest families, resulting in inequitable access to services. For instance, healthcare facility for delivery is accessed by more than 80 percent of the richest households, as against just above ten percent of the poorest ones (NFHS 3). Children from the bottom wealth quintile also have limited access to life-saving interventions (Singh, 2010). Attention to environmental factors – including nutrition, preventable diseases, safe water and sanitation, safety on roads and in workplaces, maternal and adolescent health – can greatly reduce the incidence of health conditions leading to disability. Preventing disability should be regarded as a multidimensional strategy that includes prevention of disabling barriers as well as prevention and treatment of underlying health conditions (Coleridge, *et al.*, 2010) Therefore, it is important that you need to facilitate activities to be undertaken for screening of children who are at risk or have already developed disability. Identified children must be provided services at the nearest hospital or referral centre where suitable services are available.

### **Expected actions from various stake holders**

- National, regional and local programmes of immunization (for children as well as expectant mothers)
- Public health and sanitation needs to be expanded.
- Medical and para-medical personnel be adequately trained and equipped for early detection of disability amongst children.
- Training modules and facilities in disability prevention, early detection and intervention be developed for medical and para medical health functionaries and Anganwadi workers.
- Training programmes of postgraduate, undergraduate degree and diploma in medical education should include modules on disability prevention, early detection and interventions
- Disability specific manuals for families having persons with disabilities will also be developed and provided free of cost.
- Human resource development institutions must ensure that the personnel needed to provide support services are available in adequate numbers.
- Appropriate plan of action for limiting effects of disability and prevention of secondary disabilities within the existing health delivery system needs to be evolved.
- Attention must be paid towards improving awareness of nutrition, health care and sanitation amongst adolescent girls, expectant mothers and women in the reproductive period.
- Awareness programmes for prevention needs to be built in at the school level and all government and non-government service providers as well as their officials

### **Early intervention**

Early Intervention Services are special services for infants

and toddlers at risk for developmental delays. These services are designed to identify and meet children's needs in five developmental areas. These are physical, cognitive, communication, social or emotional development, sensory and adaptive development. Early intervention includes provision of services to such children and their families for the purpose of lessening the effects of the condition. Early intervention can be remedial or preventive in nature-remediating the existing developmental problems or preventing their occurrence. Early Intervention Services are effective ways to address the needs of infants and toddlers with developmental delays or disabilities. To ascertain the eligibility of the child for early intervention certain screening and diagnostic measures are adopted. Some children develop more slowly than the others or develop in ways that seem different from other children. Any deviation from the normal development should be dealt with at the earliest as it may lead to a developmental delay or the child may be at risk of developing developmental delays.

'Developmental delay' is a term that means an infant or child is developing slower than normal in one or more areas (Anderson, Chitwood, & Hayden, 1997). The child may or may not perform the motor, social, cognitive or other activities like children of his age. A child is considered to be at risk when the child's development may be delayed unless he or she receives early intervention services.

### **Definition**

Early Intervention is a term, which broadly refers to a wide range of experiences and supports provided to children, parents and families during the pregnancy, infancy and early childhood period of development. [Dunst - 1996]

Early Intervention is the introduction of planned programming deliberately timed and arranged in order to alter the anticipated or projected course of development [Siegal - 1972].

Early intervention (EI) is a system of professional services provided to children from birth until about five years of age who are disabled, have delayed development or are at risk of delayed development. To help children with disabilities, it is essential to focus on the earliest years of development, since this is a critically important time for early learning which powerfully affects the child's future life course. Along with medical and rehabilitation services (where ever required), the children are actively engaged in an instructional program many times a week, throughout the year. It involves planned professional intervention organized around relatively brief periods of time for the very young children so that they may receive sufficient adult attention. The Early Intervention Program offers a variety of therapeutic and support services to eligible infants and toddlers with disabilities and their families, including:

- Family education and counselling, home visits, and parent support groups.
- Special education.
- Speech pathology and audiology.
- Occupational therapy.
- Physical therapy.
- Psychological services.
- Medical services.
- Nutrition services.
- Social work services.
- Assistive technology devices and services.

### Importance of early intervention

We are passing through an era which has seen rapid changes in the concept of the child and is burgeoning ahead taking long strides in understanding normal child development. There is mounting evidence documented regarding the deleterious effects of disability and handicapping condition on the normal development of a child. It is also a fact that these effects can be minimized or prevented if children can be identified as those who are at risk or have a disability or a handicapping condition through Early Intervention programmes. Thus, early intervention programmes can be preventive, curative and remedial. To realize the importance of early intervention we have to rationalize our thinking on the subject. The early intervention programmes derive their support from the various theories of learning and the empirical research on human development. When we look back into the history of child development, "Predeterminism" - the concept which held hereditary and genetic endowment as the sole important factor for development. In this view there was mere unfolding of development which was predetermined and unaffected by external influences. Then came the controversy of nature versus nurture. But the current theories support the dynamic interaction between the genetic endowment and the environment and neither of them, in isolation, can account for normal development.

One of the basic premises of Early Intervention is that it can bring positive changes and human traits are malleable. It is said that brain responds to the environment (experience) by adapting and changing its structure which is initially determined genetically. These structured and functional changes produced by endogenous and or exogenous influences that may occur at any time during the individual's life history is defined as plasticity. Of relevance to our subject is the plasticity of the learning brain where there are structured and functional changes due to environmental influences. It is because of this unique property of plasticity of the brain that it is able to cope with damage and ever changing environment. Thus, provision of specification of functions to systems is guided by stimuli, information and challenges from the environment. Researchers have also pointed out that the amount of cortex occupied by a body part relates not to the size of that part but to its sensory or motor sophistication. Thus in humans the finger tips occupy large areas of the cortex and the toes only small ones. A number of experts have highlighted the rapid growth and development in the first few years of life. We all are aware of the extraordinary rapid growth and development in the first few years of life. A few distinct observations of early years of life are:

1. Myelination is almost completed by 2 years of age.
2. Most of the gross motor and a great extent of fine motor milestones are reached.
3. The child independently moves about, exploring, manipulating and at the same time learning and acquiring knowledge.
4. During 7-36 months most young children acquire the ability to understand most of the language they ultimately use in ordinary conversation throughout their lives.
5. Personality traits are also stabilized by the age of two. It is argued that social patterns probably will not change significantly after the age of two without further drastic

changes in the environment.

6. It is observed to be the period of unprecedented growth, second only to the prenatal period. Development occurs in all the areas to a great extent and they are guided and shaped by environmental influences.

### Aims of early intervention programs

- Early identification of infants at risk
- Early identification of developmental delays
- Enhancement of normal development
- Acceleration of rate of development
- Acquisition of new behaviour/skills
- Increase in independent functioning
- Early detection and prevention of secondary handicaps
- Minimizing the effects of the handicapping condition
- Cost effectiveness
- Psychosocial support to families

### Prevention

Definition of terms from the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980). The current revision of this classification is scheduled for 1999 and is now being coordinated by the WHO Division of Mental Health.

- Impairment is an abnormality of psychological, physiological or anatomical structure or function. Impairments refer to organs. Example: Paralyzed muscles of the legs.
- Disability is the restricted ability to perform an activity. Disabilities refer to persons. Example: Person cannot walk.
- Handicap is the restriction faced by a person with a disability in fulfilling normal roles due to social barriers. Handicaps refer to the interactions of people and their societies. Example: Person cannot get a job because employers do not want employees who cannot walk.

### Prevention at three levels

- **Primary Prevention**  
Action taken prior to the onset of the disease/disability, which will remove the possibility that a disease/disability will occur.
- **Secondary Prevention**  
Action, which halts the progress of the disease/disability at its incipient stage and prevents complications. The specific interventions are early diagnosis and adequate treatment.
- **Tertiary Prevention**  
All measures available to reduce or limit impairments and disabilities, and minimize suffering caused by existing disability. This phase is also called rehabilitation, which includes physical, psychosocial and vocational measures taken to restore the patient back to normal or near normal condition

It is extremely important that the women undertake adequate and effective preventive measures during their pregnancy and immediate postnatal period and also for their children especially during the early childhood period, in order to significantly reduce the incidence of impairment and disabilities in them. Therefore, in this chapter examples of easily understood primary preventive measures, for mother and child are summarized.

**Care during pregnancy**

1. Avoid hard physical work such as carrying heavy loads, especially in fields, and other accident - prone activities such as walking on slippery ground or climbing stools and chairs.
2. Avoid unnecessary drugs and medications. Even the normally considered safe drugs which are sold commonly can potentially cause serious defects in an unborn child.
3. Avoid smoking, chewing tobacco, consuming alcohol and narcotics.
4. Avoid X - rays, and exposure to any kind of radiation.
5. Avoid exposure to illnesses like measles, mumps etc, especially during the first 3 months of pregnancy.
6. Avoid sexual contact with a person having venereal disease.
7. Take precautions against lead poisoning.
8. Avoid too much use of 'Surma' and 'Kohl'.
9. Eat a well-balanced and nourishing diet supplemented with green leafy vegetables, proteins and vitamins.
10. All women of the child bearing age need 0.4mg of folic acid daily. It is also available in folic acid plus iron tablets which should be taken for at least 3 months during the third trimester when the risk of developing iron deficiency anemia is greatest.
11. Ensure weight gain of at least 10 kgs. Have regular medical checkups.
12. All pregnant women should be given tetanus injection.
13. Woman at 'high - risk', whose weight is < 38 Kg, height is less than 152 cm, weight gain during pregnancy <6 kg or who is severely anaemia c (Hb < 8mg), having frequent pregnancies, having a history of miscarriage/ abortion/premature deliveries, must get expert prenatal care so as to have a normal baby.
14. Must consult a doctor, in case of edema (swelling) of feet, persistent headache, fever, difficulty or pain in passing urine, bleeding from the vagina, and yellowness of eyes (jaundice)

**Care at the time of birth**

1. Delivery must be conducted by trained personnel, preferably in a hospital where all facilities are available.
2. If a baby does not cry immediately after birth, resuscitation measures should be undertaken at once.
3. Babies born prematurely and with a low birth weight (<2.5 Kg) may need Neonatal Intensive Care.
4. If the baby's head appears to be abnormally small or large then a physician should be consulted, preferably a pediatrician. The approximate head size for a male child at birth is 35 cm and for female child is 34.5 cm.
5. To protect a child from infections, breast - feeding must be started immediately after birth. First milk (colostrum) must be fed to the baby and should not be thrown away, as it has antibodies which are protective.

**Early childhood care**

1. Do not allow a child's temperature to rise above 101 degree F because of any reason. It can cause febrile seizures
2. If a child gets a fit take him to doctor immediately.
3. Every child should be immunized against infectious diseases as per the recommended schedule of immunization.
4. Do not allow a child to have too much contact with

- paint, newsprint ink, lead etc. as they are toxic.
5. Take precautions against head injury, and other accidents.
6. Ensure that the child gets a well-balanced diet and clean drinking water.
7. Introduce additional foods of good quality and in sufficient quantity when the child is 4 -6 months old.
8. Vitamin A deficiency and its consequences including night blindness can be easily prevented through the use of Vitamin A supplementation.
9. Protect a child from Meningitis and Encephalitis by providing a hygienic environment which is free of overcrowding.
10. Common salt must be iodized as a precaution against goiter and cretinism.
11. Do not allow a child to use hairpins, matchsticks and pencils, to remove wax from the ears.
12. Use ear protectors to reduce the exposure to high levels of noise, if children are living or working in a noisy environment.
13. Do not slap a child over the face as this may lead to injury of the eardrum and consequent hearing loss.

**Referrals**

Suitable specialists are of vital importance for providing interventions. Referrals to specialists for opinion and advice and investigations help in understanding and confirming the diagnosis, thereby assisting in planning appropriate individualized intervention. For some children with locomotor impairments, aids and appliances are recommended to correct and prevent the setting of deformities.

Other referrals for family-related aspects are made when there are family problems like marital discord, alcoholism, financial crisis or mental illness in the family.

The Parent Training Program substantiates the interventions by addressing those issues that are of common concern for the parents. Another vital aspect of parent training programme is the parental motivation program where some potential parents are identified and trained to train other parents to sustain and encourage family members for carrying out home-based programmes. Each local government has obligation to ensure that all infants and toddlers with disabilities in the area who needs early intervention services are identified, located, and assessed. As part of fulfilling that responsibility, a child find system needs to be developed which must include procedures for referring a child to early intervention services.

Anyone may refer a child to early intervention. For example, someone may notice that a baby or toddler seems to have a developmental delay of some sort, a disability, or a diagnosed physical or mental condition. That person needs to refer to the early intervention service delivery agencies, which can evaluate the child and determine if he or she does, in fact, have a developmental delay or disability. In several districts, MoSJE has established District Disability Rehabilitation Centre for this purpose.

**Referrals at birth**

Someone notices" and "referring" the child and family to the early intervention system may happen at birth. Often this is so for children who are diagnosed at birth with a specific condition or who experience significant prematurity, very low birth weight, illness, or surgery soon after being born.

**Later referrals:** Other children have a relatively routine entry into the world, but may develop more slowly than others, experience setbacks, or develop in ways that seem very different from their peers. For these children, a visit to a pediatrician may lead to an early intervention referral. Or perhaps the referral comes from a childcare provider, nurse, family member, or friend who notices that the child isn't meeting the normal "baby" milestones such as rolling over by a certain age, or sitting up, crawling, speaking, and so forth.

**Primary referral sources:** The referral system set up must enable referrals from primary referral sources (e.g., parents, physicians, and hospital staff). These are the individuals who are most likely to be interacting with very young children. They are in a position to notice that a child may have a developmental delay or disability and thus make a referral.

### Conclusion

With more than a third of its population below the age of 18, India has the largest child population in the world. One out of 16 children dies before they attaining the age of 1, one out of 11 dies before the age of 5 years. 35% of the developing world's low-birth weight babies are born in India and 40% of child malnutrition in the developing world is in India. The declining number of girls in the 0-6 age group is cause for alarm. Children with disabilities (0-19 years) account for 1.67% of the disabled population.

Children are the future citizens of the country. If the future citizens, the torch bearers of the country are grappling with such problems of disability and survival, then the future of the country is to say the least, grim. Disability in any form hampers normal development of children, and the challenge posed by disability in India is enormous. Despite the fact that so much has been done, there is still a much more to be done.

The crucial issues are to make services accessible, to involve parents and provide services to facilitate maximum development where children with disabilities reach their full potential. Governmental efforts, especially Ministry of Health should collect comprehensive data on children with disability and 5 year targets should be set for enrollment of children with disability and closely monitoring action plans implemented. There is a need to establish adequate early detection and identification services in hospitals, PHC's community based health care services with referrals system to Early Intervention service. Routine screening for high risk pregnancies and babies will help in early detection of disabilities.

All the above efforts must culminate to make our former President Dr. A.P.J. Abdul Kalam's dream project PURA (Provision of Urban Amenities in Rural Areas) a possibility. So the adage "Catch them young and watch them grow" best defines Early Intervention.

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