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Early Intervention of a Child with Multiple Disabilities - A Case Study

Navnit Kumar

Abstract

The study aims at obtaining adequate and early intervention services for infants with multiple disabilities. A 5 month old male child was referred to for audiological evaluation at AYJNIHH (ERC). His mother noticed his problem at 2.5 months of age. A systematic approach was chosen for early intervention for the children with multiple disabilities.

For complete diagnosis of a child with multiple disabilities, the assessment at AYJNIHH includes (1) Audiological evaluation (2) Speech and language evaluation, (3) Hearing aid trial and fitting and (4) Psychological evaluation. After 10 sessions of speech and language therapy, progress was observed in cognitive and linguistic domains as assessed with Communication DEALL developmental check lists. Simultaneously the child had received occupational therapy.

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In India, the field of multiple disabilities is a new emerging field. To promote early intervention vigorously for the children with multiple disabilities further studies are needed to identify high risk factors associated with multiple disabilities. There is also the need to develop skills in gathering information regarding infants' hearing, vision, motor, cognitive, linguistic, social and emotional skills.

Key words: Multiple disabilities, Deaf blindness.

INTRODUCTION

Disability has been defined as any restriction or lack of ability (resulting from impairment) to perform an activity in the manner or within the range considered normal for human being, generally taken to be at the level of the individual (Sharma, 2005). A child with more than one condition of disability that affects learning is “multiply disabled.” As per the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, multiple disability means a combination of two or more disabilities as defined in clause (I) of Section (2) of the Persons with Disabilities Act, 1995, which include blindness, low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness.

In India, about 2 % of the total population is disabled. Among the total disabled population, 10 % of the population is multiply disabled. The percentage distributions by the type of disabilities are shown in Figure 1.

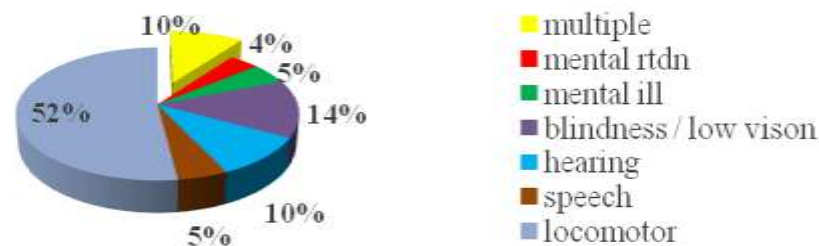


Figure 1: The percentage distributions by the type of disabilities

In India, about 7 % of persons with hearing disability are born with it (NSSO, 2002). Additional disabilities are reported frequently with this disability, because the cause of hearing disability sometimes leads to additional disabilities. The incidence of additional disability in children with hearing disability ranges from 25 % to 34 % (Moores, 2001). Only 51.1 % of the population of hearing disabled has hearing loss as their sole disability, remaining have other additional disability. Among them 4.9 % has low-vision and 4% is associated with other ophthalmological problems (GRI, 2006). The incidence of these vision-problems is greater in population with hearing disabled or developmental-delay or cerebral palsy or Down syndrome than in the general population (Wesson & Maino, 1995). 0.08 % of the general school age population has vision problem, whereas deaf students with school age population have incidence of 8 % (Wolff & Harkins, 1986).

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 includes the person with deafblindness as multiply disabled. Since 1980, the Nordic countries have defined deafblindness as a distinct disability. Recently, EU Parliament has also declared deafblindness as a separate and distinct disability (Danermark & Moller, 2008). ICF (International Classification of Functioning, Disability and Health) states that “deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations, and/or technology”. The definition includes five comments, which further clarify the definition of deafblindness:

1. Vision and hearing are central in getting information. Therefore a decrease in the function of these two senses that can receive relatively distant information increases dependency on senses that receive information more within reach (tactile, kinesthetic, haptic, smell, and taste), as well as increasing the need to rely on memory and deduction.
2. The need for specific alterations regarding environment and services depends on the time of onset in relation to communicative development and language acquisition, and the degree of the hearing and vision disability, whether it is combined with other disabilities and whether it is stable or progressive.

3. A person with deaf blindness may be more disabled in one activity and less disabled in another activity. Therefore each activity and participation in it needs to be assessed separately. Variation in functioning within each activity, and participation in it, may also be caused by environmental conditions and by internal personal factors.
4. Deafblindness causes varying needs for co-creating alterations in all activities and especially in all kinds of information, social interactions and communications, spatial orientation and moving around freely.
5. Activities of daily life and efforts demanding near activities, including reading and writing. Co-creating means that the person with deafblindness and those rearranging the environment are equally involved. The responsibility for making the appropriate rearrangements and compensations and making possible empowering situations lies with society.
6. An interdisciplinary approach that includes specific knowhow related to deafblindness is needed in service delivery and environmental alterations.

The cause of deafblindness or multiple disabilities can be either congenital or acquired, which affects the development and needs of person with multiple disabilities differently. Premature birth, Rubella or German measles in pregnant mothers, lack of proper medical care at the time of birth and Usher's syndromes are some of the major reasons for deafblindness in our country. Rubella is best known, whereas anoxia (lack of oxygen to the brain) is a very common cause of multiple disabilities and visual impairment, either during delivery or as a result of an accident later in childhood. In over 70 syndromes, hearing and visual impairment are likely to occur together (Regenbogen & Coscas, 1985). Mental retardation is a common condition that occurs with deafblindness. During communication 90 % of the information is perceived through vision and 10 % through hearing that is important for mental development (Griefhann, 2003). Mental retardation is not caused by deafblindness, although either condition can increase the delays normally caused by any one condition.

NEED OF THE STUDY

Child with multiple disabilities or deafblindness is unique. They are multisensory deprived, have distorted perception of world, appear to be withdrawn and isolated, do not

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communicate with the environment in a meaningful way which leads to serious developmental delay, defensive to touch, difficulty in establishing and maintaining interpersonal relationships, lack the ability to anticipate further events or results of their action, feeding difficulties and /or unusual sleep patterns, exhibit frustration, delay in social emotional and cognitive development and develop unique learning styles.

Therefore the need of the study is to obtain an adequate and early intervention services for infants with multiple disability.

METHOD

Participants

A 5 month old male child was referred for audiological evaluation at AYJNIHH (ERC). The demographic information of the child was taken up. His mother noticed at 2.5 months of age that the child did not startle to loud sound, unable to grasp any objects, did not make any intentional vocalization and did not shift in eye gaze during movement of object, when placed in front of eye at 1-foot of distance. Searching behaviors were observed, only when light in the room was turned on/off.

Prenatal and birth history: Mother had bleeding during first trimester of pregnancy. At full term of gestation, the child was delivered by caesarean section. Birthweight was 1 Kg and 500 gms. and birth cry was present. The child had a single instance of meningitis and septicemia (probable cause) at 3 days of birth.

Developmental history: The developmental milestones were delayed for both physical and communicative behaviors. Mother reported that his head control was yet to develop. He expresses his needs through cry and vocalization.

Medical history: At 3 months of age, he underwent otoacoustic emission (OAE) screening; the result was “refer” for both the ears. Ophthalmological examination at 4 months of age, suspected Glucoma and avascular retina in temporal retinal periphery in right eye. As reported, the diagnosis will be completed after 2.5 years of age, thus follow up after every 6 month. The Electro Encephalography (EEG) suggests paroxysmal cerebral dysrhythmia. On magnetic resonance imaging (MRI), he had cystic encephalomalacic lesion in bilateral occipitoparietal region, suspected sequel to hypoxic ischemic encephalopathy. Abnormal

visual evoked potential (VEP) were observed in both the eyes. Otorhinolaryngologist did not observe any abnormality regarding the child's speech and hearing difficulty.

Family and social history: The child stays in a joint family. None of the family members had history for speech-language and hearing problem. Mother is housewife and father is a serviceman. His grandmother and family members usually takes care of the child.

Measure

Test plan: "Systematic approach" (Chen, 1998) was chosen for early intervention for the children with multiple disability. It is functional assessment that includes (a) review of the infant's medical reports, (b) gathering information from parents, (c) conducting structured observations of the infant's response to sound and reactions to visual stimuli, (d) assisting parents in obtaining a referral and (e) providing educational services as needed.

Test: For complete diagnosis of a child with multiple disabilities, the assessment at AYJNIHH includes (1) Audiological evaluation, (2) Speech and language evaluation, (3) Hearing aid trial and fitting and (4) Psychological evaluation

Procedure

Audiological evaluation: To assess child's hearing ability a complete audiological examination were administered. Subjective test like behavioral observation audiometry (BOA) and free field audiometry were administered in a sound treated room to obtain minimum response level using MAICO MA 53. Objective tests were also administered to obtain estimated auditory threshold. Immitance test battery (Tympanometry, reflexometry) was done using GSI-38 instrument. OAE screening was done for both DPOAE and TEOAE with GSI audio screener. Auditory brainstem response (ABR) was also obtained.

Hearing aid trial and fitting: On the basis of audiological examination results, he was tried with body worn strong class (A₁) and extra strong class (A₂) hearing aid with V cord.

Speech and language evaluation: An orofacial examination was conducted to evaluate the structural and functional integrity of the orofacial mechanism. Infant scale of nonverbal interaction was used to assess the child's mode of communication. The level of expression was assessed to child's expression. Developmental schedule were assessed using

Communication DEALL. The cognitive development milestones were also used to assess the cognition. The reflex examination was administered to estimate child development.

Psychological evaluation: Vineland social maturity scale (VSMS) was used to obtain social age. To judge early motor and mental development, a Bayley scale of infant development was used.

RESULTS

The BOA and free field audiometry results are shown in table 1 and 2 respectively. It shows child had very poor hearing ability. He did not respond at any stimuli presented at loud. In free field audiometry responses were not obtained at audiometric limit.

Table 1: Behavioral observation audiometry results

Stimulus (at 2 -3 feet)	Loudness	Response
Drum	loud	Eye blinking
Jhankara	loud	No response
Tumbler	loud	No response
Hand clapping	loud	No response
Name calling	loud	No response
Stear drum	loud	No response

Table 2: Free field audiometry results

The immittance test revealed bilateral A type tympanogram, where as reflexes could not be tested due to head shaking. In ABR the wave Vth peak was obtained at 105dB pe SPL and 115 dB pe SPL in left and right ear respectively. Thus audiometric thresholds were judged at 80 dB HL and 90dB HL in left and right ear respectively. This revealed bilateral severe-to-profound sensorineural hearing loss and was recommended for appropriate hearing aid trial and fitting. Hearing aids were tried with strong class (A₁) and extra strong class (A₂) hearing aid with V cord, the child was fitted A₁ hearing aid with ear mould, PP 180 receiver, and tone control at N, volume control at 3-5.

The orofacial examination revealed normal appearance of oral structures. Sucking was deemed adequate for normal speech production. His nonverbal mode of

Frequency	Intensity	Responses
500 Hz	70 dB HL	No response
1000 Hz	75 dB HL	No response
2000 Hz	80 dB HL	No response
4000 Hz	85 dB HL	No response

communication on “infant scale of nonverbal interaction” was judged at level-1 (1-3 months) i.e., behaviors are usually in reaction to the adult’s action or the general environment, and the “level of expression” at pre-intentional behaviour (cry). The Communication DEALL development schedule suggests gross motor, fine motor, receptive language, expressive language, social skill, cognitive skill of the child was not at the initial level as described in item no 1. Only activities of daily living, emotional skills had emerged (within 0-6 months).

The child's "cognitive development milestone" was infancy (0-6 months) i.e., sensorimotor reflexive stage (total absence of control over movement). The clinical reflex examination results were shown table 3.

Table 3: The clinical reflex examination result

Reflex	Results
Babinski	Positive
Grasping	Yet to develop
Rooting	Integrated
Sucking	Integrated
Startle	Absent

Psychological evaluation showed moderate developmental delay, and had inadequate gross and fine motor skills. He was judged moderate deficits in social skills.

The child was provisionally diagnosed as delayed speech and language development with bilateral severe to profound hearing loss with moderate developmental delay and visual impairment. He was recommended for speech-language stimulation and therapy, regular use of amplification, aural hygiene, special education guidance, physiotherapeutic consultation, and counselling.

After the assessment procedures were completed child attended speech- language stimulation therapy at the AYJNIHH speech and hearing department once a week in session lasting for 45 minutes. His parents accompanied him and participated in treatment session. Multisensory approaches were selected for the child. The long term goal was chosen as to achieve communication up to child level of participation. The following short term goals were chosen for 10 sessions.

1. **To facilitate development of social skills:** Communication is primarily a social behaviour that links people with the world around us. It begins with daily interaction between child and care givers or parent that enables the child to express their needs, feelings, observations and ideas. A multiple disable child totally depends on the

environment as compare to single disabled child. Thus in the absence of communication a child became isolated and unable to control the environment.

2. **To facilitate development of cognitive skills:** A cognitive skill helps to process the stimuli around us. It enables the child to understand the close relationship offers by the parent or caregiver and made the child a sense of security. This bonding between parents or care givers and child helps the overall development of the child including the development of communication. The children with multiple disabilities especially with deafblindness may have difficulty in establishing appropriate bonding with parents or care giver in course because eye contact could not be established due to the visual impairment. Additional motor problem may cause difficult for parent or caregiver to hold or handle the child. The additional health problem sometime leads to the unique way of communication, which made difficult to interpret by the parents.
3. **To facilitate development of receptive communication:** The receptive skill enables the child to develop anticipation. Anticipation means the knowledge of what comes next. The children with multiple disability have lake in the ability to anticipate that's why they feel threatened when someone approach to them. When the child understands what will come to next, he will better prepare for the next events.
4. **To facilitate development of intentional communication skills (vocal: fuss, Moto Gestural: reaching, pushing):** When the people around the child's environment understand their needs and take steps in satisfying needs it will make the child 's environment responsive. If the children with multiple disability or deafblindness get the responsive environment since beginning, he will starts trusting others and feels motivated.
5. **To improve auditory skills:** Auditory skills are important for child's mental development. Speech is auditorly processed that helps to recognize own name. An auditory skill enables the child to draw attention to sound in the environments that make the child to explore the environment in much better way.

The activities selected for the above short term goals are shown in the table 4.

Table 4: The short term goals and activities

Short term goals	Activities
To facilitate social skills	<ul style="list-style-type: none"> • Keep the child in lap and gently move, catch, dance, jump, swing along him, singing song or talk in pleasant tone (motherese). • Touch and feels adult facial features (hairs, nose, moustache,)
To facilitate development of cognitive skills	<ul style="list-style-type: none"> • Hold, touch, cuddle and gently stroke the child frequently even if no visible response from him. • Yours mouth will be close to the cheeks while speaking and Help the child to feel your mouth, face, bangles while you talk. • Child will feel toys, objects around the household, functional object that he uses (bottle, spoon, clothes, and comb) with your hand touching him.
To facilitate Receptive communication	<ul style="list-style-type: none"> • Use touch and object cues immediately before an activity / action (e.g., use of neckerchief means food is being given)
To improve auditory skills	<ul style="list-style-type: none"> • Child will be called by name in simple, relevant, context based and child's daily routine (bathing, feeding) in different intonation. • Play with environmental sounds; sound made by toys, body and making sound with your mouth on his hand.
To facilitate development of intentional communication skills	<ul style="list-style-type: none"> • Help the child to reach and grasp toys • Start vocal play by imitating the child's vocalization pattern (e.g., when child say /a/ you will also /a/ by giving tactile feedback)

After 10 sessions he progress was assessed with Communication DEALL developmental check lists as shown in figure 2.

Simultaneously the child had received occupational therapy, thrice a week in sessions lasting for 30-45 minutes to achieve initiation of head control, neck flexion the child underwent supine neck flexion, rolling, supine to side lying, therapy ball activities. The prognosis for

improved language is good if hearing aid is used consistently, activities are incorporated with activities of daily living, ample parental and care givers participation .

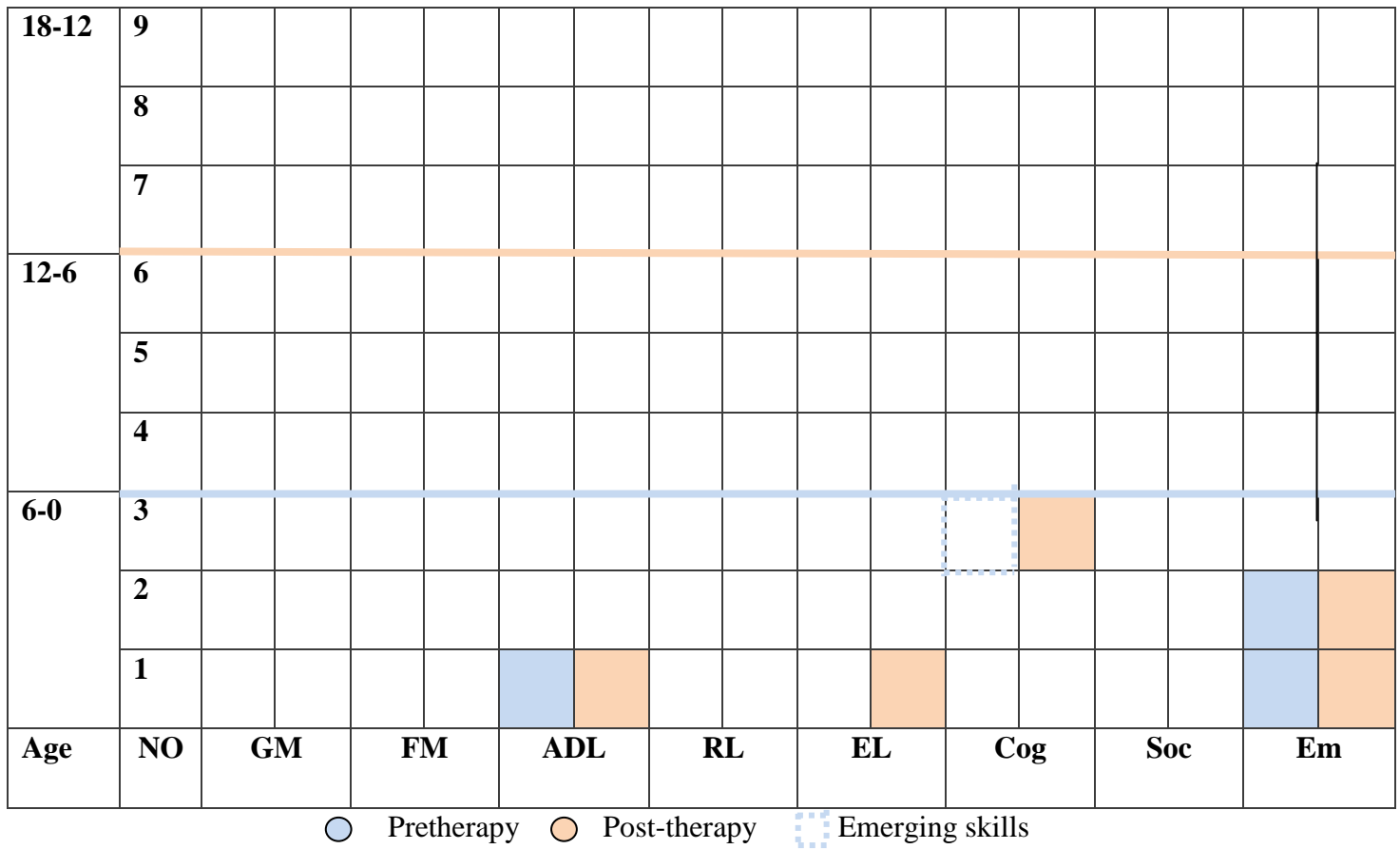


Figure 2: Progress after 10 sessions as shown on Communication DEALL developmental checklists. GM- gross motor; FM- fine motor; ADL- activity of daily living; RL- receptive language; EL- expressive language; Cog- cognitive skill; Soc- social skill; Em- emotional skill.

The communication DEALL checklist includes 8 domains. Except expressive language and cognitive skills remaining other domains didn't had improvement after 10 sessions of therapy as shown in table 5.

Table 5: Expressive language and cognitive skills after 10 sessions of therapy.

Domain	Pre-therapy	After 10 session
Expressive	Show random	• Random vocalization of the child

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language	vocalization other than crying.	increases, especially when parents/ family members near around him. <ul style="list-style-type: none"> • cry when room becomes dark
Cognitive skills	Doesn't recognize mother.	<ul style="list-style-type: none"> • Child stops crying when mother takes up.

DISCUSSION

The child with multiple disability especially with deafblindness and additional disabilities represents an extremely diverse group. The term visual impairment includes range of vision loss from low vision to light perception or to the total blindness. Their effects may be blurred vision, field loss and decreased in visual acuity. Similarly hearing loss can range from ability to hear partial to total deafness. Additional disabilities of these children may include mental retardation, cerebral palsy, autism or behaviour disorders. For these children difficulties are not added but multiplied, creating a unique disability by itself. Loss of two important senses i.e., hearing and vision results in severe difficulties in interpersonal relationship, communication and mobility that's lag behind the child in all domains of development.

The first 6 months of life auditory perceptual learning is vital for acquiring oral language and speech (Pratt, 2005). Speech development is a nonlinear process that reflects environmental influences and development interaction among emerging skills for cognition, language, affect, and motor control (Smith & Goffman, 2004). A cognitive and linguistic skill acts as catalyst for the speech development (Nip, Green & Marx, 2009). The child with multiple disabilities especially with deafblindness lags in cognitive and linguistic skills that act as constraints in early motor skills. They have limited abilities to coordinate the movements of oral structures that restrict early speech development and phonetic inventories. Thus infants with multiple disabilities are likely to require early intervention to facilitate their learning and development. The first four to five years of life are very important for the development of speech and language skills, delay in early detection and intervention of hearing problem has its irreversible negative impact on auditory processing skills, academics and behavioral repertoire (Hall & Muller, 1997; Kumar & D'Mello, 2006). Early intervention

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services during the first three years of life can have significant positive effects on the cognitive development and social adjustment of low birth weight, premature children and on the overall development of young children with disabilities (CARE, 2006).

To achieve early intervention for children with multiple disabilities the functional assessment is more suitable than formal assessment (NIMH, 2003). Functional assessment is not norm based but provides information regarding children at present using abilities and things in the environment that support their use. This information can be directly applied to make appropriate intervention strategies for the child with multiple disability. Formal tests are norm based which may not be appropriate for the population of multiple disabilities, because the items used rely on vision and hearing. It provides information about the potential capacity of the child that is not useful for education planning.

Early intervention of the child with multiple disabilities must focus on child specific appropriate therapeutic strategies in the view of critical age for speech and language development. It must look for total communication. They lag in most of domains so the goal should be planned in such a way to cover all the domains. The deaf blindness is a separate disability, whose treatment requires a special kind of understanding, enduring patience and workable means of communication (Rathna, 2008)

CONCLUSION

The Joint committee on infant hearing (JCIH), 2007 and American academy of ophthalmology (AAO) recommendations play major roles in early intervention. Every infant with confirmed hearing loss has at least 1 ophthalmological examination to assess visual acuity (JCIH, 2007) whereas AAO has recommended every infant at least 1 ophthalmological examination to assess visual acuity. JCIH also recommends regular developmental assessment at 6 months, till 3 years of age. An early interventionist is any professional who provides direct services to infants with disabilities and their families. These professionals may include physical therapists, occupational therapists, nurses, speech and language therapists, audiologists, orientation and mobility specialists, psychologists, social workers, and teachers certified in the areas of early childhood special education.

Even in the developed countries the infants with multiple disabilities may not have easy access to educational professionals who know how to screen infant's vision and hearing. Further, socioeconomic and other conditions may restrict family's access to such medical services (Halpern, 1993) as audiology, ophthalmology, or optometry.

In India the fields of multiple disabilities are new and emerging field (Paul, 2007). This field is far behind to develop quality service for such population. There are many aspects which have to be taken up on priority to provide quality services to such individuals in making them self reliant. These are Early Identification and intervention, Incidence and Prevalence of deaf blindness or multiple disabilities, Assessment and Evaluation, Professional Development, Social Communication, Networking of Deafblind individuals and their family members, and advocacy.

Though multiple disabilities pose a serious challenge but this by no means is insurmountable. Modern technology can made them independent to enjoy the quality of life of their choice. They can contribute to the community development through their active participation. Considering above lacunas, to promote early intervention vigourously for the children with multiple disabilities further studies needed to identify high risk factors associated with multiple disabilities, skilled in gathering information regarding infants hearing, vision, motor, cognitive, linguistic, social and emotional skills

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Navnit Kumar
 Research Officer
 Department of Speech Language Pathology
 All India Institute of Speech and Hearing
 Mysore 570 006

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Navnit Kumar
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Karnataka
India
navnitaiish@gmail.com

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