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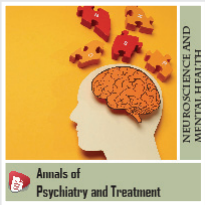

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Mini Review

Understanding Inclusive Development for Individuals with Multiple Disabilities

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Abstract

Individuals with multiple disabilities face a greater challenge due to a combination of various disabilities across the world. It not only poses a challenge to the parents but also to the professionals who work with them regularly in any educational or rehabilitation set-ups across the world. Any individual with multiple disabilities should receive professional help as early as possible, so that the individual can be helped to achieve their potential. Such individuals will not be developing as other individuals with similar age groups due to various reasons and might have difficulty in generalizing due to various reasons. It's important that we, as professionals, set up realistic goals that are small and achievable, as such individuals can learn and achieve only in small steps with a lot of practice and repetition.

Individuals with multiple disabilities have shown issues with all muscle movement, with understanding, and often with seeing and hearing as well. Communication is very difficult for them. Often, we as professionals may not know how much an individual with multiple disabilities understands, and the attempts to communicate may be unfamiliar to us and may pass unnoticed. So, due to various reasons, some professionals might wrongly label such individuals. As professionals, we must try our best to provide such an individual's understanding and expression in order to ensure a proper diagnosis. This article focuses on the study of inclusion of individuals with multiple disabilities and will provide a road map for understanding inclusive development for individuals with multiple disabilities, both in various countries, along with India.

Introduction

Persons with multiple disabilities have a combination of two or more disabilities (e.g., cognitive, movement, sensory), such as those with Intellectual disability and cerebral palsy. The U.S. federal government defines as "Multiple disabilities" means concomitant impairments (such as mental retardation blindness, mental retardation-orthopaedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments [1]. Orelove & Sobsey (1996) defined multiple disabilities as individuals with intellectual disability requiring extensive or pervasive support and who also possess one or more significant motor or sensory impairments and or special education health care needs. The co-morbidity is reasonably high in Multiple Disabilities. The core areas of concern integral to management are the same, i.e., communication, cognition, mobility, and socialization. The other common factor among these four disabilities, however, is that they are, without a doubt, the most marginalized and neglected groups even within the disability sector.

Some examples of multiple disabilities are listed below:

- Deafblindness (Visual Impairment + Hearing Impairment)
- Visual Impairment + Hearing Impairment + Mental Retardation
- Visual Impairment + Mental Retardation
- Cerebral Palsy + Mental Retardation/ Hearing/ Speech/ Visual problems

In the United States, individuals with severe and multiple disabilities are legally entitled to education and other support services; however, in the rest of the world, these groups do not enjoy the same rights. Those with severe and multiple disabilities are identified early in life by their noticeable delays

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in development or by their physical abnormalities. Historically, in many cultures, the presence of severe physical abnormalities at birth has been associated with stigma. Current technology has enabled interventions that extend both the length and quality of life of these individuals. Legislation in the early 1970s addressed the right to education and other rehabilitation services for all individuals with disabilities. In 1975, the Education for All Handicapped Children Act (known since 1990 as the Individuals with Disabilities Act, IDEA, 2004) [2] formed the legal basis for public education for all children, including those with severe and multiple disabilities.

An individual with multiple disabilities may show the following characteristics:

- Difficulty with vision
- Difficulty with hearing
- Difficulty in communicating their needs
- The rate and speed of learning are slow
- Difficulty in moving the body from one place to another
- May have Medical complications that accompany severe disabilities (include seizures, sensory loss, hydrocephalus, sclerosis)
- Difficulty participating in games involving motor skills
- May execute self-injurious behaviour

Motor Development in multiple disabilities

Activities such as running, dancing, throwing, kicking, walking, and crawling (gross motor activities) or activities like fastening lace, sewing, buttoning, unbuttoning, stitching, tracing, writing (fine motor activities) are some examples of motor coordination activities. Individuals with multiple disabilities have difficulty in motor coordination, which is visible directly in the routine or age-appropriate motor activities like somersaulting, holding a pencil, and writing, etc. These difficulties are seen despite average or above-average general intellectual abilities in the child. However, primary conditions like intellectual disability, cerebral palsy, muscular dystrophy, ADDs, PDDs, sensory impairments, and neurological conditions exacerbate the situation. The developmental history of these cases shows delays in motor milestones (such as neck holding, turning over, crawling, creeping, sitting, standing, walking, and so on). It is quite evident from the simple tasks that individuals with multiple disabilities are not able to perform due to their motor coordination problems.

Cognitive development in multiple disabilities

Due to interactional effects, making instruction and learning complex is difficult in multiple disabilities, due to frequent limitations in controlled movement, vision, hearing, communication, or cooperative behaviour, and it is difficult to perform cognitive assessments. So the assessor should use more of a criterion-referenced test rather than focusing on a norm-referenced test, which is more reliable in assessing the deficits.

Aetiology of multiple disabilities

There are several factors that cause severe and multiple disabilities, and they are divided as follows:

Prenatal causes include.

- Chromosomal abnormalities
- Viral infections
- Drug and Alcohol use during pregnancy
- Mother's malnutrition
- Physical trauma to the mother

Perinatal causes, including

- Lack of oxygen supply to the baby's brain
- Physical injury to the baby's brain at birth
- Contracted infections during birth

Postnatal causes include.

- Childhood infections such as meningitis & encephalitis
- Traumatic brain injury from an accident or abuse
- LLead poisoning
- Reactions to medication
- Exposure to toxins or other environmental conditions

With other disabilities, the severity and complexity of the disability depend on the genetic abnormality, the amount of damage to the brain, and the environment in which the child is raised.

Assessment

Assessment is an important aspect in deciding the intervention for students/individuals with multiple disabilities, so assessment is a continuous process to know the abilities and progress of an individual in different areas of development. It is defined as a systematic process of collecting information about a student's Qualities, Characteristics, behaviours, and the environment, which can further aid in providing intervention. Clinical assessments conducted by medical professionals are used to determine the nature, cause, and potential effects of an individual's injury, illness, or wellness. This allows the professionals to compile the best possible treatment options based on numerous physical, mental, and medical factors. For individuals with multiple disabilities, functional assessment is the best possible option as it will help us understand the needs of the individual that are required for him or her to function independently in a given environment. The following aspects are undertaken in a functional assessment:

- Motor (Gross motor and Fine motor)

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- Activities of daily living
- Communication- Comprehension and expression
- Socialisation
- Cognitive/ Academic
- Sensory aspects
- Orientation & Mobility
- Pre-vocational/ Vocational
- Recreational skills

The primary measures used to diagnose these individuals are individual intelligence tests and tests of adaptive behaviour. Early assessment of movement limitations, muscle tone and flexibility, seizure activity, breathing control, sucking and swallowing, vision and hearing, and genetic makeup are also conducted, and prenatal assessment of genetic material or physical identification of deformities *via* sonograms may be conducted. Accurate psychological testing of these individuals is challenging due to their frequent limitations in controlled movement, vision, hearing, communication, or cooperative behaviour. Thus, interviews with family members and educators regarding the person's adaptive behaviour skills (i.e., communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work) may be more informative and reliable than a norm-based IQ or achievement score.

Understanding additional needs of individuals with multiple disabilities

Children with multiple disabilities or severe disabilities often have significant needs relating to their healthcare, personal care and educational needs apart from this, certain additional needs in terms of emotion are found in individuals with multiple disabilities like disruptive to classroom activity or any activity, impulsive, inattentive, distractible, appears pre-occupied, extreme resistance to change and transitions (familiar to unfamiliar environment), low self-esteem, unable to work in groups, engages in self injurious behaviour, has no regard for personal space and belongings, persistently tries to manipulate situations. Since these needs often hinder their learning process, we have to be obliged to link with other therapists who might provide intervention to overcome this emotional turmoil and make them functionally independent [3].

The current trend to include individuals with severe and multiple disabilities in classrooms and community activities, along with their peers having no disability, has been particularly controversial. Special education placement data show a gradual growth of students with disabilities who are placed in a general education setting, but the growth for students with severe and multiple disabilities is much slower. Some schools have expressed their inability to include these students or provide the necessary supports and services to achieve a meaningful education for all involved. Some general education teachers have communicated unwillingness to have these students in their classroom, even with support, and they also may lack the required skills necessary to teach these students in general education classrooms. However, there are numerous examples of schools meaningfully including these students in ways that promote social and educational participation, as well as evidence to support the benefits of inclusion for students with severe disabilities and typical classmates.

Teaching strategies for a child with multiple disabilities

To make the individual function independently, we have to provide effective teaching and develop a curriculum that empowers the individual to achieve personal, social, and economic competence, and must be devised to make life easier. Since independence is the goal, we need to devise our teaching strategies by providing choice for communication, problem solving, exploration, and independent mobility. Reward and reinforcement are very basic to the learning environment of the child; proper attention and praise have to be provided as per the principles of classical and operant conditioning.

Parents should be made to understand that the techniques of reward and reinforcement will reduce skill-deficient behaviour and reduce problem behaviour. While teaching, we should be more functional and meaningful because an individual ultimately has to work or live in their natural environment, and the skills taught should be directly related to the environment and taught naturally. This type of teaching will help the individual to learn and remember better. Further learning with real objects and the objects used daily by the individual will be more beneficial, depending on the objects that are not common. We should also remember to have fixed routines, which will help the individual to anticipate what is going to happen to him next.

Literacy Instruction for individuals with multiple disabilities

While describing the early knowledge of text that the children obtain before any conventional literacy instruction is emergent literacy, coined by Marie Clay. Emergent literacy appears from the print, alphabet knowledge, naming of the letters, phonology, knowledge of vocabulary, and usage of words, which is an early act of reading, writing, and speaking. Often, the home literacy experiences of children with multiple disabilities are different from those of their peers without disabilities, as pointed out by researchers. The learning characteristics of children with multiple disabilities are slower than those of their peers due to the difficulty in processing, maintaining, and generalising the information. Presently, it is very difficult to find out if there are any commercially available assessment tools to ascertain literacy skills. Teachers use informal assessments to understand the literacy level of children.

Augmentative and alternative communication

Augmentative and alternative communication attempts to compensate for limited verbal communication skills by integrating symbols, devices, techniques, and strategies to enhance or encourage communication. Augmentative and

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alternative communication includes "unaided modes" of communication, such as gestures, signs, and facial expressions, or "aided modes" ranging from the low tech—such as drawings and tangible symbols—to the high tech—such as speech-synthesized devices and laptop computers. Sign language is the most obvious choice of communicative skills that can aid communication and can be very effective in developmentally capable individuals with dual sensory impairments. However, in individuals with multiple disabilities and additional cognitive issues, sign language can sometimes be challenging. Gestural communication alone often restricts social interaction in this population to the immediate present, to items or things that can be touched at that particular moment. Materials and tools designed to augment communication in students with multiple disabilities can be used to bridge this gap and provide these individuals with the means to communicate and make purposeful choices in their lives.

Assistive Technology (AT)

There are a variety of AT devices that are used to help children with severe and multiple disabilities in the classroom. Communication boards, computers, head sticks, and adaptive switches allow individuals with multiple disabilities to communicate effectively with others. Teenage Switch Progressions allow students to press a switch to activate activity-based instruction on the computer. Other types of AT technology include wheelchairs, walkers, speech synthesizers, alternative keyboards, pointing systems, talking clocks and calculators, voice recognition software, picture boards, Braille machines, reading machines, magnification software, phonics ear devices, telecommunication devices, and sound magnification systems.

Space / Satellite technology

This type of technology is also considered an important aspect in doing away with barriers and improving the quality of life of individuals with multiple disabilities. Space or satellite technology can help us reach the unreached and help us in providing home-based services, and can also help us largely through online and web-based services.

Therapeutic needs for multiple disabilities

Apart from providing educational intervention, therapy is an important aspect for individuals with multiple disabilities. Therapies such as Physiotherapy, Occupational Therapy, and speech therapy are needed. Let us look at a nutshell at what these terminologies mean.

Physiotherapy: Physiotherapy provides services for persons with multiple disabilities & movement difficulties to develop, maintain, and restore maximum movement and functional ability throughout the lifespan. A physiotherapeutic rehabilitation programme is personally designed based on an individual's unique situation, needs, and goals, and carried out by a professional physiotherapist through exercise and pain-relieving modalities.

Occupational therapy: The main aim of occupational therapy is to make it possible for individuals with multiple disabilities to participate in the activities of everyday life. Occupational therapists make these activities of everyday events by working with people having multiple disabilities and communities in order to engage them in meaningful occupations by suitably modifying the occupation or restructuring the environment for a better occupational engagement.

Speech therapy: Individuals with multiple disabilities often have difficulty using speech for communication purposes. These difficulties arise due to the multiple associated conditions like cerebral palsy, intellectual disabilities, hearing impairment, etc. Speech therapy deals with the speech problems of an individual. However, the field of Speech Pathology doesn't only tackle speech, but also language and other communication problems of an individual.

Sensory integration therapy: Dr. Jean Ayres defines "Sensory integration as the ability to synthesize, organise and process the incoming sensory stimulation from the body and the environment to produce purposeful goal-directed responses". Individuals with sensory processing disorder have difficulty processing information from the senses (touch, movement, smell, taste, vision, and hearing) and responding normally to that information. Children with Autism, Asperger's Syndrome, Cerebral Palsy, and other developmental disabilities often have Sensory Processing Disorder (SPD). However, it can also be associated with premature birth, brain injury, learning disorders, and other conditions.

Independent living skills for adults with multiple disabilities

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) promotes, protects, and ensures the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities and to promote respect for their inherent dignity. This relevance has direct reference to article 37 (Work and Employment) of UNCRPD to work on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a work environment, which is open, inclusive, and accessible.

The concept of independent living is based on the belief that the control over one's own life is important and that personal independence can be increased by managing one's own affairs, participating in day-to-day life. In independent living individuals are given the choice to choose their own priorities in consultation with their peers who are persons having disabilities.

Training in adult independent living for persons with multiple disabilities started as a movement in an organised manner particularly under the influence of urbanisation and industrialisation. In the subsequent times many developmental programmes have been launched in which both the government and non-government organisations have worked together. Gradually a paradigm shift has occurred replacing the charity mode with rights based model. This has been possible due to the international obligation.

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Multiple disabilities can significantly impact social and cognitive development, as a result the function of individuals with multiple disabilities are frequently compromised. Some adults learn to function well in society. They can maintain gainful employment, others never develop the communication and self-help skills necessary to live independently.

Correspondingly adulthood is an issue of increasing concern. It would be prudent as well as humane to assess each person's needs and abilities as part of an individual's plan for support that will enable them to use their abilities, realise their dreams and attain the best possible Quality Of Life (QOL). Like most people, individuals with developmental disorders, intellectual disability continues to grow and change over time. Their development is not frozen in time and forever remains the same. Research shows that adults with multiple disabilities can continue to improve throughout their lives. With appropriate supports over a sustained period, the life functioning of persons with multiple disabilities will generally improve. The criterion for providing independent living skills (AILS) is not the intelligent quotient, but the person's level of functioning. The best curriculum package can be selected and modified according to the individual's need and functioning level.

Self-advocacy and Independent living

Self-advocacy means speaking or taking action on behalf of oneself or on behalf of a particular issue. Self-advocacy aims to allow persons with multiple disabilities to learn to speak for themselves, listen to others, make decisions, solve problems, and ultimately develop leadership skills. Self-advocacy movements address the fundamental issues of our expectations of individuals with special needs, who have historically been among the most devalued, neglected groups in society. The movement tries to claim for them a valued status for themselves and to be seen by others as valued people; in other words, to become a true and equal citizen of their community. It is essential for every human being, not only for the sake of earning money but towards economic independence, which leads to self-esteem and self-dignity. Economic independence not only brings improvement to Quality Of Life (QOL) socially and economically, but also ensures dignity and recognition in the family and society. While developing adult independent living skills, there is a greater need to enhance the functional abilities of a person with multiple disabilities in order to equip them to contribute economically to self and their family.

Road map

Innovative models in including individuals with multiple disabilities

Inclusive Education has now gained the acceptance of the global development agenda all over the world. The post EFA 2015 and the post MDG 2015 goals have also considered inclusive education as a viable strategy to reduce exclusion in the society. Innovative model is the development of new, unique concepts supporting the mission of Inclusion of multiple disabilities.

1. Family inclusion: The UNCRPD describes disability as an evolving concept of a 'social' nature. Families remain the first and most immediate environment where children with disabilities can develop their potential and enjoy a fulfilling life. Some parents were not supportive of Inclusion as they felt that their child's education will focus more on academic curriculum rather than functional curriculum. Parents believed that students with severe disabilities who were included in regular classroom settings would be rejected socially (Freeman & Alkins, 2000). Hence when an individualised education programme is carried the families especially the parents must be involved, they should be provided with appropriate training to carry out activities at home.

2. Educational inclusion: It is reported that many children tend to leave school early due to poverty, distance or an inappropriate curriculum. Hence educational inclusion can be promoted to have a single language-based curriculum, which is activity based along with effective instructional techniques which is based upon research. It should include a strong focus on positive reinforcement and there has to be frequent opportunities for the child to respond to instruction. The daily recording of academic work and behaviour problems need to be worked out and should have frequent review of progress and timely changes in procedures if progress is not happening.

3. Community inclusion: Community Inclusion is the opportunity to live in the community and be valued for one's uniqueness and abilities, like everyone else. Community Inclusion should result in community presence and participation of people with disabilities similar to that of all others with a disability label.

4. Occupational inclusion: In our society, persons with disabilities must have access to education and training in marketable skills to facilitate entry to decent work at the start of their working lives. They must also have access to education and training on a continuing basis, in the form of lifelong training throughout their working lives, to maintain decent work. The new UN Convention on the Rights of Persons with Disabilities is a strong statement of this approach. To facilitate this process and to monitor the effectiveness of training provision and employment promotion for individuals with multiple disabilities, we need to know what vocational training institutions are doing at present and what more they need to do to effectively implement the new policy of inclusion. We need to document good and promising practice in these areas. Hence the occupational inclusion should have proper reservation policy, accessibility, technology, advocacy, and awareness, appropriate skill training.

Working with families and communities

One of the primary tasks in making the rehabilitation programme effective is understanding the needs of individuals with multiple disabilities and their families. It would be more appropriate correlating these needs in the empowerment process, especially for sustaining the vocational/livelihood economic independency for individuals with multiple disabilities as these needs are dynamic at both ends of individual family level cascading from psycho- somatic needs

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to developmental needs, socio economic needs to safety measures. The most crucial and spurting need of individuals with multiple disabilities and their families are often economic independency. There are different models of vocational/ livelihood empowerment programmes being practiced across for bringing economic independency. All these models have emerged as a response to the needs and in enhancing economic independence for individuals with multiple disabilities and their families.

Community participants through Community Driven Development approach (CDD) ensure addressing the needs of creating a more independent and generalisation of learnt skills and also reducing pressure of limited resources in independent living programmes. CDD is a bottom approach of the community participating and implementing these programmes. Community people are involved at every level of strategic planning of the programme and are implemented by them thus inculcating the ownership in the empowerment process. One of the primary tasks of the CDD programme is developing human resources as Social capitals. Once the social capital is identified and provided training, these professionals in the community becomes well equipped for enhancing the programme with their active contribution to the individuals by:

a) Providing simplified ongoing handholding support to beneficiaries

b) Inculcating peer pressure amongst the individuals through their contribution in the empowerment process

c) Channelising support services, convergence and linkages for sustaining empowerment

d) Developing ownership and self-advocacy roles.

Peer support – Key to inclusion of children with multiple disabilities: the role of teachers

Inclusion in the general education classroom provides all students the opportunity to participate, learn, and feel a sense of belonging within a group. It does not mean everyone must complete or compete on the same work in the same way; and allows for accommodations so that everyone is able to participate to the greatest extent possible. Years of research on inclusive practices indicate the strong positive impact of peer support. Peer support is a strategy that involves placing students in pairs or in small groups to participate in learning activities that support academic instruction and non-academic skills. It provides teachers with a learning tool to enhance instruction for students with and without special needs. However, there are several challenges that may lead to poor takeover of the role by the peers; which may result due to their lack of training and orientation.

As much as it is highly essential that all in immediate school environments are oriented to the needs and characteristics of the impairment and associated condition; to remove their fears and apprehensions related to the special needs. It is still more essential that the peers selected for support are trained on skills and strategies to: (a) adapt class activities to facilitate student participation, (b) provide instruction related to IEP goals, (c) implement relevant behaviour intervention plans, and (d) provide frequent feedback to the student with special needs. The essential role of the teacher in an inclusive setup, is ensuring meaningful planning to adapt peer-support strategies to meet the needs of students. Additionally, selection and prior training of the selected peers, is highly essential to help explain the overall goals of the peer- support strategy to the peers. To implement positive and effective peer support, we must: identify individual student learning strengths and needs; develop and explain roles/expectations in peer partnerships; teach basic strategies for supporting the scholastic and/or co-scholastic participation of peer partners; and provide means for ongoing feedback and assistance to peer partnerships.

Peer support interventions are not sufficient by themselves and they do not eliminate the need for adult support. Successful peer supports use a structured, collaborative approach to provide students with specific roles and supports to build successful relationships. We must create spaces that support and encourage students to work together, be it through group projects, buddy systems, as an academic support, aide in sports and recreation, general caring or in a competitive spirit; that will ensure creating avenues for more peer interactions and collaborative learning opportunities. Peers are one very powerful resource that is often overlooked, underutilized and perhaps not well understood. Teachers must work out strategies to build this resource and boost their attitude and skills for ensuring sustained support in the long term.

Models and best practices for the education of children with severe and multiple disabilities

Given the variety of combinations of physical, medical, educational and social-emotional challenges that children with severe and multiple disabilities bring to each learning environment; a diverse set of professionals and disciplines is needed to provide support. While we may have evidence from research, policy and our collective wisdom of the use of different approaches to intervention; but services for individuals with multiple disabilities is a relatively new concept. Further multi-disability-specific interventions are an untouched territory. Each discipline of intervention brings a unique set of skills and experience to the individual; but it is recognized that the discipline-specific interventions often fails in meeting the diverse and often extensive needs of children with multiple disabilities. Moreover, even the multidisciplinary and interdisciplinary models do not serve the purpose of ensuring support and services needed by the individual with severe and multiple disabilities.

To achieve a truly collaborative model of all services, a transdisciplinary and cross-disability model is the key to serve individuals with multiple disabilities. However, it is least in practice; most institutions are for single-disability and most professionals and services are disability-specific, resulting in a dilemma. Further, the ratio of human-resource, the competency-level of professionals, the overall resource material, infrastructure, equipment etc. is required to be high; which becomes another area of concern for achieving outcomes

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of services for individuals and their families. The key elements of best practices for the education of individuals with severe and multiple disabilities includes: Cross disability approach of institutions; Trans-disciplinary model of services; Focus on activity based learning; Practice of Universal Design for Learning; Specific resource and professional development; Parents as partner in special education; Buddy- development programs; Technology support etc.

Ensuring that children with multiple disabilities are active participants in all aspects of their lives and that they achieve valued life outcomes can be a daunting endeavour for families and professionals. And given the myriad of their needs, a successful outcome requires not just collaboration and planning among a large number of individuals; but also, an acknowledgement of their right to grow, learn and prosper, like everyone else.

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