HIGH SUPPORT NEED: PARENTS NEED

"Necessity for Support"

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Preface

Needs of high support: Parent’s needs is great resource for parents, professionals, stakeholders, and educationist, general and special educator who wants to know about the needs of parents of children with high support group. It will support them to understand the importance of parents, need articulation to provide appropriate rehabilitative measures. This book will help them to identify, assess, guide to parents on their children needs. There are many book available in general education and parental needs but this book different from all in which help one who wants to develop a model of service to children with high support needs in the early childhood stage and it will be the resource.

This book has ten chapters and each chapter deals about different age group starting from early childhood age, school age, adolescents, adulthood and geriatric high support needs. It helps the reader to understand what is high support needs, and available resources, different needs in different ages, managing their needs, guidelines for availing services etc. It gives evidence based knowledge on high support needs and parents, it cater the needs of children 3 years to old age 60 years. The book guide us to know the special group and different needs throughout their life, parents role and responsibility, availability of services and helping them to overcome their problems. An attempt was made by authors to include items, which are culturally relevant to Indian context.

There are limited number of books and studies conducted in the field of high support needs with special needs. There are many books available in early childhood education but the needs specified was general children and their educational influences. There are very limited literature available for special needs and that to very little be explained about high support needs in the inclusive setup. This book helps everyone to understand the early childhood high support needs and parents needs.

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CHAPTER -1

CHILDREN WITH HIGH SUPPORT NEED

- Benjamin Victor. G

Objectives

This chapter will help the reader to understand

1. Children with High Support Needs (C-HSN)
2. Recognize Children with High Support Needs (C-HSN) Ecosystem
3. Prioritize and opportunity chores for Children with High Support Needs (C-HNS)

Introduction

Families are always the pivot to an individual’s lives. What affects one member of the family can affect all family members, as family is a system in which no one member can be viewed in isolation. When it specially concerns young children, families assume critical roles that significantly affect the children’s overall well-being, development, bonding, values, practices, etc., which are the fundamentals upon the children learn and develop their chores expected of them in their families, neighborhood and society. Perhaps, one of the crucial step for meaningfully supporting children with disabilities understands the families and their perspectives on evolving family centered interventions. Further, as families are central to their children’s overall present and future development, it would be much more crucial to understand families of children with special needs especially to the Children with High Support Needs (C-HSN) which will be the first step for planning any support or interventions for them.

Children with disabilities are like any other children. An early attention to their developmental needs and providing support will assist them and facilitate their overall development and independency. One of the fundamental principles while addressing children with disabilities is “the more the inclusive and ecology based, the better is the child progress and quality of life. Any person with High Support Needs in a broader sense refers to persons who are severely disabled/ those requiring some extent level of support for their day to day functioning. As we know that each child with special needs is unique so also is their level of high support needs and assistance requirement will be more. Furthermore, as we also know that building on the child ecosystem and providing opportunities, children with high support needs can be effectively assisted to cope with their individual needs.

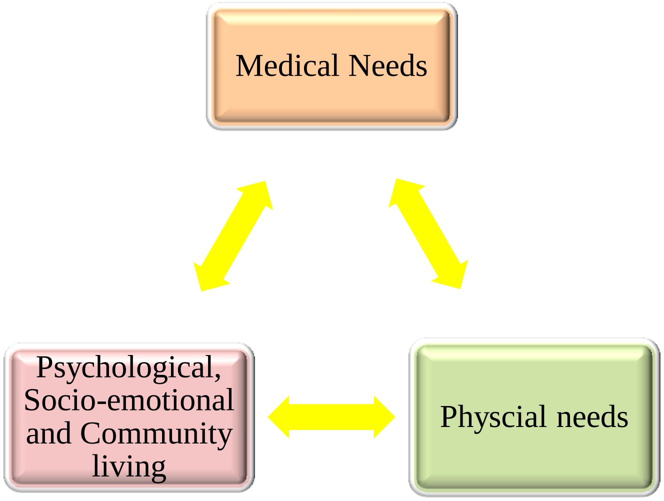
Definition

Person with disabilities High Support Needs refers to a person requiring an intense support, physical, psychological and otherwise which may be required by a person with benchmark disability for daily activities, to take independent and informed decision and to access facilities and participating in all areas of life including education, employment, family, community life, treatment and therapy (as per the notification amendments to the disability rights rule 2017).

It will be appropriate for us to draw an analogy to understand the term Children with High Support Needs (C-HSN). These are children with severe disabilities who will require a spectrum of support, services and assistance for functioning on day to day basis. The needs are very dynamic and emerging in nature as the child grows which can be advantageously built upon a family centred approach to make it more meaningful and help C-HSN optimum to their independent functioning.

Needs of children with High Support Needs

C-HSN requires various levels of inter-reinforcing support and assistance to meet their functioning and community living. The assistance support/needs may intensify and become dynamic as the child grows thus making the parents/ care giver to expand their support and assistance. As we know that every C-HSN has abilities and understanding the need and its paradigm will help both the special educator and parents/care taker to advantageously nurture and support C-HSN in their independency by helping them to see life as a rewarding experiences. The needs of C-HSN may be broadly classified as follows,



- **Medical Needs**: Generally children with High Special Needs may need frequent medical support such as medication for the epilepsy, Psychotic drugs, etc., hospital stays, equipment, and accommodations for disabilities, etc. Establishing a good support system is very important when dealing with uncertainty and any medical crises. Further additional medical support may be required during the process of the child development as they are more prone and vulnerable for infections due to their decreased participation in chores. It will be important for a special educator/parent to understand how personal and environmental factors are associated for restricting the participation of C- HSN and plan for an inclusive program.

- **Physical Need*:*** Children with High Special Needs will exhibit a range of support for addressing their movements, communication, daily living activities, etc. Further these need will be a prerequisite skill for which the child will have to be assisted for optimal functioning in their daily chores A combination of therapies such as physiotherapy, occupational therapy, Neurodevelopmental and Sensory Integration therapies, Speech Language therapies, etc. helps. Further the key for the special educator/parents for comprehensively supporting the needs of C-HSN will be to plan for a trans-disciplinary approach of service delivery of the Multi-disciplinary team expertise support or in other words the special educator or the care provider will be the focal or the nodal person for converging and leveraging support services with the multi-disciplinary team members.
- **Psychological, Social, emotional and community living:** Children with High Support Needs due to their disabling conditions will exhibit lack of social and emotional development such as expressing themselves, maintaining relationships, being aware of and anticipation of hazards, and responding appropriately etc., Independent community living skill with family centered approach/ecology based interventions will help the child psycho-socio-emotional development and assist them to cope with their developmental needs.

Parents of children with high support needs

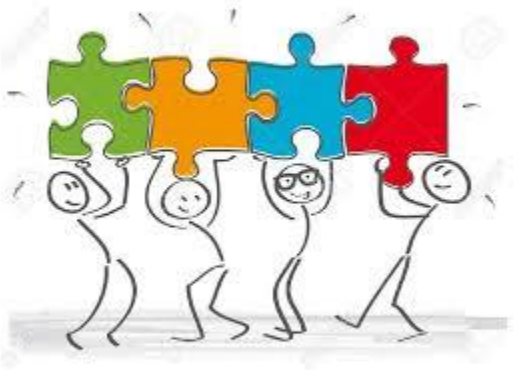
The family members particularly the parents are a key source of services and support for Children with High Support Needs across their life, helping people to remain living at home and in the community. Parental relationships and their dynamics are critical in understanding the context of family support and intervention approaches. For example, siblings play important roles in the lives of Children with High Support Needs across their life span and frequently assume greater family care giving roles when aging parents pass away or are no longer able to provide supports (Arnold, Heller, & Kramer, 2012; Heller & Arnold, 2010; Heller & Kramer, 2009). Furthermore, supports are often bidirectional and operate at multiple levels within families. The emerging needs/compound care giving needs of Children with High Support Needs drives parents/care givers for accommodating various support services, compromising, restricting their life spheres, etc., Parent needs of C-HSN are dynamic and developing in nature which broadly includes,

- **Information and Communication*:*** One of the most crucial and the inevitable need of parents/care takers will be for information and communication on the various themes for understanding their C-HSN. This will include a range of information such as causes, needs of C-HNS, functioning level of C-HSNs, availability of rehabilitation services and support, support peer group, institutional care support organizations, social safeguard for their C-HSNs, etc., Often the challenge is that these information which are available to special educators, parents/families are in parts and intermittent and are not comprehensive due to which most of the time they either get exploited, unable to assist the child in their optimum development and or left from being mainstreamed.

- **One Stop Holistic Rehabilitation Services** – C-HSNs will require a multi-disciplinary rehabilitation support as their needs are inter-reinforcing in nature. The most common concerns and expectation of any parents of C-HSNs will be ensuring a comprehensive holistic rehabilitation services to their children in a most cohesive manner such as therapies, special education, vocational and adult independent living, etc., The biggest challenge and constraint parents face is on the information of a holistic service under one roof and the accesses to these services in a continued manner which will benefit the child. One of the best contribution that a special educator can provide to families is helping them is to compile a ready reckoner inventory book that will provide information on the following for helping them to avail, access, and benefit from these support and services.

Impact of Parental Support

One of the most two fundamental emotion and challenges that always surface parents/care takers is that, “Is there anyone who understands me” and “What will be my child’s future after me”. It would be pertinent for us to understand that parents/care takers of C-HSN are doubly at a disadvantage and vulnerable both in their personal life as well as in their socio-economic life. In this rippling vulnerability, perhaps special educators who are primarily responsible can be the compass to help parents/care takers in finding the support and services requited for their child. This can be best facilitated by helping the parents build confidence, share their best practices and cope up. They need help provide them



a window for peer mentoring and support to nurture their C-HSN through Parental Support Groups.

Parent Support Groups are peer groups primarily formed by the parents of disabled children as a platform for sharing, learning and supporting mutually one another. Further these peer groups can also advantageously contribute in voicing the interest of parents for policy formulation, argue in the role of advocacy for enforcing safeguard measures etc., This collective responsibility of the forum will the first step for making families and C-HSN to connect all the dots and bring quality and dignity to life.

Assessment of children with High Support Needs

Unlike children with disabilities, assessing C-HSN will require a multi-disciplinary team assessment, as these children may have developmental issues in many areas. Further as the team assess the child present ability, strength, limitations, needs, etc., these inputs will be the foundation to assist and help the rehabilitation team (educator, therapist, social worker, doctors, etc., to plan holistic interventions support and services. The general process of assessment of a person for certifying a benchmark disability of 40% will include the evaluation of the individual function in various areas/domains as per the IDEA scale. The team to evaluate this would include a medical practitioner, psychologist, counselor, and District Disability Rehabilitation officer.

Further according to the RPWD Act 2016, the process of assessment of person with High support needs is as follows,

- ✓ A person with Benchmark Disability or any other person or organization on his behalf may apply for High Support to the authority
- ✓ Authority refers the request to the assessment board
- ✓ Assessment Board makes an assessment of the case and sends a report to the authority in which it certifies the need for High Support and the nature of support that will be required
- ✓ The authority takes steps to provide the support as mentioned in the report

Children with High Support Needs and their Quality of Life

Quality of Life (QoL) refers the general well being of an individual. WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept that looks at the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment. One of the most commonly used terms in rehabilitation is quality and dignity of life. Perhaps it will be hard to realize that often the real meaning of these terms is less addressed in terms of the ground reality of the services, support assistance, etc.,

As C-HSNs have a diversified requirement of services and support assistance, and considering the various existing apex institutions, large scale community program, etc, still the optimal benefits of the low hanging fruits are yet to be accessed by the parents of C-HSN. Further the constraint of reach and magnitude for service deliveries, capacitating parents/care takers and infusing inclusive strategic planning the quality of life of C-HSN still remains at the horizon. It will be pertinent to foster the collective and affirmative action of institutions, service providers, parent groups for enhancing the quality and dignity of life of C-HSN in a time bound and a sustained manner.

Role and responsibilities of Professionals on Parent Support

As we know that the needs of parents of C-HSN are compounding in nature, it will be much more crucial for the rehabilitation professional who will be the mentor and the path finder to parents. As each family is unique and the parents/caregiver would be in any level of the spectrum of understanding and cooperation, it will be the responsibility of the rehabilitation professional to ensure that the parents/care takers/family members are understood appropriately with their ecosystem, involved in the planning process, and are in their comfort zone for believing that their C-HSN can be optimally made independent within their life time.

Transdisciplinary and Interdisciplinary approach to cater to the needs of High Support Needs

The various approaches for providing effective rehabilitation services to families of disabled persons are multi-disciplinary, trans - disciplinary and inter disciplinary models. These are the strategic approaches through which comprehensive rehabilitation services and support assistance are provided to individual and their family members. It would be critical to understand the above approaches in its simpler format in reference to C-HSNs as follows

- ✓ **Multidisciplinary approach** - Team of specialists/experts extending their services to C-HSN, however the experts/specialist may not be interacting with each other. Most of the time they will be working in isolation and are independent to one another.
- ✓ **Trans-disciplinary approach** – The team of professionals/specialist/experts come together, assess and evaluate C-HSN, work on a common agenda by providing transfer of skills and knowledge to a person (nodal person) who receives it and in turn provides these services and support to C-HSN/their parents.
- ✓ **Interdisciplinary approach** - The team of professional/specialist/expert come together, assess and evaluate C-HSN, work on a common agenda by providing services and assistance to the child/their parents. The team evaluate the progress of C-HSN on a regular basis through case studies and conference where

parents/care taker will be part of this team and included also in the process of setting up agenda's and subsequent goals.

Role of institutions in supporting parents with high support needs

Institutions are the lifeline for parents/families of C-HSNs. Developing family centric interventions will help in rippling responses both in the overall development of the child as well as assisting families in their coping and managing with their C-HSNs. The broader role of institutions in supporting C-HSN can be categorized as follows,

- Communication, Information & Dessimination
- One stop rehabilitation service deliveries
- Capacitating parents/Care takers/Families members
- Human Resource Development programs
- Research & Documentations

Across ages of children with high support needs

It will be a memorable and gratifying moment for parents to see their children grow and move from one stage to another stage in life. Similarly, the need of C-HSN unfolds as their progress in their development moves from one stage to the next. It is important to understand that the needs C-HSNs gets more complex as they develop and cross each stage in life, especially for a girl C- HSN. The need for menstrual hygiene, safety, etc., becomes the biggest concern to parents/families. Besides that the concerns of the other siblings, the taboo/stigma that the community poses of them/their families are issues that have to be dealt with. Furthermore providing a comprehensive service delivery to families of C-HSN will not only help the parents/care takers to prepare and manage the needs of children better but also build confidence and be sure their C-HSN will progress across all the stages. The broad possible needs of C-HSN across their ages can be categorized as follows,

Stage	**Broad needs**
Childhood period	Information &communication to parents/care takers/family members Holistic Early intervention – Medical, Rehabilitation, etc., Inclusive environment and eco system
Adolescence age	Rehabilitation and support services Community living skills and Independent daily living chores Pre-vocational training, Functional academics Social safety net
Adult age	Inclusive vocational opportunities Recognition, appreciation, , etc

	Social safety net and entitlements

Developing and implementing evidence based intervention strategies for children with high support needs

There are various models, demonstrated strategies/ interventional services being practiced by various institutions. Despite the various efforts, the question of whether the families of C-HSN do really get the optimal benefit. Perhaps one of the challenge is disclosure and availability of information on the interventional approaches, service deliveries strategies, etc which normally remains within a group of people/professionals. In a simpler context, Evidenced Based Interventions are those activities that executed, tracked (time series, longitudinal studies, pilot studies, etc.,) and proved that these impacts will be the outcome.
The following broad activities can be taken up for an effective planning and implementation of an evidence based intervention services for C-HSNs.

1. Understanding the needs of C-HSN and their families.
2. Developing hypothesis, outcomes, intermediate outcome.
3. Choose appropriate approach/strategies. Develop Standard Operation Practices (SoP), deliverables and outcomes.
4. Monitor the activity through Process monitoring, Progress monitoring and Concurrent Monitoring and document at every stage
5. Disseminate the demonstrated proof of concept with suggestion for scaling up/expansion, Deeping the interventions.

Addressing gaps in the research to practice and practice to research

It is very important to always to review and document what is one (research to practice) and how it is done (practice to research) especially when services are extended to C-HSN and their families because every level will be an indicative insight for the special educator for course correction and re-defining their interventions and practices. Often this is either taken for granted or loosely managed which results in the quality of the program delivery besides ascertaining the intervention usefulness, appropriateness, etc. Some of the few steps that can facilitate addressing gaps in research and practices are as follows,

1. Bringing common understanding by informing the team members on the service/ interventions
2. Helping the team and the families to be a common platform by giving feedbacks, using participatory monitoring tools, etc., on the agreed themes/studies- time series, pilot, etc.,
3. Helping the team do qualitative documentation, analytics and inference, etc.,

Process of diagnosing and planning the intervention

The heart of any intervention program lies in early identification, diagnosis and appropriate intervention planning. The challenge and constraint with our C-HSN and families is that very often parents have the tendency of shopping behavior of consulting many people on their child's condition due to which the crucial period or formative period gets lost. At times this also gets cascaded due to traditional practices, beliefs, lack of information, etc., Hence it is important for a special educator to understand families and their ecosystem, to help them internalize their child's present status, help them give priority to the child's needs and required services - all built upon a family centric approach.

The following broad guidelines for diagnosing and planning interventions for C-HSN with the key principle of making it a participatory program

- Learn about the families' ideas and preferences and provide choices in programming.
- Involve the families in program leadership and in decision-making, recognise and honour and respect diversity.
- Develop responsive and reciprocal relationships and use respectful, responsive, and two-way communication.

Summary

This chapter narrated about children with High support needs with multiple disabilities needs. The roles and responsibilities of parents are wide and children needs related to their cognitive, physical, psychological, motor and personal skills should be focused in early life. Quality of life will be met when the supports are provided appropriately. There are many approaches in rehabilitation services among them transdisciplinary and interdisciplinary approaches the parents will be partner. In catering the needs of children with high support needs the role of institutions are most important.

Check your progress

1. Define High support needs
2. What is transdisciplinary team approach?
3. Write role of parents in decision making process
4. Need and importance of role of institutions in catering the needs of C-HSN
5. How do assess the gap of support needs for C-HSN?

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CHAPTER –2
PARENTS AS PARTNER IN EDUCATION AND REHABILITATION OF CHILDREN WITH HIGH SUPPORT NEEDS

-Ravikumar. R

Objectives

1. Understand that the child with disability is an integral part of the family
2. Know the meaning of a partner and the responsibilities of a partner
3. Understand that the parent has primary responsibility of nurturing and training the child with disability
4. Understand that the child with high support needs can be educated and trained to become independent and economically as productive as useful citizen.
5. Identify the ways of developing the parent partnership and its effects on the development of the child with high support needs
6. Resolve the difficulties experienced by the parents in caring and training their children.
7. Study the effectiveness of parent partnership in education of children with disabilities

Introduction

One of the most effective means of ensuring academic success is to engage families in their children's education. While family engagement confers benefits on all students, those with disabilities often require a greater degree of parental involvement and advocacy than their peers without disabilities in order to be assured of receiving the same level of instruction as the general student population. Children with disabilities often face multifaceted classroom challenges requiring special attention from instructors and active engagement from their families. Their families play a number of supporting roles, including as their advocates and as people who can provide valuable insight into their specific needs to instructors, who may at times feel pressed by trying to meet the needs of diverse groups of students. There are rarely any simple answers to balancing the needs of each individual child with disabilities with others' needs, with competing structural, bureaucratic, pedagogical, and emotional factors often adding extra layers of effort and complexity for everyone involved.

Despite, parent constitutes an important member of a multi disciplinary team to design an ecological based curriculum for children with special needs who have been educating in special schools and training institutions, marked poor responses in many cases. Parents tend to resort in to traditional method of handling their child in spite of high frequency of strategic inputs are offered. Further they often compare their own child's performance with other child's performances resulting in to discouragement and depression. But when families and educators work together as partners, it enhances the likelihood that children with disabilities will have positive and successful learning experiences.

The Historical Background

In the past, people with disabilities were institutionalized for the purpose of feeding and caring only in fact it rests the responsibilities on the charity organizations where they actually dumped and detached them from the society. Mostly they were treated as charitable objects and the society considered that doing some charitable activities for them will be holy activity ("Dharma Kariyam") and enough for their survival. The parents ought to choose this option as because of this prevailing societal attitude about people with disabilities. This approach dragged the people with disabilities in to seclusion and deprival of opportunities for socialization. Then medical model emerged where the children with disabilities treated only on medical ground.

Later the conceptual changes took place in the perspectives of the society and social model concept emerged as a result of this, deinstitutionalization of children with disabilities was initiated. Since then the children with disabilities taken to therapeutic and rehabilitation centres for getting therapeutic intervention and rehabilitation services. As such more emphasis was given on education of the children with disabilities and thus special school concept developed with an aim of providing special education and other habilitation services like therapeutic, behavioral and etc., Later inclusive concept formulated and overall constitutional changes took place all over the world to include the people with disabilities in to society in all aspects of life by providing equal opportunity and rights without any discrimination. After this, the responsibilities of family became inevitable and they must take appropriate action to bring out their children in to society for enabling them to be independent and lead a dignified life in the society. In order to achieve these objectives, the parents of the child with disability should come forward to alienate the social stigmas and be optimistic in their approach.

Meaning of a Partner

1. Has equal responsibility in carrying out the task or business,
2. Is well acquainted with the facts and matters concerned with the task,
3. Should be equipped with the skills and competencies to deal the matters effectively and appropriately,
4. Must have real concern and show interest in all its activities or businesses,
5. Should have consistency in working in day to day affairs, receptive to the modifications and ability to resolve the issues,
6. Must understand the critical areas of performances in which more support is needed to contribute from other field experts.

Parents as Partner

Partnership smoothen the process and links the relationships between the partners for achieving larger outputs. Parents are highly dedicated partners in the process of education and rehabilitation of children with high support needs. Highly motivated team of experts is required for developing programs for education and rehabilitation of children with high support needs which includes parents and family members. The parents are linking the professionals with the child for evolving the potential and systematic programs for obtaining optimum level of performance of the child. More over the partnership strengthens the rapport between the child and professionals. In order to achieve the best outcome of the training, the parents have to play a role of "partner" and thus a parent can be a partner in education and rehabilitation of children with high support needs.

In general, partners have certain roles and responsibilities which will also applicable to the context of parents as partner in the process of education and rehabilitation of children with high support needs.

Importance and Needs of Parental Support

The parents and family members play a vital role in educating and caring the children with disabilities especially children with high support needs. Unless and until the parent establishes a good rapport with the child, there won't be any progress visualized in the training and education. The ultimate aim of inclusion strategy will be materialized only if the parents support provided consistently otherwise a big gap will be developed. Stern efforts have to be taken from the parent side to enhance the quality of life. The special educational planning is ought to be bound with the parent partnership to retrieve maximum possible outcome in the child's progress. Active participation in the training process will improve the efficacy of the learning of the child and strengthen the confidence level of the parent. The process of partnership between parent and professional should go as parallel track like railway tracks.

The following components have to be developed with right quantity and each area ought to be concentrated well to strengthen the parent partnership program which maximizes the benefit of the systematic program.

a) Accepting the Disability

Acceptance in human psychology is a person's assent to the reality of a situation, recognizing a process or condition without attempting to change it or protest it (Wikipedia). The terminology for each disability is depicting their nature of disability and nomenclature also changes over the time for each disability. Accepting the disability by a parent is a highly linked with such terminologies and certain factors like social taboos, stigma and etc., Acceptance is an essential component for any progressive work. If a parent accepts the reality of their disabled kid, then the program for development will be more easy and paving way for good progress in the child with special needs, otherwise the task will become more complex for the professionals who are dealing the child.

b) Attitudinal Changes

Attitude is a settled way of thinking or feeling about something. Attitudes are associated beliefs and behaviors towards some object. They are not stable and are subject to change by social influences (Wikipedia). Parents of CWHSN tend to have attitude of worthlessness and desperateness as because of poor prospect of their disabled child. The belief system of their community also precipitates the attitudes and restrains them towards progress. Mostly they resort in to traditional method of treating the disability and wanted to resolve problem in an ad hoc basis only. Attitudinal changes will make them to realize their actual potentials and encourage developing suitable strategies for improving the skills of their child.

c) Addressing their Needs

The children with high support needs have diverse needs and their specific needs are to be meeting out with adequate strategic planning and effective methodology. If their needs are not meet out at right time, the trainer and the professional will be stagnated and stuck with the preexisting conditions only. Hence, the parents ought to look after their specific needs as and when arises and address it to the respective people for resolving the issues.

d) Applying the Learnt Strategy

Strategy is a plan of action designed to achieve a long term or specified target. This will be helpful for getting a maximum possible outcome from the sources. Parent ought to be trained to apply the strategy in training their child at home and other social settings. Most of the training institutions have given enormous inputs for the parents and families to deal their kids effectively but they quite often failed to apply the learnt strategies while dealing with their kids and searching further professionals help for their issues.

e) Active Learning for Accelerating Autonomy

Learning is a continuous process and it has active role in a person and develops as s/he grows when suitable environment is provided. The children with disabilities need such optimum climate to learn new concepts and skills. Mostly they are not allowed to learn themselves by the parents as because of their poor condition of their disability and over protection, also the parents themselves do the skills for their child especially the personal skills. Involving the children in sports activity will make them to learn many concepts spontaneously and improves their physical, mental and social well being. The parent has to act as catalyst for change and accelerating the autonomy in the child by allowing active learning process. Disallowing them, doing for them and helping their child to perform a skill will lead for restriction of learning and pose to dependency.

f) Assuring the Consistent Parental Support

Support mechanism is an essential component for achieving the progress. In the disability education system, parental support plays a crucial role in developing positive changes in the child’s progress. Enabling the parents and initiating the parental cooperation will ease the process of education and training the children with disabilities. More over the parental support should be consistently provided to maximize the results of the program. Potential parents in terms of activeness and skillfulness will boost up targeted behavioral development of the child with disabilities. Traveling along with child for each and every activity is an essential strategy for the parents. Mostly parents show interest in the initial phase of training and later slowly withdrawing their support or disinterested in the process. This will negatively reflect in the progress of the child with disability. Despite consistency is maintained by the parent, possibility of regresses in the progress of the child will be noticed in few cases due to severity and associated conditions of the disability. Hence, consistency in the parent support is solicited for designing effective program planning.

g) Accessible Environment

Accessible environment is another important prerequisite for enhancing the parent involvement. If the structure is not in accordance with their needs leading for frustration and stagnation in the attitude of the parents. Barriers in the accessibility areas like toilets, bathroom, pathways, staircase, living areas and communication system precipitate the learning of the child with disability and barrier free accessibility will improve the efficacy of the child and attitude of the parents. Involving the child with disability in all social activity will enhance the socialization and improves their cognitive abilities in many life concepts.

h) Appraising the Performance

Performance of the child must be appraised periodically and keeping the records of the child's educational and other therapeutic interventions is so important for an effective management of the child's curricular and co curricular design. A parent alone can monitor every nook and corner of the progress of their child and notify the professionals about positives and negatives then and there.

i) Advocating their Rights

The rights of the child with disability should be protected and shouldn't be denied as because of their disability. The citizen's charter of the governments and constitutional provisions ensure the equal opportunities for the people with disabilities but most of the parents unaware about their child's rights and prevailing constitutional obligations. Educating and updating the parents in rights perspectives is so important for enabling the child to lead an independent life. The parents must be proactive in knowing their child's rights and raise their voice for their voiceless children.

j) Altruistically Motivated

A parent must act altruistically on behalf of disabled community. Their work shouldn't be based on their own child but it should be altruistically motivated one for the benefit of other disabled children too. I have seen some parents who actively involving with the professionals and learning many techniques but failed to use it for other students who have similar needs like their child. Their learning shouldn't be confined to their own use but it has widely to be used for others too.

Education of the People with Disabilities

Education is the process of facilitating learning, or acquisition of knowledge, skills, values, beliefs and habits. Normally education takes place in formal and informal settings whereas the former has systematic planning, training strategies and structured evaluation and the latter develops in day to day life happenings and situations. In the case of children with high support needs both formal and informal education are deployed to bring out the maximum output from them. Children learn from the moment they are born as they begin to absorb information and make sense of their world. As well as providing the basics for growth and development: food, comfort and security, parents also provide stimulation through everyday activities, games, rhymes and language that help a child to learn. Many of these activities are part of everyday life preparing and eating meals together, doing the washing, shopping, watching TV, visiting friends, and family but for young children they are opportunities for discovery and learning.

This emphasizes the importance of parents and the home environment in supporting children’s learning and development. Mostly this happens naturally as part of family life. Parents want the best for their children and do what they can to achieve this. However, once children start school it is not always easy to know how best to help your child. As children grow older it is easy to forget the strong influence that the home and the community still have on their learning and education.

Parent Partnership in Education

Education is a process of developing an individual into a responsible, purposeful, innovative, creative and useful being. It aims at developing the innate potentials of an individual to the optimal level which makes him useful to him and the society where he finds himself. It is also regarded as a means of transmitting knowledge and culture from one generation to the other.

Special education, or special needs education, is the practice of educating students with special needs in a way that addresses their individual differences and needs. Special education is the individually planned and systematically monitored arrangement of teaching procedures, adapted equipment and materials, accessible settings, and other interventions designed to help learners with special needs achieve a higher level of personal self-sufficiency and success in school and community.

Children with disabilities may have co morbidity conditions like difficulty in seeing, hearing, communicating, moving, learning and tactual sensations. Learning of academics is a herculean task for the persons with intellectual and developmental disabilities. Many parents getting confused about their learning pace of academics with that of their peers and feel boring while they train the academic skill trainings as they are not showing interest and progress. Further they lack techniques to improve their efficacy and train the basic concepts in academic learning. To learn simple calculation one must be familiar with the pre mathematic concepts like more & less, values of numbers and place values.

A parent has to have clear idea about their child’s present condition and learning capabilities which is presented in varying degree for each and every individual. Further they must learn to teach them technically, skillfully, friendly and effectively, not dictating their children and over protective them during nurturing or training.

Parent Partnership Habitual Learning & Training

Repeating something many times creates habits. Habitual learning plays a vital role in education and training of children with developmental disabilities. The children with intellectual and developmental disabilities are educated and trained few skills repeatedly as they have poor cognition and adaptive deficits. It has been starting at very early stage of life and the parents are to play a crucial role model to habituate good habits in their offspring. For example, if the parent folds the beddings after wake up, then this habit will transmit to their kids and they will learn to do it by habitual learning.

Infants begin to make sense of their environment the moment they are born, and can detect patterns as early as two months old. By 4 months old, the child will be able to recall objects and events that are not present and by 1 year old he will be able to imitate even novel actions more than a week after he has observed them. Household routines like arranging bed, maintaining personal belongings like brush, washing plates after meals and keeping cloth rakes with neat & clean are acquired through habitual training. In Indian context, male children are not permitted to perform these household activities at the same time the girl children are forced to do such activities for the whole family. This gender disparity among the children will create different kind of negative social attitude about their responsibility. Hence the parents should give equal opportunity to their kids irrespective of their gender and motivate them to do the work as much as they can.

This is a critical role of parents in child development. Give the child some household chores or ask them to help in your business work from a very young age, so they value what they have and have a sense of ownership. There are parent types who are over authoritative by always giving instructions and rules to the kids or overprotective always trying to please their child.

Teach them to do it right. You can’t expect your kid to be perfect on their first attempt, but that doesn’t mean they can’t try, and for heaven’s sake don’t undermine their effort by redoing it for them. Praise their effort, then show them what they missed and teach them how to fix it themselves.

Parent Partnership in Community Involvement

One of the important aims of education is to prepare a person for effective community living. Therefore, it is of the greatest importance that the community should be involved in the education of the people with disabilities in their neighbourhood and known to their circle. This will ensure the community for better acceptance and understand the potentials of these special needs kids which will be fostering the education, social well being and suitable employment. Many parents complained that the society is giving all possible harassments directly or indirectly.

Accessing the community resources are important component for effective community living for the families who are having child with special needs as human beings are interdependent in nature. If a family needs an expert support for their ward can access with local service providers or find with the help of neighbours references. Orienting and sensitizing the neighbours is very much important tactics for effective community participation in the education and support process of people with disabilities. The families of such children should not segregate themselves from the community and must be approachable to its members by volunteering to its activities. Prolonged isolation can have adverse effects on the social life of the family having child with disability and will severely affect the community participation and learning. Building rapport with the neighbours, relatives, friends, co-workers and religious groups & social groups will enable the families to create a strong bound for developments. A small gathering shall be arranged and invite peers from neighbours during their birthdays and sensitize them for social acceptance. Having realized the actual need of the child with disability, community in turn will join hands in the development and education of their child. The parents can moot social awareness groups to organize disability. Therefore, parent has to play a crucial role in building the positive relationship in the community in spite of having some limitations.

Parent Partnership in Activities of Daily Living Skills

One must be independent in his/her personal skills like brushing, toileting, dressing, bathing, eating and grooming at one stage or before attaining adolescence. Activities of Daily Living skills are essential activities that we perform in our daily lives. Most children with disabilities have difficulties performing self-care. The nature of the disability, the child's strengths, environment, and family support all contribute to the child's level of independence. ADL skills training should start early in life.

Participation in everyday life has a very significant influence on our health and well-being. It is important that we help develop ADL skills in children and encourage them to be independent, thus decreasing their dependence on caregivers. The children with intellectual and developmental disabilities show gross delay in achieving personal skills. These skills are basic construct for any human being for leading independent life and maintain their personal appearance neat and clean. If an individual is weak in personal skill will be a great burden for their parents and family and will reflect when they go out of their home. These skills ought to be taught at home situation by their parents only as early as possible. Late acquisition and not attainment of these personal skills will be a great stagnation in the progress of the children. More over these skills will not be trained by others especially opposite genders due to gender difference and age inappropriateness. For example, if a 16 years old boy has difficulty to wash after toileting will be a greater embarrassment for a women caretaker or special educator and vice versa and at the same time, even a mother cannot take him to public toilet as well. As long as the child with disability is dependent in ADL skills, tend to be rejected for outdoor activities and possibilities of social seclusion as well. Hence, the parents must give priority to train their child's personal skills at home situation as early as possible which will reduce the burden of the family and s/he can lead an independent life even after the life of parents.

Parent Partnership in Sexual Education

The persons with intellectual and developmental disabilities show varied range of sexual behaviors which creates lot of embarrassment to the family members in public places. People generally think that persons with intellectual and developmental disabilities do not have sexual impulses (asexual) like normal people and some think that they are over active in sexuality. But in reality, they too have same sexual feeling as like normal people but they differ in their expressions. The Parents often associate sexual development with the teen years but kids develop an emotional and physical foundation for sexuality in many subtle ways from infancy. Lack of knowledge about sexuality of their children will lead to exploitations and abuses.

Parents must educate them to be aware of about their sexuality and beware of unusual touching of private parts by others. Many a times these children are abused by known people only who may be relatives, neighbors or peers of the school. Parent must be vigilant always and train them to be cautious on this exploitation. Most of the children with special needs are attracted for eatables and other social benefits which are yielding reason for such sexual exploitation. Pornography is another threat to the children community as they could be exploited by known people easily. So parents must spend time with their child and enquire if anyone is supplying such edible items for their children frequently. Both boys and girls are vulnerable for such exploitations and might exposed to. Personal hygiene should be educated for both sex children especially their genitals should be neat and clean always which should be inspected by the parent then and there to rule out the abuses.

Parent Partnership in Vocational Training & Job Placement

The ultimate aim of special education is to make them independent and enabling for getting suitable job placement. Unlike olden days, varied types of vocational trainings are going on and lot of job opportunities are created by many agencies for people with disabilities in open employment settings for jobs like office oriented works, manufacturing units, factories, packing units and small entrepreneurship. In early days, traditional vocational trainings like chalk piece, candle, wire basket, phenyl making were more prominent whereas sustainability and profitability is highly compromised. Parents tend to think that job placement for the persons with high support needs are not practical one as because of the severity of disability and associated conditions of their children. But systematic and continuous training will foster the job opportunity of people with high support needs and possible to be employed in a sheltered workshop or self employment settings.

Fundamental things to be followed by the parents for making them employable and ways of successful employment

- Ensure that the child is independent in daily living skills: If a person wants to be employed, he/she must be independent in personal skills like toileting, dressing and eating. For example, If a person has an issue of uncontrolled toileting problem, the employer and co workers will get embarrassed. Independency in toileting skill is most important one than any other personal skills for work place.

- Make the child to communicate his/her needs, desires, issues to others as and when required – If a child with disability wants to be employed, s/he must convey his needs and matter either verbally or gestural. Reporting ability should be developed for any employment settings. So the parent must educate them to report after completion of work which should be started at home itself.

- Enable them to travel from one place to another by themselves.(Mobility skills) : The child must be allowed to travel independently from home to school after attaining adolescence stage and encouraged to move to the nearest places on their own. During travelling time, we can provide a basic mobile phone to communicate to the parent and teacher which will ensure their safety and safe reaching of their destination.

- Educate them to acquire basic concepts, fundamental mathematic and reading & writing skills for successful placements: Understanding basic concepts like color, shape, texture, fundamental mathematic skills like more& less, basic counting up to 10 numbers, big & small and reading skills like letter and sight word identification like toilet, drinking water, danger, entry and exit are essential for performing basic operations of the work place and comprehend the situation.

- Give priority to manage their behavioral issues: Behavioral problems in the person with disabilities will be a greater hindrance for successful employment and it should be managed and modified appropriately. The parent should be proactive and disclose all the facts about the behavior issues presented in the person to the employer which will ensure the continuity of job and assures the mutual trust.

- Train them to be self advocate for resolving issues arising then and there: Human life is facing various challenges every day which is also common for the people with disabilities. The parent should educate them to fight for their rights and advocacy skills to be imparted from childhood. This will ease the risk of abuses and exploitations.

- Educate them to handle simple financial transactions and keeping the money as safe as possible: Unfortunately the persons with intellectual and developmental disabilities found difficulty in transaction of money. The parent must give orientation on money savings and though they don’t even understand the value of their remuneration.

- Develop rapport with employer and co employees: Parent must have good rapport with employer and co employees for a successful and sustainable employment. Punctuality and integrity should be maintained by the special employee and communication protocol should be maintained properly. Normally employers will respect and accredit the prompt and sincere employees as they deserves for it. Now a day, corporate companies are adopting the mandated government legal provision of 4 % reservation in jobs for the disabled. This legal provision will be useful to get job opportunity for them in private sectors and the only ongoing concern is sustainment.

- Retention in the Job: Many of them could be able to get jobs in good companies but failed to retain their job due to some minor errors and inefficiencies. This is a great threat and uncertainty for a parent which leads to lot of confusion in transition planning. Regular follow up and "On Job Training" will solve this issue and smoothen the process.

Parent Partnership in Co-curricular Activities Training

Co-curricular activities are defined as the activities that enable to supplement and complement the curricular or main syllabi activities. These are a very important part and parcel of educational institutions to develop the students' personality as well as to strengthen classroom learning. Co-curricular Activities have a wide horizon to cater to the cultural, social, aesthetic development of the child. Some of the co curricular activities are sports, musical activities, art & craft works, dance and etc.,

Co-curricular activities **help students with disabilities to develop problem-solving, reasoning, critical thinking, creative thinking, communication, and collaborative abilities. Participation in** co-curricular activities will **help students in emotional development, social skill development, and overall personality development.** This is why the importance of co-curricular activities is immense.

The persons with intellectual and developmental disabilities have cognitive impairments which resulting in to poor academic performance and remarkable delays in many functional skills. The curriculum for them requires a greater emphasis on co curricular activities as it fosters more developments and in fact it strengthens their academics too. These co curricular activities especially sports activities will keep the disabled person active, goal oriented and cooperative with others. It brings lot of spontaneous changes in their physical, mental, behavioral, social and emotional skills provided regular trainings. Parents should allow their children to take part in co curricular activities regularly to get maximum benefit.

Benefits of Involving the Child in Cocurricular Activities Regularly

- We can see many positive changes in the child as s/he gets rewarded with the activity whereas achievement motivation is developed. This will enrich their self learning ability and moving forward to further skill development.

- The child will be self disciplined as s/he interestingly participated in the activity and learns the code of conducts, rules and regulations and general ethics.
- Spontaneous movements in the sports and physical activities will enable them to acquire more physical stamina, concentration, emotional stability which will be useful for improving their performance in day to day activities.
- It helps to reduce their behavioral problems and eradicate their sexual deviant behaviors.
- It enhances their innate abilities and showcases their talents to the community. For example, if the child with intellectual disability receives medals in special Olympics games will be of great honour for himself and for the family in the society.
- The parents can visualize the developments and can easily monitor their progresses periodically and review the activity as and when required.

Difficulties Experienced by the Parents

We can now look at the difficulties that can arise when parents teach disabled people with intellectual and developmental disabilities.

- In our society in general parents who have children with intellectual disabilities and other developmental disabilities are not able to handle these children properly due to lack of knowledge of their children.
- Those who had children with disabilities were unable to put into practice the things they had learned when they were taught how to handle them.
- There are a variety of misconceptions in the minds of parents of children with disabilities, so these parents found difficulties to teach these children the right way.
- Because a child with a disability has more than one additional disability, Parents of such children have more problems dealing with these children.
- The parents experience greater tribulation in handling these children both in nuclear and joint family types.
- Widows and separated families found very difficult to manage their disabled children as they suffer with finance, social exclusion and non availability of resources at their locality.

Some Important Barriers to Parental Involvement

a) Time

Most of the parents are busy in their works and bread winners of the family, who may either working full time or part time bringing up their children on their own.

- Have more than one child attending different schools.
- Have a baby or other caring responsibilities
- Work shifts or work away from home
- Have a complex family structure with parents who are separated; some might have new partners.

b) Location

The area parents live in can be a significant factor in how parents are able to be involved with school based activities. This includes:

- Parents and pupils may have to travel some distance to the school and may have difficulty with transport or have to walk through unsafe areas
- Where children are being educated some distance from their home and live in a hostel.

c) Lack of confidence

Parents may feel uncomfortable in school surroundings for a number of reasons:

- It may bring back unpleasant memories of their own school days
- Some may feel that their own lack of knowledge or skills puts them at a disadvantage
- Some parents may have difficulty themselves with reading or writing
- Parents may feel that there is no place for them in the school or that the school is not welcoming
- Some fathers may feel out of place and that they don't have a role because many activities held during the day are mainly attended by mother.

Many parents feel that membership of a formal parent body is 'not for them'. They may perceive them to be 'closed' or 'formal', or not see themselves as the right kind of person to be involved. These perceptions can be a real barrier to parents putting themselves forward. Every parent wants the best for their child but may have difficulty in participating in some activities. This does not mean that they are not interested or not doing what they can to support their child's learning but they may find it difficult to be involved in the school. The key is to ensure that as many opportunities as possible are available to the parents.

Effectiveness of Parent Partnership in Education of Children with Disabilities

One can easily visualize the effects of parent partnership in the education of children with special needs. As long as a parent having good partnership with their child's education and training pedagogy, the progress will be steady and noticeable. The special educators and the professionals are really struggling to bring out the parents in to the training mission. Each parent must understand a truth that every child is unique and their needs are vary from person to person and we cannot have uniform progress pattern in each child as happens in the regular school student's academic performance. The parents ought to accept the reality that they are varied level of disabled child and find out the suitable strategic planning and determine appropriate resources and supports as well as specific information-sharing practices that facilitate their learning. A parent will know about their child better than anyone else does. When a parent have a strong and respectful relationship with their child's school and teachers, will be a great boon for them to get optimum information that they need to help their child get the most out of his education.

In many cases, the more comfortable parents are talking to teachers, the more likely they are to devote time to volunteer for training their kids and participating in other school activities. Parent volunteers can be essential in the continuation of after-school activities and academic improvement. Teachers are the first line of communication between parents and the school, so it falls to communicate often, ask for help and engage parents as an active part of the learning process. There are parents who do not enquire anything about their child with special educators and completely shouldering the responsibility on educators and blindly following the advice of the educators. Some parents who do not even care about what's going on in the education of their disabled kids and showing disinterest in matters of their disabled child. In some cases, single parent only will take initiatives where as the other one not even hears their demands and not considers the basic needs of their child. Progress and results will be highly getting impacted as due to these three types of parents. The more they participate the more they experience and less participation and non-cooperation will severely affect the developments of the child.

Learning at home

Children learn from the moment they are born as they begin to absorb information and make sense of their world. As well as providing the basics for growth and development: food, comfort and security, parents also provide stimulation through everyday activities, games, rhymes and language that help a child to learn. Many of these activities are part of everyday life, preparing and eating meals together, doing the washing, shopping, watching television, visiting friends and family but for young children they are opportunities for discovery and learning.

This emphasizes the importance of parents and the home environment in supporting children's learning and development. Mostly this happens naturally as part of family life. Parents want the best for their children and do what they can to achieve this. However, once children start school it is not always easy to know how best to help your child. Schools can do a lot to make the links between what is being taught in school and learning opportunities that exist at home and in the community.

- Parents get lots of encouragement from the school to take part in their children's learning and there is evidence that they do take part
- Schools and teachers keep parents informed of what their children will be learning in school so that they can discuss this with their children at home
- Parents and staff tackle areas of difficulty and concern together
- Schools provide specific fun activities for children and parents to do at home
- Parents support their children's learning by helping with homework and making links with other areas of school work
- Parents spend one-to-one time with their children and also enjoy shared family activities/visits
- Parents and children know that everyone's contribution is valued
- Children receive additional support from the individual attention they get from their parents
- The ways of communicating with parents reflect the diversity of parents and their needs

Teachers discuss with parents and children the activities they undertake at home so that these can be incorporated into their learning in school. There are open channels of communication so that parents feel comfortable talking to teachers and making them aware of how children's learning is being supported at home.

Summary

Parents are vital partners in education and training of the children with disabilities. The importance and needs of parental partnership is highlighted in this unit. They can take active part in their child's learning process and influence & monitor day to day activities at home. They can link the child with professionals and schools for effective and successful learning. To be a successful partner in the training process, a parent of a child with disability needs to be accommodative in nature and optimistic in all their approaches.

Parent partnership can be build in education, community involvement, habitual training, daily living skill training, sexual education, rehabilitation, co curricular activities, vocational training and job placement skills.

The more parents involved in their children's education, the better their entire class's motivation, behavior, and academic achievements. The effectiveness of parent partnership in education and training of children with disabilities and various difficulties faced by the parents are illustrated in this unit. To sum up, a parent can be an effective partner in education and rehabilitation of child with high support needs if he/she applies the learnt strategies as and when required.

Check Your Progress

1) What do you mean by parent partnership in education of child with disability?
2) What is the background of educating the persons with disabilities?
3) Elaborate the importance of parent partnership.
4) Elucidate the ways of developing community support for the people with disability?
5) What are the challenges faced by the parents while partnering?
6) Explain the domains of partnership mentioned in this unit?
7) Who can train the ADL skills?
8) Do you think that the habitual learning will be of helpful to the intellectual and developmental disabled people?
9) Is it possible to give sexual education by the parents?
10) Does co curricular activities really helping to develop much strength in the intellectual and developmental disabled people?
11) Elucidate the ways of successful job placement & retention.
12) Explain in detail about successful parent partnership.

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CHAPTER -3

CATERING TO THE NEEDS OF PARENTS DURING EARLY CHILDHOOD

- *Dhanavendan K.K*

Objectives

1. Explain about the nature and characteristics of children with high support needs
2. Describe the various types of children with special needs
3. Define special needs and early childhood special education
4. Describe the process of early childhood special education process
5. Explain the various needs of children with high support needs during early childhood
6. Describe the impact of disability in early childhood and role of parents

Needs of Children in Early Childhood

Early childhood development is crucial period for a child to develop sensory, motor, social emotional, language and cognition. The early year's development is the foundation for child healthy development. It motivates the child to learn to do and identify the different and variety of sensory functions, tactile, visual and taste, feel, ect. The early childhood care and education focus the totality of the inputs with respect to health, nutrition, stimulation and preschool education, love and nurturance that must be provided top all children to ensure their optimal development.

Young children with disabilities needs lots of input to develop their sense of security from parents, bonding, encouragement when they do or attempt to do new things. Parents of children with special needs supported with lots of management techniques on training, and guidance to support the child overall development. By providing appropriate stimulation to the child he/she will achieve the developmental milestones even near to normal. Identifying early and providing support in early will increase the child brain development.

The period of early childhood also referred to preschool age because at this age the child is learning skills that will help her to do tasks associated with schooling. The concepts that are learnt develop from actually seeing things and doing various activities. The preschooler can speak in sentences and ask questions about things and peoples. They learns about numbers, colours, shapes and the reasons for everyday events. They learn to make friends and value his/her relationships with people.

Children ability to imagine a major spurt during this period. This can be seen in their play. They enjoy playing games that require them to pretend and make believe. Preschooler play together only for short durations and then they begin to play independently through they may be with each other. But a child with disabilities in preschool age is different from a typically growing child. They unable to play with their peers, difficulty in focusing, maintaining attention, understanding the concept of sharing, making friends, playing together, and difficulty in understanding pretend and make believe play.

Most of the disabilities cannot be cured, it is also true that timely and appropriate intervention can help a child with disability to learn several skills. The earlier intervention is started, the better are the chances of increasing the child's functioning. Providing relevant education, health, nutrition inputs to the child achieve his overall physical development and its support the child overall wellbeing. The early childhood special education often focuses on children learning through play, based on the research philosophy of Jean Piaget. Preschool education emphasize learning around the age of 3-6 years. The early childhood special education depends on parents only, they are the integral part of early childhood special education.

Early childhood special education provide on a one-one basis. The special education teacher work with one child at a time and follow another child. Early childhood special education focuses the overall development of the child with disabilities. Early childhood special education provided in the special education classroom by the trained special education teacher. There are set of specially designed teaching and learning materials to be used to train and teach the children.

Children with special needs shows difficulty in learning concepts, understanding or carrying out a task. Children with special needs to learn a concept or a skills as a whole in one or two attempt, so that they need extra care and support. The teaching may need to be repeated and practiced over a period of time.

Developmental Disabilities and Delay

The diagnosis of developmental delay varies from profession to profession. Delay is said to exist when a child is performing like a typically developing child of a much younger age. A 5- year old with the social skills of a 3 ½ year old may be described as having a delay in social development. The 3 year old who toddles about like a 15 month old is likely to be taught of as having a delay in motor development. Some children have delay in two or three areas.

At-risk

Many infants and young children are said to be at-risk or at high-risk. This means there is reason to believe serious problems are likely to develop. Infants that are born with low birth weight are likely to be considered at high-risk; they are in grave developmental danger.

Screening

Children could be conducted before birth, immediately after birth or at a later stage when a disability or delay is suspected. Children with disabilities detected after birth. Based on the developmental assessment of child protective response, and the basic survival reflexes whether are normal or any deviation for further observation. The neonatal assessment can identify the child high risk. The child with cerebral palsy may be identified at birth if the child has any stiffness of muscles in the body or limps. The child after three months we can see lots of development takes place.

Developmental Milestones

1. Social smile -2 months
2. Neck control-3 months
3. Recognize mother -4 months
4. Rolling over by-6 months
5. Sitting with support 7-8 months
6. Creeping – 6-7 months
7. Crawling 9-10 months
8. Standing -10-12 months
9. Walking 12 months

If the child fail to achieve any of the normal milestones or delay in the milestones he /she will be suspected having some disability or deviant. The screening need to be done on the basic of child developmental milestones of physical motor skills, cognitive skills, social and emotional skills, activities of daily living skills, communication skills, play and leisure time activities, participation of the child in his environment, how the child is interacting with other children, sharing, asking help, express his/her needs by the team of professionals.

- Screening done on taking the history of child
- Screening/ observation of the child milestones
- Detailed assessment on child strength and weakness in relation to his overall development

Special Education

Special education defined as specially designed instruction that meets the unique needs of the child with disability. It includes special methods of teaching, special teaching- learning materials, use of assistive devices and specially designed physical environments- classroom or playrooms for children.

Special Education can be Understand as:

- In special education every child has right to receive education.
- It is an individually based system of education, where education is provided keeping in mind the child's needs and abilities.
- Learning is broken down into series of simpler and smaller steps. Repetition, practice and reinforcement are important aspects of teaching.
- Learning environment is specifically designed that it promotes learning. The learning environment includes the learning experiences provided by the teacher; the learning materials and the physical arrangements of the room.

Early childhood special education programme focus the early stimulation of early intervention activities in the classroom settings. Since early childhood areas concern about all areas of development.

- Developing physical and motor skills

- Using all the senses
- Developing language and communication skills
- Developing thinking, reasoning, and problem solving skills
- Learning to interact with people
- Carrying out activities for personal care

Developmental Domains

There are five different developmental domains of children which all related to each other. They can be referred to as the SPICE of life:

Social

Refers mostly to the ability to form attachments, play with others, cooperates, share, and create lasting relationships.

Physical

Development of fine motor (small) and gross motor (large) skills.

Intellectual

Learning to make sense of the physical world

Creative

Development of self-awareness, self-confidence, and the ability to cope with and understand feelings.

Communication

It is referred to one's ability to understand others and make oneself understood. It is most important as far as our ability to understand concepts and form relationships with people is concerned.

Vision

Primarily, one's ability to move around, and reading, and writing. In other words, vision is important for learning in the home and in the classroom.

Hearing

The sensory system equally important for optimal growth and development. If a child cannot hear, it becomes very difficult for him/her to learn to speak. It is also possible that she/he may never learn to speak at all.

Importance of Early Childhood intervention

Research in the field of early childhood development has established that the first six years of life are crucial for development in all areas. The rate of learning and development is most rapid in this period for all children with or without disabilities. The lack of adequate care; nurturance and stimulation can delay or hinder development to a considerable extend. The early years of life are particularly crucial for children with disabilities who may be lagging behind in achieving the developmental milestones. If not appropriately utilized, precious time is lost by the time the child reaches school age.

During the first two years of life, there is a '**plasticity of the brain'**, different parts of our brain performs specific functions. Thus, if one part of the brain gets damaged, the function it performed would get affected. However, very early in life, the brain is still plastic and adaptable. In other words, if stimulated early, the brain cells next to the damaged cells learn to take up the responsibilities of the dead cells. When plasticity decreases, which happens as the child grows older, other parts of the brain, even if stimulated, are unable to take on the functions performed by the damaged part and their abilities may be lost forever. This is the major emphasis on the early intervention and in the early childhood age.

The process of Early Childhood Special Education

1. Screening and identification of children with disabilities

The first step in the early childhood special education process is screening the child. Screening is the first level of assessment and it is the process of collecting basic information regarding the child to decide whether there is any chance of the child having a disability. The screening process usually begins when a parent, family members notices a delay in the child development.

2. Diagnosis and functional assessment

The screening process indicates a developmental delay, and a perceived atypical development or disability in the child, there should be a detailed assessment is conducted to diagnose the child's condition and to identify the child's specific intervention needs. This is done through diagnostic and functional assessment. The functional assessment gives about the child's strength and difficulties and challenges faced by the child and the specific areas in which the child needs educational training and other interventions.

3. Development of programme plan

After a detailed assessment is done, the early childhood special education teacher call for team meeting to discuss the assessment result with the parents. The multidisciplinary team members and the parents plan to meet the child's needs during the early childhood special education age. This plan in the early childhood special education called **Individualized Family Support Plan (IFSP).** This is a plan of the actual inputs that will be provided to the child to foster her development in different areas. It is called an individualized plan/programme because the plan is specifically worked out for each child depending upon the needs of each child and their family.

Once the child starts going to special school or regular school this plan is called **Individualized Education Plan (IEP).** This plan made by the special educator in consultation with the family members. The IEP also has the role of other professionals to discuss and plan goals to train the child's individual needs. The individualized education plan carried out with one to one basis and in group teaching situation. One-to-one basis means that the special education teacher works with the single child. Group teaching means that the special education teacher works with a group of 3-4 children together.

IFSP includes the following information child's strength and needs identified on the basis of functional assessment of the child in different areas of development.

- Information about the family's strengths and resources in order to determine areas where the family needs support and guidance.
- The inputs, training and services that the child and the family will receive from the teachers.
- Where and how the child and family will be receiving the services, training and support.
- The main outcomes expected to be achieved for the child and the family after the implementation of the IFSP and IEP.
- The evaluation strategy and criteria which will tell the team members whether outcomes have been achieved.

4. **Providing individualized education to the child and training to the family**

This is refer to the actual training on educational stimulation, therapy, education inputs and training provided to the child and the family so as to foster the child's development in all areas.

5. **Evaluation and feedback**

Once the stimulation, therapy and education inputs begins to get provided, the teacher and the multidisciplinary team members need to evaluate at regular intervals whether the child responding to their inputs and whether their approach to intervention is appropriate. This is done by evaluating the child's progress and one's own training strategy. The feedback obtained through this will help in modifying the IFSP/ IEP and the provision of services.

Individual Family Support Plan (IFSP)

An IFSP is developed for the family as a whole to support the parents in fostering their child's development, keeping the unique strengths and needs of the child in mind. The IFSP plan is based on the child's strength and needs, family's strengths and needs, family's resources, the resources available to the family through the community and cultural needs. Thus, while an IFSP is developed to support a child with disability in the early childhood years, it achieve this by supporting the family members and guiding them to respond to the child.

An IFSP plan focuses on the child and the family together in a holistic manner.

The earliest growth and development of the child takes place within the family. The parents are the first people with whom the child will interact and they are in the best position to ensure the child's survival, growth, development and give the child a sense of emotional security through love and nurturance.

The IFSP for the early years of childhood is based on the premise that the family is the child's greatest resource and that the child's needs are closely linked to the needs of the family. The most effective way to support children and meet their needs is to support and build upon the strengths of their families.

The parents are also the child's first teachers. However, parents also need guidance about how best to respond to their child's different needs, what specific activities they should carry out and how they should carry them out.

Parents can foster the child's development only when they are in a state of emotional well-being, have been able to overcome the trauma of learning about their child's disability and when they feel supported by people around them. The IFSP takes into account the family members need for support and makes an attempt to respond to the family's needs so that the family feels supported and can respond to their child better.

Individualized Education Plan/ Programme (IEP)

Once the child starts to go to preschool- regular preschool that is inclusive or a special school- the plan is called an Individualized Education Plan. The child may start going to a preschool between 3-6 years of age. The IEP is primarily focused on the child's needs.

The family starts to spend more time to teach the child on preschool based activities. The child also learn to understand the community and environment for to get ready for formal school either in a regular school or a special school. The focus is now on teaching the child new skills in communication, interacting with group, pre-academic skills such as pre-reading, pre-writing and pre-number skills.

The family continue to support the child to acquire new skills within the family and the environment. If the child going to the special school he/she will be learning the concepts of pre academic skills, communication, socialization, motor skills, and learn to achieve activities of daily living skills as per age appropriate. The special education teacher helps the family through guidance and support to help her child at home.

Preschool Development

Cognitive development

According to Jean Piaget, there are four major stages of cognitive development:

Sensorimotor

This stage occurs between the ages of birth and two years of age. Intelligence is demonstrated through motor activity with limited use of symbols, including language; the infant's knowledge of the world is primarily based on physical interactions and experiences.

Preoperational

The second stage occurs between ages of 2-7 years. Intelligence is increasingly demonstrated through the use of symbols; memory and imagination are developed as language use matures. The typical thought process in non-logical, non-reversible, and egocentric.

Concrete Operations

This developmental state occurs between ages 7and 12 years. During this stage (characterized by conservation of number, length, liquid, mass, weight, area and volume are learned) intelligence is increasingly demonstrated through logical and systematic manipulation of symbols relating to concrete objects. Thinking becomes operational, reversible, and less egocentric.

Formal Operations

This final stage of cognitive development takes place from ages 12 and beyond. During this stage, intelligence demonstrated through the logical use of symbols related to abstract concepts. Thinking becomes abstract, hypothetical, and early on, egocentric.

Emotional development

Emotional development concerns the child's increasing awareness and control of their feelings and how they react to them in a given situation.

Social development

Social development concerns the child's identity, relationships with others, and understanding of their place within a social development.

Physical development

Children need daily opportunities to engage in gross motor and fine motor activities. They are growing fast and need to move and use their bodies throughout the day. Gross motor activities offer children opportunities to use large muscles through jumping, balancing and running. Fine motor activities are often referred to as manipulative or table-top activities. Included writing, drawing, painting, cutting, pegboards, puzzles, and blocks.

Aesthetic development

Experience in art and music should be available every day in preschool classrooms. Emphasis is on exploration, spontaneity, self-expression, and appreciation rather than on completing a specific product or learning a particular tune. Art and music activities should represent the cultutes of the children and staff in the classroom.

Right to Education (Children Free and Compulsory) Act 2009

The **Right of Children to Free and Compulsory Education Act** or **Right to Education Act** (**RTE**) is provides the education as mandate for children from 6-14 years.

As per article 21 section 3(2) of Right To Education Act elementary education of children with disabilities and support the severe and multiple disabilities can opt the education as per their needs whether general education or special education or home based education. All the children has right to select their educational options. The state shall provide appropriate preschool education age of three years to six years. As per article 45 every state shall provide early childhood education for all children before their age six.

Understanding Special Needs: Special Education Needs

The term special education needs is a short form of special education needs and is a way to refer to students with disabilities. The term special needs in the education setting comes into play whenever a child's education programme is officially altered from what would normally be provided o students through an Individualized Education Plan.

Understanding Special Education

Special education and special needs education is the education of students with special needs in a way that addresses the student's individual differences and needs. Ideally, the process involves the individually planned and systematically monitored arrangement of teaching procedures, adapted equipment and materials, accessible settings, and other interventions designed to help learners with special needs. They need to achieve a higher level of personal self-sufficiency and success in school and community than would be available if the student were only given access to a typical classroom education. Common special needs includes challenges with learning, communication, emotional and behavioural disorders, physical disabilities and developmental disorders.

Benefits of Early Childhood Special Education

Early childhood special education focus was ensured in the constitution of India 86th amendment in the article 45, state should ensure to provide appropriate education to below six years of age.

1. The early childhood special education as a right of all children with disabilities.
2. Takes stock of the progress of members states towards achieving the Education For All (EFA) goal 1.
3. It ensures all the children with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities where they live.
4. There should be reasonable accommodation of individual requirement is provided.

5. Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.
6. It facilitating learning of Braille, alternative script, augmentative alternative modes, means and formats of communication, orientation and mobility skills and facilitating peer support mentoring.
7. It promotes the learning of Sign Language.
8. Education of blind, deaf and deaf blind children in appropriate language, modes and means of communication and in environments that maximize academic and social development
9. It ensures teachers who are qualified in sign language and/ or Braille and teaching children with disabilities.
10. It encourages the general education teachers and special education professionals get training in disability awareness, use of appropriate alternative and augmentative modes, means and formats of education, education techniques and materials to support persons with disabilities.
11. Ensuring barrier free environment, accessibility in technology, including accessible classroom to encourage learning the child as par with general education child.

Classification of Developmental Disabilities

As per the Rights of Persons with Disabilities Act (2016) there are twenty one disabilities identified among the types there are neurodevelopmental disabilities listed like, children with visual disabilities, low vision, hearing disabilities, speech and hearing disabilities, intellectual disabilities, autism spectrum disorder, cerebral palsy, locomotor disabilities, muscular disabilities, specific learning disabilities, multiple disabilities, and deaf blindness. These children with disabilities needs are very unique and each have individual specific needs.

Multiple Disabilities

Multiple disabilities is a condition when two or more disabilities occur at the same time in the child. A child having more than one disability is called multiple disabilities. Multiple disabilities affects the children, physical, sensory, cognitive, communication, and social interpersonal performances. A number of children have more than one disabilities. It has been estimated that 20-50 percent of children with serious hearing deficits have additional problems. The same is true of children with cerebral palsy.

Intellectual Impairment

It refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more following applicable adaptive skills areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and home work.

Cerebral Palsy

Cerebral palsy is a non-progressive brain damage occurs in the child before, during, and after birth. The result of the insult affects the child coordinated movements, maintain posture and balance. The child also face difficulty in learning to do his activities of daily living, participate effective social, express emotional, communication and cognitive skills.

Autism Spectrum Disorder

It is a neurodevelopmental disorder characterized by impairment in social interaction, social communication and restricted pattern of interest and repetitive behaviour. Its affects information processing in the brain by altering how nerve cells and their synapses connect and organized; how this occurs in not well understood.

Specific Learning Disabilities

Difficulty in reading, writing, and doing arithmetic's. Children having trouble in reading, which accounts for the majority of children with learning disabilities is referred to as dyslexia. Dysgraphia is the term sometimes used to describe problems in printing and writing the spelling. Dyscalculia is the term used to describe the child difficulty in doing mathematic calculation and solving arithmetic problems. Some may have problem in motor planning is called apraxia.

Speech Impaired

The impairment of speech articulation, voice, fluency, or the impairment language comprehension and oral expression or the impairments of the use of a spoken or other symbol system. Might be a characterized by an interruption in the flow or rhythm of speech, such as stuttering, which is called dysfluency. Speech and language problems account for the second largest category of educational disabilities. Speech and language problems often accompany other developmental disorders. Children with cerebral palsy may have serious speech problems as may children with hearing impairments and severe emotional disturbances. Problems in this area can lead to serious disruptions in cognitive and social development.

Hearing Disabilities

Deafness is a hearing loss so severe that individuals cannot process spoken language, even with hearing aids or other forms of amplification. Hard of hearing refers to a loss that has a negative effect on a child's education, but not to the same degree as it does on children who are deaf.

Locomotor Disabilities

It is defined as a person ability to execute distinctive activities associated with moving both himself and objects, from place to place and such inability resulting from affliction of musculoskeletal and /or nervous system.

Neurological Disability

A neurological disorder is a disorder of the body’s nervous system. Structural, biochemical or electrical abnormalities in the brain, spinal cord, or in the nerves leading to or from them, can result in symptoms such as paralysis, muscle weakness, poor coordination, and loss of sensation, seizures, confusion, pain and altered level of consciousness.

Behavioural and Emotional Disorder

Behavioural and emotional is a broad category which is used commonly in educational settings, to group a range of more specific perceived difficulties of children and adolescents. Attention deficit hyperactivity disorder, depression, bipolar disorder, and eating disorder. These terms refer to patterns of behaviour that depart significantly from the expectations of others.

Visual Impairment

Is vision loss of a person to such a degree as to qualify as an additional support need through a significant limitation of visual capability resulting conditions that cannot be corrected by conventional means, such as refractive correction, medication, or surgery. Visual acuity of less than 20/60.

Deaf-Blindness

Dual sensory impairment, it affects the child whole perspective and image. The child with dual sensory impairment learns through tactile mode, and compromise with other senses. The child considered as multiple disabilities.

The Child - Needs

Needs are essential part of all living on the earth. Human beings have needs but certain needs tend to be more important in childhood. Children are highly dependent on parents and others (siblings, guardians, teachers, and friends) for fulfillment of their needs. If their needs are met adequately, they continue to develop as balanced individuals and can be assets to the family, the society and the country. If a child born with disability it is going to be different and difficult to manage by their parents.

Children with special needs broadly be categorized under following heads:

Physiological Needs

Human beings have basic needs for air, food, water, light, physical activity, rest and sleep which are particularly important in childhood. If children have sufficient fresh air, a balanced diet, access to clear water, adequate light, activity, rest and sleep, their growth and development will be smooth. Unfortunately if the child born with disability the needs are so complicated to support and the parents struggle to provide and fulfil the needs appropriately. However, a normal child or a special child the physiological needs are same but the children with special needs are need our constant support and help to achieve their full development.

Emotional Needs

The need for love is one of the most basic needs of any human being. A child who is not loved feels dejected and unhappy. The parents and teachers must bestow their love and affection on children. Moreover, children need security and conflicts in the home make children insecure. Special needs children due to their disability in understanding the emotions and expressing their own emotions makes difficulty in satisfying one's own feelings, sharing enjoyment, love, bonding and so on. There is close relationship between the physical and emotional factors. An imbalance or disturbance in the child's physical growth is will most likely be reflected in his/her intellectual functioning and personality adjustment. Children with special needs emotional climate is likely to affect the physical health of the child and it may hinder his/ her normal physical growth.

Psychological Needs

A.H. Maslow (1954) gives the following list of psychological needs:

- To experience a sense of union with other people (to belong)
- To be secure
- To enjoy a feeling of independence
- To be adventurous and to have new experience
- To know, to construct and to create
- To experience a sense of personal growth

Social Needs

One of the important social needs in children is to have a feeling of belongingness, i.e., the feeling of belonging to someone, a group of people or a place. In the earlier stage of life, children need to belong to a family. While they grow up, they need to belong to groups. Acceptance by their peer group is very important. If they feel they are being left out, they may indulge in anti- social activities. Children with special needs fail to achieve socialization due to their mobility, visual, auditory, and intellectual skills. Social skills mainly depends on child intelligence, how to behave with others, initiating and maintaining conversation, making friendships, and joining in group activities all skills are hindered due to their disability.

Intellectual Needs

The desire to learn and to know is very strong in children. They are by nature very curious and ask many questions ranging from the mundane to the bizarre. They need opportunities for self- expression and creativity. They feel very happy when they are free to speak. Children have a need to learn and to develop their abilities. School programme must satisfy the intellectual needs of the children. Children with special needs with specific learning problems require more special attention. Children with special needs to be provided supplementary remedial instructions and help. The educational programme must be adapted to the needs of the children and their needs.

Literacy Development Needs

As per the recent development of national education policy it is strongly projects and mandate of every child from the age of three years to six years, learn education in a joyful way, fun filled environment, and they use the knowledge to find out truth, analyze critically, solve the problem effectively. They should be provided strong literacy and numeracy foundation for future development. They can have option to use technology due to their slow pace. Functional literacy, functional reading, functional writing, learning the concept through practical and experiential learning. Children with disabilities also has equal rights and importance learn together with their normal peers, learn to read, write as per the growing needs of global perspectives. SSA, become Samagra Shiksa, and the sustainable Developmental Goal 4 also strongly emphasis the universalization of elementary education. Every child has the right to literate to live independently.

Language and Literacy Development

Functional use of language and support of children's emerging literacy are essential during the preschool years. Functional communication skills enable children to control their environment by using speech or signs to get what they need and want. Literacy development is also an important goal. Though formalized instruction in reading and writing is not considered appropriate in preschool curricula, nevertheless, preschool classroom must provide a rich literacy environment with many experiences that help children learn to read. There must be opportunities for children to see books, hear and tell stories, engage in word games, play with sandpaper and magnetic letters, write and draw.

Physical and Motor Developmental Needs

Healthy mind lies only in a healthy body', is an old adage and is true to the core. The physical development of the child is very important for a number of reasons. Appropriate physical development gives an invaluable contribution to the all-round development of an individual. When a child is busy in some physical activity, he is emotionally as well as mentally involved in it. Physical development of the individual is important both for the individual and social development. It is also important for ethical, moral and spiritual development. If a child with physical or multiple disability unable to perform the physical activity alone, and he/ she depends on their parents or professionals. When the appropriate training and physical activities in the form of motor skills and fine motor activities provided on daily basis and need based, it help them to acquire the overall wellbeing and independent in their life.

Adaptive Behaviour Needs

Adaptive behaviour refers to the abilities or skills needed by people in order to cope in their everyday lives and to adapt with one's environment. Personal needs or self-care skills like, eating, toileting, bathing, brushing, dressing and grooming. Children with high support needs depends their caregivers. Due to the physical, cognitive and motor impairment they unable to achieve these skills. Personal needs of children with early childhood with high support needs will be measured through observation and specialized assessment tools on activities of daily living skills. The ability to indicate and regulates self will be assessed and if any functional dependencies or disabilities found and it will be managed through IEPs (Individual Educational Programme) therapies. Activities of daily living skills enhances children eye-hand coordination, handling objects effectively, holding, transferring, bilateral coordination, bi-hand coordination, dexterity, manipulating utensils, and improves feeding and dressing skills. The early learning of self-help skills improve their academic skills also.

Language Development Needs

Speech is the only a form, or medium, of communication in human beings, though the most important one. Other forms of communication are facial expression and other bodily movements that show different emotions, touch, sign, written symbols of words and art such as music, dance and painting. Language permits the communication of information from one generation to other. It passes wisdom to future generations. It performs the following main functions:

- Language helps to communicate ideas to others
- Language helps in the formation of concepts
- Language helps in the analysis of complexities
- Language helps us to focus attention on ideas which would otherwise be difficult to keep in mind.

There are two kinds of competence in language must be identified. One is linguistic and other one is communication. Linguistic competence involves the increase of one's vocabulary and improvement of the ability to construct proper sentences by using the rules of grammar. The communication competence is developed through specialized training through speaking, group discussion, play and competition.

Communication Development Needs

Communication is a dynamic process of both sensory and motor act to demand and get something from a person or from the community. If one was unable to communicate appropriately to the opposite person he /she may fail to achieve his needs. In Early years children with high support needs face more challenges in communication both verbal and nonverbally. Communication always depends on the person who tries for express his/her needs. In children with severe or high support needs the challenges are modalities, sensory, motor involvement, and cognitive skills. These skills are affected due to the insult in the brain. Communication ability may assessed by speech pathologist and hearing ability may assessed by audiologist. Children with early childhood special education level need earlier screening and therapy to improve the quality of life through therapy and other supports.

Health Needs

As per the national education policy every child should be provided appropriate health and nutrition in the early childhood age to grade 12. It is imparting the nutritional importance and the developing mind. Children with special needs also need energy and strength for them to cooperate for sitting in the classroom for learning academic activities, other related activities like therapy needs. The children with cerebral palsy may have associated condition like seizure disorder, child with autism spectrum have additional health needs like antipsychotic medicine for them to reduce the stereotypic behaviour, child with severe multiple disabilities needs dental needs, oral care, skin care due to their immobility, daily nursing care etc,. many children with severe multiple disabilities in the early childhood level mostly non-verbal they unable to express their needs, for food, bowel, bladder care, oral and sleeping. They must be provided appropriate health and nutritional care for them to improve their quality of life.

Information Needs

Families is the most important decision making agency of their child life. The parents and the family members always need information on their child diagnosis, prognosis, assistive devices, technology, possible correction in any of the deformities found in the child limps or body, furniture's, education and other wellbeing of the child. Information on high support needs always measured with need analysis and need questionnaire on handling the child, providing appropriate services, taking social help and placement options. Every age of the child family members need the guidance and counselling support for transition from preschool level to schooling.

Medical Needs

Medical needs may be evaluated whether the child has any medical health issues like, eye problems, hearing issues, cardio related septal defect, seizures or any malfunctioning related to general health issues and any specific issues to be measured by the medical doctor or pediatrician. Medical health issues may starts from oral hygiene, respiratory, cardio-thoracic problems, and dental related issues like gingivitis, tooth carries, tooth alignment problems, swallowing difficulties, nasal deformities, cleft lip and hard and soft cleft palate and swallowing issues in early childhood special education.

Love and Nurturance

Love and nurture are essential and central to the development of the child. It lays the foundation for learning social and emotional development. When the mother takes care of and responds to the child affectionately, mutual attachment develops. This attachment forms the basis of all later relationships. When the child appropriate behaviour was rewarded he/she feels it is easy to relate to others. Every new relationship that the child experiences influence s his/ her attitude towardsself and others.

Early Childhood Special Education Intervention

Early childhood special education provided to the child based on the needs. The special teacher plan for the child special education activities based on the functional ability and age. The teacher assess the child and plan the special educational plan based on the IEP. The activities to enhances the child overall development areas like activities of daily living skills, socio- emotional skills, cognitive skills, physical and motor skills, communication skills, concepts like colour, geometrical shape, size, measurements, pre writing skills, pre reading and pre mathematical skills, play and leisure time activities.

Goals are planned based on the team evaluation with the discussion of family members, the IFSP Individual Family Support Plan will be written and the plan implemented. Programmes of early childhood special education is an essential part of the child development. How early the child was identified and how early the intervention provided it is matter of success. The early childhood special education focus the overall development of the child as it was instructed in the early intervention programme. The teacher and the team of professionals working together for the success of the child developmental milestones.

Early childhood special education intervention consists of multidisciplinary team services provided to children from 3-6 years of age to promote child health and wellbeing, enhance developmental milestones, minimize developmental delays, provide remedial teaching, improve functional literacy and numeracy skills, reduce structural disabilities, prevent secondary functional deformities, promote children adaptive functional skills, and overall family sustainable development through holistic approach. The intervention focus to reduce the family crisis related to the child with developmental disabilities.

Impact of Disability in Early Childhood

A child with a disability will be able to do some things just as well as other children do. The child with disability will do their activities very slow compare to other children. Children with disabilities may not able to understand their problems due to their poor or fair cognitive abilities. They will slow in learning to achieve one or more concept in the life of the child. Any disability, whether acquired later or present from birth, is bound to have a deep impact on the child’s life. The child certainly feels different from others. Disability may make the child face hardship.

The child with disability depends on the care giver or the primary care provider for his/ her most of the needs. Due to the mobility he/she may depends parents for most of the activities of daily living skills. The disability make the child to challenge him/her for socialization, play and recreational skills. Most his activities boundaries will be his/her home environment only.

The disability directly impact the family as well. The grandparents feels that their next generation will be there in the community, parents feels all the children are good except my child and they may think that this is fate because of my karma, children with disabilities peers feels that his brother/ sister become immobile or non-verbal he would not talk to me and its shame for me he is disabled.

The child's disability directly and indirectly affects the family relationship, positive mental state, social wellbeing. Parents neglect the child with disability into the scenario, some parents may redicule or embarrass the child or convey to her that he is no good. Some may feel guilty, thinking themselves to be the cause of the child's disability. This may lead them to overprotect the child and they may not let her do anything by himself. Some parents may have a sense of shame.

Disability is not a pity, disability is not the primary one, the child is first, and his disability or impairment is next. Children with disability shows better skills achievement if we do encourage, identify early and intervene early they do wonders. Disability is present in the one part of the brain only, due to the insult the whole body is not responding, otherwise they are understanding, they also have love, feelings, aware about different senses, respond appropriately with our communication.

Children with disabilities face difficulty in making friends and relating to people due to lack of communication, difficulty to play actively with other children due to their motor milestones, children have emotional difficulties low confidence, showing inappropriate behaviours, lack of motivation to share their enjoyment within the family or others.

Parent-Teacher Relations

Parents teachers must work together to provide consistency for young children. Teachers need to establish regular communication with all parents. This allows teachers and parents to discuss the child's behaviour on a regular basis, so that if a problem occurs, teachers and parents already have a relationship established that will facilitate their addressing the problem in an efficient and productive manner.

Kanna Unique Needs

Kanna attends the early childhood special education center. She seems to follow and understand all that is done in the class. She unable to speak, has squint eyes, uncontrolled movements, she falls both side of the chair frequently while sitting on the chair due to her cerebral palsy. She has difficulty in walking, loss balance while try to walk, has difficulty in learning the concepts of numbers, reading, storytelling, group play and games. We need to understand the unique needs of the child, meeting the needs, facilitating her education and ensuring that her optimal development is fostered. The parents and teacher and other care givers have to consciously and deliberately adapt the environment in such a way that the unique and different needs of the child. The child need to support to play, communicate, share her enjoyment, write, read, participate story, rhymes, make friends and learn concepts and skills speak and interact with others.

Role of Parents

Parents of children with special needs in the early age make them unhappy due to their child was diagnosed as disability. Parents shows lots of emotional experiences the birth of the child with disability in the family. The psychological emotions experienced like, shock, denial, anger, depression, vanity, disparity and acceptance. They may have different emotional state like shock, like disbelief, guilt and shame about the child with disability, they denial along with shock. Parents begins to believe and hope that if they do certain activities for the good of others. They show their anger due to coping with a child disability experience by the family. Feelings of guilt, bitterness, unhappiness and shock never completely leave the parents.

Parents motivated to understand the nature of the child disabilities. The teacher and the team must educate the parents to accept the truth of the child's disabilities. The impact of the child disability makes them experience loss of everything. Parents should be educated themselves on acquiring knowledge about the children with high support needs.

1. To learn about the normal physical development of the child, developmental milestones of all the domains like communication, social, adaptive, conceptual and play skills.
2. To learn about prevention of secondary disabilities related to children with cerebral palsy.
3. To learn to acquire handling techniques of home management of the child with high support multiple disabilities.
4. To learn to adapt the child on home based intervention and materials and adaptive devices.
5. To learn to transfer the skills to family members and siblings.
6. To educate self to search for services within the community like schools, balwadika schools, resource centers etc,.

Role of Professionals for Empowering Children with High Support Needs

1. Educate the parents on handling the child with high support with multiple disabilities
2. Explain the family about the various developmental needs
3. Support the family on mental health and hygiene
4. Teach them on handling the child health and nutrition needs
5. Educate them to promote positive attitude towards accepting the child disability and helping the child to achieve his needs.
6. Provide information related to possible technological, adaptive devices, supportive measures related to psychological, and physical, special educational, orthotic and prosthetic devices, and devices related to sensory impairments.
7. Guiding educational activities at home.
8. Arranging team meeting once in three months to review the progress of the child and change or modification of the programme.

Early childhood special education is most important and crucial period for development of the child. The needs are vary for child to child. Some child may have mild degree of problems and some may have severe needs. The early intervention and the early childhood special education professionals must assess the child needs and plan appropriately for the child holistic development.

Summary

High support needs with multiple disabilities needs are wider and professionals support needed each development period of the child.Special educational needs for the child overall development should be addressed. There are different needs are concern with the child with high support multiple disabilities like physical, physiological, cognitive, motor, communication, socialization, play and leisure, health and nutrition, and love and care. Special education programme is a specially designed step by step instruction to address the need of the children with special needs. Screening is a process of assessing the child different strength and weakness for to plan appropriate intervention strategies. Parents are the primary role care provider, they need to be educated appropriately to care their children to bring out better changes in their life. Children with disabilities categorized as per the RPWD act, children with locomotor disabilities, multiple disabilities, cerebral palsy, visual impairment, hearing impairment, intellectual disabilities, autism spectrum disorder, and deaf-blindness.

Check Your progress

Fill in the blanks

1. Early Childhood special education focus the ____________________________.
2. Screening is done at ____________________________________.
3. Special education is a _________________________instruction.
4. During the first two years of life, there is a __________________ brain found.
5. Expand RTE act
6. Define multiple disabilities
7. Define high support needs

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CHAPTER -4

CATERING TO NEEDS OF PARENTS DURING SCHOOLING

- *Arpita Yadhav*

Objectives

1. Understand the high support needs and their challenges in education
2. Understand the importance of physical accessibility for education
3. Understand the importance of medical support and aids and appliances support to complete the education
4. Understand the importance of communication.
5. Understand the importance of support of peer and siblings.
6. Understand the importance of collaboration of school and parents and teachers.
7. Understand the importance of appropriate and timely assessments.
8. Understand the challenges of parents.

Introduction

When a child took birth, parents weave lot of dreams around the child and make future plans. But when a child with disability that too with high support needs took birth, it shatters many of them due to lack of support systems available. They need services right from early intervention to school education to vocational training to medical support to employment…

Early intervention sets the base for the growth if the parent gets it at right time. After early intervention parents looks for the education of their child – that is where they faced the maximum challenge. Parents need appropriate services for the needs of their child under one roof. They also want a holistic approach and clear roadmap for their child, to actualise the child's maximum potential.

The major hurdle is to choose the right set up for their child and to get him admitted in that. In special schools' admission is bit easy but in mainstream or inclusive setups they face rejections after rejections. What they want a smooth process and universal system to address the needs of their child, which they find it difficult to get.

When they get the admission, they need an environment where the child gets to have his peer group and gets included and that is another challenge for them as parents. Many of the times parents take the child out from the mainstream and put him in special setups due to various negative experiences in the mainstream setup.

This is also important to understand that socio-economic background does play its role in the admission and choice of schools and getting the child any type of education. There are segments where the education is not otherwise important, and takes a back seat for the child with disability or it may be the condition of child which came with so many co morbid conditions and makes it more challenging for the child to be able to go to school. Sometimes search for medical cure takes so much time and energy of parents that crucial years got wasted of the child.

Let's first understand what the high support needs are-

The High Support Needs Considered to be -

When a student need:

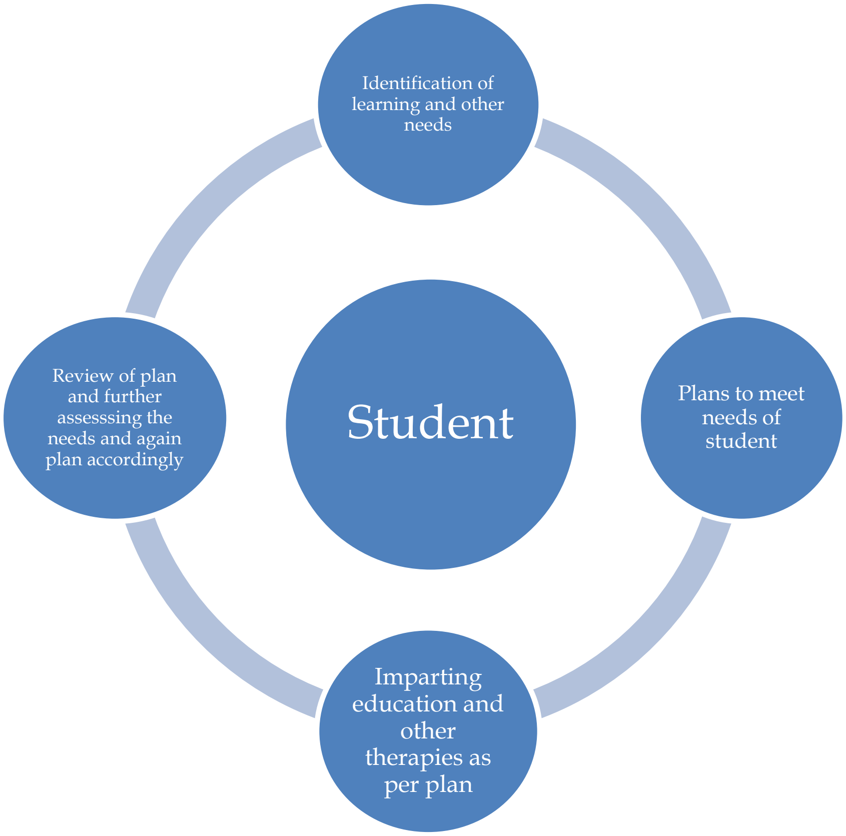
1. Adopted teaching and learning program to meet his needs.
2. A classroom where he can communicate with other people directly.
3. Help by the expert on a regular interval- it can be weekly or monthly depending on needs.
4. Curriculum adaptations as per the need.
5. Daily support for mobility/ personal care or for language and social communication.
6. Have one or more comorbid conditions.

Few examples to understand whom we consider as high support needs:

1. A student with cognitive delay development, at the age of 12 he may be performing at the age of five. He still is learning bye –bye, hello as a toddler of 5 years.
2. A nonverbal student relies on sign language or gestures to communicate.
3. He/ she may need other person to communicate for him/her.
4. Student may need specific writing tool/or arrangement for writing work – like braille, computer, or a person as writer.
5. A student with physical disability – which affects him/her in his/her day to day work like-eating, speaking, swallowing, sitting, dressing bathing etc.
6. Different and difficult communication and social behaviour, difficulty in social interaction, communication and imagination. Repetition of words, sentence, actions and behaviours.
7. Self-harming or aggressive behaviour towards others and towards surrounding environment.

Assessments

Assessment is most crucial to define the road map of the student and his growth keeping his specific needs in view. Parents need the help of specialised people to get the correct and appropriate assessment for their child. It helps them also to have a clear road map for the future for the child and as well as it leads to early acceptance and realistic expectations from the child itself.



Areas to be assessed in early childhood – Student or child need to be assessed on all development milestones. Where and how much he is lacking? He needs to be assessed on his medical and other therapeutic needs.

Assessment helps parents, educators and families to understand about child's development, growth and behaviour.

Assessment helps to access to

1. A proper understanding of the student in all developmental areas like: cognitive, physical, speech and language, social-emotional, and their learning styles.
2. Identify the various needs of children like- extra time, curriculum adaptation, and a break on a short interval etc.
3. Educators to create an appropriate education plan as per their specific needs and provide specific support accordingly.
4. Derive a path for the student to achieve his/her goals and needs with the required support and interventions.
5. Parents get a realistic view and it helps them to accept the reality, it also brings both parents and educators at the same page about the child.

Let's Understand the Various Needs of High Support Needs Students are:

What is need – let's be clear about it

A need can be something for a person to live a healthy life, but for student with high support needs have variety of needs which include physical, biological, social, cognitive, sensory, psychological, educational, medical, and societal and many more. Let's understand each need for children with high support needs.

Physical and Physiological Needs

These needs include some of the essential needs for the survival like food, water and shelter. Some needs are specific to motor part of our physiological and physical needs- like movement, posture, mobility etc.

What Physical needs mean for High support needs?

Students with high support needs may have physical challenges as well. These challenges can be related to motor movement, postures, communication, basic day to day living activities which includes-eating, bathing, dressing, toileting. Some students may have challenges in hearing and vision and they find it difficult to receive the information by hearing and sight while some may hear or see but can't process the information, they receive. Thus, the physical needs are more than just physiological needs.

Picture source; http://www.granton-knives.co.uk/special_needs.html

How it impacts

The students encounter various barriers in their learning processes. It can be in the form of physical barrier i.e. infrastructure of school building/ classroom. It can be a barrier in mobility due to inaccessible building or roads or transport. Also, can be other barriers like not having appropriate curriculum and therapy and medical services. These challenges hinder the learning and can cause difficulties with reading and writing and other areas of development. They also impact the social and emotional well-being of the students with high support needs. This leads to exclusion of students and their families as well. Parents needs appropriate service for their child if they don't get access to such service it will lose their hope and can trigger further negative impact on student and parents both.

The support required

They need support/accommodation or adaptation for the fulfilment of their physiological needs as well as physical needs. These supports are accessible school building/ classroom/ transport facility, availability of teaching aids and appliances, availability of human help for ADL and other physiological needs, availability of appropriate trained professionals for education/ therapy/ medical needs.

Without the above said support it is difficult to have sustainable growth in learning of children with high support needs. Parents feel overwhelmed if they are asked to do everything on their own. Schools have big responsibility but they lack in providing all the support.

Socio Economic Needs

A Socio economic need does not mean only the income but also the educational achievement and financial security. It is also a subjective perception of society about social status and social class. It also encompasses the opportunities and privileges afforded to families and children with disabilities within that society.

How it impacts

Socio economic needs impacts the life of students with high support needs and it is vice e versa as well, high support student in a family may change the equation and creates the varied degree of socio-economic need.

Understand with an example

A baby with severe disability took birth in a middle-class family – the impact can be – the major time of the family members will go in to taking care of the child, it also can lead to leaving job for one of the parents for the very same reason. The friends and family begins to cut thread whereas new friends from the disability sector joining in.

If we see the impact – income generation is less, expenditure is high, social status is changed, choice of school and education for the child is changed, social meetings are less due to various visits to experts of disability for the child. The circle of friends and family member changed. Future goals changed; financial security becomes major concern. Dynamics of family may get affected- it can lead to separation and divorce of parents. Dynamics in society changed, family and child can be subject to exclusion at various levels.

Other example - is when a child with severe disability took birth in lower socio-economic status.

Impacts can be- very less or no intervention or low-quality intervention. At early age family still runs around try to do the needful in the hope of getting cure, but as child reaches to education level it took back seat,they may need to choose between the food and education. For their abled one's and they choose food and education, but for the high support need child they may only consider food as the necessity.They lose hope due to not getting any immediate results, expectations from the child die down .It further triggers the financial burden and more social exclusion. Family disputes and abuse can arise.

Picture showing the community and school engagement in the develoment and growth of the student with high support needs

https://www.shutterstock.com/image-vector/social-inclusion-handicapped-people-illustration-young-1381646417

Support Required

Support needed at various levels

- **At Hospital** --When the diagnosis happens – immediate counselling is required for the parents and other extended family. It can help them to understand the situation better and lead to early acceptance of the child.
- **At Rehabilitation Service--**After diagnosis and immediate counselling, they need to be linked with early intervention services and if there is financial crisis then they also need to be linked with various government schemes to get some support.
- **At School**--For the education of student with high support needs,the inclusive school/ special school should be equipped for all the essential services for the child. Specialised individualised education plan for the student to be developed and executed.
- **At Home**- an enriching positive environment for the better learning is very much needed for the child.
- **At Society**- Regular interaction of child with high support needs with family and friends from neighbourhood community. It leads to inclusion of the children.

Communication Needs

Everyone communicates for basic reasons- to make their needs and wants known to others, to express pleasure and displeasure, and to make choices about their surroundings and activities. They communicate to socialise with other people. Communicate to learn- to ask and answer questions, to process and understand the information, and also to demonstrate the knowledge. Communication is absolutely essential for successful school participation, but students with severe disabilities or high support needs often struggle with even basic communication skills. Student with high support needs with restricted communication abilities are expected to use body movements, squeals and cries, expressions, behaviors and conventional communicative forms e.g., gestures, symbols to communicate for a variety of communicative purposes.

How it Impacts

- **Learning –** For learning it's an utmost important ability to learn. The student with high support needs and with challenged communication face lots of barrier to learn and understand at same pace as their peer.
- **Socialisation –** School is a place to develop lifelong friendships, students with high support needs due to their restricted or different way of communication, often left behind and didn't get the opportunity to be part of the group of friends. It makes them feel isolated and excluded and leads to emotional issues.
- **Self-Worth –** Students with communication challenges often got labels like – they can't learn, they are dumb and many more. These labelling impacts badly on their self-worth. Though it's not true, they are smart and can learn but then they didn't get their communication partners to understand and share it with larger group.
- **Emotional Aspect-** Student with high support needs often find it difficult to express their emotions in real sense. Either they don't have the vocabulary or they don't have the mode of communication to express those emotions. That leads to lot of emotional challenges for them.Sometime it leads to behaviour challenges as well

***Images of Various type of communication devices**

https://www.speechandlanguagekids.com/teach-your-child-to-use-an-aac-device/

The Support Required

- **At School –** Students with high support needs with restricted communication abilities require an empathetic and supportive teacher. A student might use low tech supports such as pictures, mid- tech voice output device or high-tech computer communication systems. Whatever the student is using teacher needs to make sure it is available all the time. Student should be allowed to communicate when he wants. The program should be inclusive of parents, special educator, class teacher, speech and language therapist, siblings and friends/ peer/ buddy.

- **At Home—**Students with high support needs requires communication partner at school and home. Teacher or peer group can play a role of communication partner at school but at home the responsibility lies on parents and siblings. It is also important that communication should not be only need based but it should be broad and age appropriate. It is also important that they get enough exposure of the outside world other than the school and therapy services.
- **For Social well-being—**it is important that they get to connect with their immediate society. They need to visit their neighbourhood families, places, their family friends, and to communicate with them. They also need to get opportunity to visit home of their school friends, to be able to learn to communicate in an informal setting and to learn to communicate and behave at these places.
- **For Emotional well-being—**Emotions are important to be expressed but student with high support needs find it difficult due to their restricted communication abilities. At times they expressed their emotions through their behaviours and labelled as behaviour challenged students. It is the role of parents and teachers/therapists to teach them to express their emotions appropriately and how to communicate about their feelings, it's very important for the well-being of the student and their families.

Augmentative and alternative communication (AAC) is the use of devices or strategies that support or replace verbal communication. There are strong evidences for the use of AAC for students with high support needs

Few practices for teaching AAC to students with severe disabilities are-

- using natural way of teaching,
- use minimum prompts,
- Train peers and teachers to use the devices,
- try multiple modes of AAC, to decide the most effective
- teach single symbol for a variety of purposes, to reduce pressure on student.
- introduce the use of communication devices at child's early age for his better learning.

Cognitive Needs

Cognitive needs may vary for students with high support needs. We can divide them in to 3 categories.

1. For physical high support needs
2. For intellectual high support needs
3. For academic high support needs

Let's first understand what is cognition?

Cognition means thinking skills and thought processes that we acquired through our previous experiences. Cognitive abilities are important for learning at any age. Learning needs can vary across subjects and situations. Students with high support needs may learn at slower pace than their peers despite appropriate support and plans. Their learning challenges may be short term in one or more areas or severe and long term in other areas.

How it Impacts

The students with various high supports need have various cognitive needs. Students with only physical high support needs require various adaptation accommodations to learn. They need more and more stimulus for their brain along with assistive aids and accommodation. Due to their physical challenges their learning curve is not same as their peer group.

The students with severe intellectual challenges needs got impacted more. As they need support in learning in –basics- to ADL, to read,to write, to do simple calculations, to take decisions for their life.

Students with academic high support needs are the one who does not have any other major challenge but academics is painful and way beyond. Though that is true for the other disability also but for them it's also a pressure from the parents and teachers to perform. These students need lots of modification and support to perform and learn, and they can but many a times their needs overlooked and they got various negative labels. That leads to impact their overall well-being and self- esteem. They may develop as a non-compliant adult and rebel.

https://www.gettyimages.in/photos/disability?mediatype=photography&phrase=disability&sort=mostpopular

Due to the severity of disability of their child and low performance from various reasons. Parents worries about their education, future security and their life after the parents. All these worries make parents anxious about the child's abilities. School years are the toughest for them as around them other children from their family and friends are going to school and doing well.

The Support Required

- **At School-** Students with high cognitive needs require detailed procedural planning in an inclusive or special school. They need to have clear, direct and short instructions to learn. It is important that school should also give them enough time to practice and enough curriculum modification. While planning educators should stress teaching students the skills that will help them functioning as productively and independently as possible in inclusive environments. Importance of communication and social skills should be given emphasize. They should also be taught skills like self-management, goal setting and choice making.

How teachers can help students to do self learning-

- Teach self-monitoring techniques.
- Students can work out their projects in different colours.
- Encourage students to use any mode of communication
- Assign a peer tutor and allow them to support as and when needed, it can be reading aloud to writing texts for the student.
- Peer tutor also can re teach the concept to their buddy with high support needs.
- Model various meta cognitive strategies to help student to use his maximum potential.
- Maximize students' potential by using both visual and auditory stimuli in their teaching.
- Teach students to question.
- Provide students with a visual schedule of classroom.
- Provide multiple opportunities to practice.
- Use flashcards
- Teach the meaning of key vocabulary words.
- Introduce only one concept at a time and wait until student master it.
- Provide learning aids to help students focus.
- Provide recorded lessons.

At Home –Parents need to follow all the instructions given by the school to ensure learning and life skills. They also need to believe in the abilities of their child and keep motivating him. Parents should ensure to give exposure to their child to get enough experience. House hold chores are one of the important ways to regulate various sensory and behavioural needs of the students.

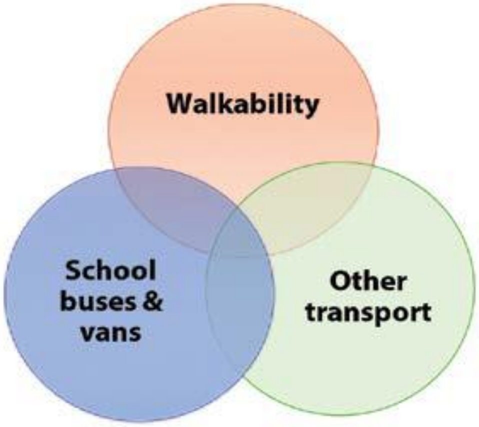
At Society – Parents should be in contact with their extended family and, friends and neighbourhood. It is important for the inclusion of their child in the larger society.

Transport Needs

It is universally known fact that most children with severe disabilities are not able to attend school due to inadequate transport facility. **Transport is missing link.** While **transportation** is "a problem," very less has been done to answer this problem. Provision of transportation is important for more children with disabilities to attend the schools to enable them to be productive and independent adults within an their society

How It Impacts

For many parents there is no way for their child with high support needs to get to school. For others, there is a very difficult choice between keeping their child at home, and send him through the unsafe roads or unsafe mode of transport, or to pay the high cost to use safe mode of transport.



What needs to consider

- **Medical Diagnosis and Health Needs:**
  Any medical equipment's or medicines or any chronic condition, which may need specific arrangements
- **Physical Needs:**

Any supported walking aids- a wheel chair or crutches or walker

- **Safety Needs:**
  Need constant supervision to use transport and during school hours.
- **Behavioural Needs:**

Need supervision for his behaviour issues, difficulty in using group transport facility.

What Is Required

To cater the needs of students with high support needs require following points to be covered-

1. **Wheel Chairs safety facility-**The busses used to transport physically disabled students in wheel chairs shall be equipped with proper securement devices.
2. **Medications Needs-**It is the responsibility of the parent to transport their child's medication to and from school.
3. **Special Seating Arrangements-**to make the student sit alone, in close proximity to the driver or with a peer buddy for any physical and otherwise support requirement
4. **Behaviour Interventions-** Trained staff to identify possible causes of behaviour and create an intervention plan during the transportation time.
5. **Special Reinforces-**For the student with high sensory or anxiety needs, to give a toy or activity to keep their attention during the ride, to help them in completing the journey with ease
6. **Adult supervision-**If needed parent/teacher/ assistant should ride the bus with the student
7. **Regular bus picks student up-** location to pick up and drop should be the same every day**.**
8. **Cost and distance-**The cost of transportation needs to be in consideration of all the aspect. Parents unable to pay transportation costs often have no choice but to keep their children out of school. **Walkability" is an obstacle for many parents of student with high support needs** the condition of roads and footpaths in both rural and urban areas often prevent student with high support needs, from travelling to and from school, even if it's on a walk able distance.
9. **Vehicle size-**In various schools small vehicles and autos are used for transportation, which are affordable but safety is always at risk with these vehicles
10. **Technology should be used-** Usage of technology can assist the parents to have a better coordination and check on safety of their child.

Medical and Therapy needs--

It has been observed and experienced that students with high support needs have many comorbid conditions and some are therapeutic and some are medical as well. As per the law, schools are responsible for providing students with high support needs all the physical therapy, occupational therapy, health services, and speech therapy. Which they need to benefit from their education.

How it Impacts

To cater those needs parents are always on the go. It is tiring for the child and financially and physically draining for the parent. It's been observed that depression/ anxiety/ sleep disorder is very common and higher in parents with special needs and it's more in parents of children with high support needs. Students with high support needs get stigma when they need to be pull out from regular classrooms for therapies and other intervention services.

The Support Required

There is a need of strong social security system for the high support needs. Medical facilities at a lower price and therapies to be part of education only, so those students get the therapies with in school. Parents support group at every school and out side school is very much helpful, that needs to be created.

Role of the Teacher

Teachers are responsible for developing and implementing the program in the classroom. This includes curriculum, classroom practice, providing a safe and orderly classroom environment, having IEPs and creating a participatory environment in a variety of other activities that support instruction. Teachers may need to consult and collaborate with special educators, therapists and including the parents, and may have to coordinate the work with one or more professionals.

Role of the Parents

- Acceptance of the child.
- Encourage to enhance feelings of self- esteem in the child.
- No comparison of the performance of their child with other siblings.
- All children have different and unique strengths and competencies, and this uniqueness must be identified and nurtured.
- Parents who convey hope provide a major force in helping children overcome adversity and become resilient.
- Parents can help children develop a sense of responsibility and contribution to their family.
- Parents can provide opportunities for their child to make choices and decisions, and promote self-discipline.
- Parents can help the children deal effectively with their challenges
- If possible, parents should attend training programmes for better understanding of medical and therapy needs of their child

Support for complex medical needs at school

Schools can get specialist training for teachers and education support staff to meet the child's health care needs. Training can take place every six months.

Procedures covered in training include:

1. tube feeding
2. tracheostomy care
3. suction
4. oxygen
5. stoma care.

All these are required to ensure the attendance of child with high medical needs.

Schooling/Inclusive schooling needs

Parents of high support needs and other special needs always want to have their child to be in regular inclusive school. The facility needed for any child with high support needs vary as per their area of challenges. If they can't get through the inclusive setup, they then run towards the special school setup.

Having high support needs can be one of the most marginalizing factors in a child's life. Inclusive education has proven effective in helping all students learn even while the challenge of implementing inclusive education system remains.

What is Inclusive Education and how it impacts

There are five main components of inclusive education

1) Placement of all students in natural typical settings-all students with high support is in age-appropriate general education classes, for most or all of the school day, for all academic and non-academic sessions, during classes and other school activities. Pull out happens only for specific reason for very specific therapy or medical needs.

2) All students learning together- All students with high support needs receive same instructions and learn together during the same academic and non-academic general education activities within their classes and throughout the school. Access to other classmates, and positive interactions between peers with and without disabilities, are maximized throughout educational activities and the school system.

3) Supports and modifications within classroom to meet appropriate outcomes- Supports and modifications, related to curriculum and instructions occur within general education classes to ensure effective learning environments for students with high support needs and learning outcomes are in accordance with IEP and / or general curriculum, or both.

4) Belongingness, acceptance, and being valued: All classmates with and without high support needs share a sense of belongingness in regular education environments and activities. Students with high support needs valued by both adults and students without disabilities throughout their educational environments.

5) Integrated services by education teams: Education teams plan, implement, and evaluate instruction in collaboration and integration with general education activities for each student.

Sibling participation needs

The birth of a child with a disability or the discovery that a child has a disability has a profound effect on any family. Siblings of that child suddenly need to adjust to a brother or sister who, because of their condition, may require more of a family time, attention, money, and psychological support. Yet it is an important concern to any family that how they both understand and adjust with each other. It is important because the non-disabled child's reactions to a sibling with a disability and vice-e-versa, can affect the overall adjustment and development of self-esteem in both children.

How it Impacts

Living with a brother or sister, with a disability, can be rewarding, confusing, instructive, and stressful. Children react towards a sibling with a disability with feelings of love, empathy, pride, guilt, anger, and support; these reactions have great impact on the levels of stress and coping ability of the sibling with a disability. The positive or negative nature of the relationships between siblings and among family members may be influenced by factors such as these:

- the financial and other resources
- their lifestyle
- the child-rearing practices
- the type and severity of the disability
- the number of children in the family
- the age gap between children in the family
- the other stress-factors that exist in the family
- the coping mechanisms and interaction within the family; and
- The kind and quality of the support services available in the community.

Non-disabled siblings may wonder what is wrong with them that their parents love their sister or brother with a disability more. Siblings may feel embarrassed or ashamed as they recognize differences between their sibling and someone else's brother or sister. They may also feel protective and supportive of their sibling.

The Support Required

Parents need to be very careful to develop a harmonious relationship of siblings. Siblings without disability need time, correct information and attention to understand their sibling with high support needs. The responsibility lies on parents. Parents should -

- Be open and honest and accept the disability.
- Do not make siblings a care giver for their disable sibling and use respite care and other supportive services.

- Spend quality time with the non-disabled sibling
- Let siblings settle their own differences and welcome other children and friends into the home.
- Praise all siblings and listen to siblings, teach them to interact.
- Recognize that they are the most important, most powerful teachers of their children.
- Involve all siblings in family events and decisions.
- Demand the child with high support needs to do as much for him or herself as possible.
- Recognize each child's unique qualities and family contribution.
- Recognize stress factors for siblings and strategize to minimize negative effects.
- Use professionals when needed to help siblings and join sibling-related organizations.
- Create opportunities for a normal family life and normal family activities.

Peer Needs

In inclusive classrooms, peer supports are a great way to help meet their classmates. Effective peer supports with teacher's guidance can benefit all students in classroom, with and without high support needs.

For students with high support, peer supports can impact

- Increase the interactions with classmates
- Help them develop new friendships and supportive relationships
- Expand their social networks
- Promote their sense of belonging
- Ensure more participation in class and school activities
- Improvement in their social competence and social skills
- Inspire higher expectations from teachers and peers
- Boost their use of communication systems
- Enhancement in their independence and self-determination
- Support in acquiring new academic skills
- Facilitate greater academic engagement and curricular access
- Support progress toward educational goals
- Less stigmatizing and intrusive sources of supports

What is required for effective Peer Support?

Peer modelling

- Peers do live demonstrations of required and targeted social skills.
- Peers modelled various familiar situations which students with high support needs are likely to encounter.
- Peers can easily tell the student with high support needs what they are doing and why.

Peer buddy systems

- Peers does many incidental teaching during non -structured, routine classroom activities
- Buddy systems can emphasize increasing and improving communication of a student with high support needs with outside world.
- Formal and structured buddy programs can focus on learning outcomes for students with high support needs during inclusive classes

Friendship groups

- Free time during lunch, recess, can be designed to bring together students with disabilities and their peers for socialization and fun.
- This arrangement works well when inclusion is minimal or if a student with high support is new to a school.
- It creates a good opportunity to build social relationships and provide informal support for students with high support needs.

Cooperative learning

- Students work in small, mixed-ability groups and enhance each other's learning.
- Co-operation, mutual support, and shared accomplishments are more important than competition
- All students' works as team and work together toward a shared goal; team is successful only when each member achieves the goal.

Peer tutoring

- Students with high support need get support by a classmate, a peer, or an older student, through one-to-one instruction on a particular topic, assignment, or skill.
- Peer tutoring programs can help students with high support needs to choose the role between tutor/tutee or can fix the role with mutual understanding.
- Especially effective in gradual learning in which there's one correct answer that the tutor is able to guide the tutee toward.

Aids and appliances need

For most people, technology makes things easier. For people with disabilities, technology makes things possible. Assistive services and technology can enable students with high support needs to get their place in society and contribute to their family and community. Assistive technology means products and other related services that enhance the functioning of people with disabilities. It can be a game changer for person's life. These aids and appliances and services include communication, mobility, self-care, household tasks, family relationships, education, engagement in play and recreation. Assistive technology can enhance the quality of life for both students with high support needs and their families.

The Barriers Student with high support needs face and how it Impacts

Student with high support needs face extreme challenges to avail the academic, social, and community participation. Very few students with high support needs complete the education beyond primary level than those without disabilities. Their future mostly will be as an uneducated and unemployed individual. Most of them live in poverty in adulthood than their peers without disabilities. Due to their high dependency and lack of accessibility and support one of the parent loss job and it's a loss of family income, because they become primary caregivers. In some cases, siblings have to play the role of caregivers, depriving them of the opportunity to go to school and participate in the community.

Without assistive technology and accessible environments, student with high support needs -

- May not be able to go from home to school,
- To see what is written on the blackboard,
- To hear and understand the teacher,
- To read the textbooks, to use toilet facilities,
- To participate in sports and recreation, and
- To interact with classmates.

Definition of Assistive Products

The International Organization for Standardization (ISO) defines assistive products more broadly as any product, especially produced or generally available, that is used by or for persons with disability: for participation; to protect, support, train, measure or substitute for body functions/structures and activities; or to prevent impairments, activity limitations or participation restrictions. This includes devices, equipment, instruments and software.

What is Assistive technology and device show it Impacts

Assistive technology is one of the important elements to support inclusion of student with high support needs in combination with other supports such as personal assistance, sign language interpreters and barrier removal. Meaningful access to assistive technology and accessible technology for student with high support need is critical for many to access and benefit from education. Assistive technology reduces pressure of care giving from the parents.

- Protective headgear can ensure the physical well-being of children with epilepsy and enable them to participate in activities important for social well-being.
- A pressure relief cushion in a wheelchair can protect a child with severe physical disabilities from pressure sores and associated fatal infections.
- Ramps and handle bars can help children to access education facilities, and a hearing aid can help a child with a hearing impairment to use education services.

- Parallel bars can help children with balance challenges to develop balance and strength.
- A communication board can support a child with speech difficulties to express her.
- A screen reader can make it possible for a child who cannot see to access information on the web.
- A splint can enable a child to join the family at a cultural event.
- An alternative way of showing time can help a child with an intellectual disability to meet with friends on time.
- Assistive technology can impact on self-image, self-esteem and sense of self-worth, as it can increases the chance of getting education for the student with high support needs.

Example of Products

Mobility -Walking stick, crutch, walking frame, manual and powered wheelchair, tricycle. Artificial leg or hand, leg or hand splint, clubfoot brace, white cane, GPS-based navigation device.
Sitting-Corner chair, supportive seat.
Standing - standing frame
Cooking-Adapted cutlery and cooking utensils,
ADL-dressing stick, shower seat, toilet seat, toilet frame, feeding robot
Vision-Eyeglasses, magnifier, magnifying software for computer,
Academic- Braille systems for reading and writing, screen reader for computer, talking book player, audio recorder and player, Braille chess, balls that emit sound
Hearing-Hearing Headphone, hearing aid Amplified telephone, hearing loop
Communication -Communication cards with texts, communication board with letters, symbols or pictures Electronic communication device with recorded or synthetic speech
Cognition- Task lists, picture schedule and calendar, picture- based instructions, timer, manual or automatic reminder, smart phone with adapted task lists, schedules, calendars and audio recorder Adapted toys and games.


https://www.thearcbaltimore.org/programs/assistive-technology/

https://epthinktank.eu/2015/06/22/assistive-technologies-to-support-people-with-disabilities/

Curriculum Adaptation needs

To get success in school education and to be part of the larger group of students with same age group students with high support needs requires many accommodation and adaptations. These are physical and curricular. Curriculum adaptation helps every student with mild to severe disability. Student with high support needs modification/ adaptation/ accommodation at various levels or at every level to achieve success in education. Just because a student has high support needs and require modifications to the curriculum do not mean that he may be removed from the class or school. Their success lies in having appropriate modifications, adaptations and accommodations in classroom activities and instructions. These are individualised and based upon their learning style, interests and needs

Let's first understand these terminologies

Modification means to make changes in the content to be taught to the student. For ex – giving an easier assignment in comparison with others in class.

Accommodation means to help student to work around his disability. For ex- if a student can't hold pen and write, but can paste his answers, if the letters or words has been given. The student is still expected to know the same material and answer the same questions the only difference is, that he doesn't have to write his answers.

Adaptation means modifying the difficulty level of content but having the goals in same line as other in the class.

Parents often gets the feedback from the school that child can't learn here because of their high needs or disability. On the contrary if the curriculum made flexible and gets all the components – modification/adaptation/accommodations, then majority of the students with high support get success.
Curricular modifications also need support from assistive aids and other physical modifications as well. Functional curriculum also needs to be taught alongside the main curriculum.

How it Impact

The experience a student with high support needs get in school years can be positive or negative. If the curriculum adaptations are made and practiced then it will give a positive experience to the child.

The Support Required

The following support required-

Quantity-Teacher needs to reduce the number of items student needs to learn or do this will reduce pressure to complete the syllabus. And add more practice activities.

Time- Teacher needs to give time to complete and understand the given task to the student, It will be helpful if the student have individualised time line.

Level of Support-Student should be given the personal assistance to complete the task. The assistance can be in the form of peer tutoring or support staff or teacher itself.

Input-While teaching students with high support needs teachers need to change their ways of instructions? One can use different visual aids. Or can be enlarged text, can be pictorial description, can be auditory lesson.

Difficulty- Teacher should ease the difficulty level of work as per the skills of student with high support needs. For ex use of calculator to do computation than to make them do the same with pen and paper.

Output-teacher should allow student to use their way of giving answers, for ex the student can use his communication device or book to answer or may answer through pointing or pasting the pictures.

Participation- To increase participation in class teacher should arrange various group learning opportunities, the student with high support needs may just hold the book and his group may read the passages from the book but that gives him an opportunity to lead and be part of the group.

Alternate Goals- Teachers needs to adapt the goals or outcome expectations. For ex if others in class are writing their answers, the student with high support needs can answer by pasting or colouring.

Functional Curriculum- provides different ways of instruction and materials to meet student's individual goals. When other class students do their history class, student with very high support may do the communication class at that period.

The usual challenges of parenting are ten folds for parents and primary caregivers of children with special needs. Among the many challenges few are as follows:

1. To learn about the disability
2. To research, locate and access effective treatments and resources
3. To cope with the emotional and physical demands of caring for child with high support
4. Running between medical providers, therapists, and school personnel for the various intervention services for the child.
5. To be an advocate for appropriate school interventions, accommodations, and/or placements
6. No health insurance for the treatments and interventions and paying hefty amounts for them.
7. Not able to avail all the services or quality services due to financial burden.
8. Broken family, single parents.

The needs are innumerable having a child with disability and if the child ahs high support needs, parents go through various emotions and various challenges to meet the needs and demands generated due to the condition of the child. The no of divorces is higher in families with disabilities. The stress is very high for parents. A recent study found that mothers of adolescents and adults with Autism and other with severe disability had levels of stress hormones comparable to soldiers in combat.
The emotional impact is enormous and may include--

Fear and worry about –

- Their child's pain and his future.
- The question, whether they are doing enough or
- Doing the right things to help their child.

Guilt over-

- To be able to protect the child.
- Not able to balance between other children, spouse and aging parents
- Their jealousy and resentment of those with "normal" children

Feelings of isolation because -

- Miss out on many family-oriented activities because child's needs not support him to participate successfully.
- Face criticism and judgment about their parenting from people around who don't understand their child's disability
- Feel like an alien around parents of neuro typical children.

Grief over

- The loss of hopes and dreams they had for the child
- Not having the parenting experience, they would imagine
- Recurrent reminders of what their child misses out on leading to chronic sorrow

Parents of children with special needs are often exhausted and become depressed more frequently. They have same reserves of time and resources for self-care, like anyone else with typical child but they are even more depleted than other parents with typical child. Though their need for refuelling to care for their child and for themselves is much higher. To be sustained through the marathon of caring for a child with special needs, it is essential that parents attend to their own needs. Often the most beneficial support and information parents receive are from other parents of children with special needs.

Role and responsibility of Parents

Parents play most important and crucial role in the education of their child especially in early years, because they have unique knowledge of their child's strengths and needs. Research tells us that children do better in school when their parents and families are involved in their education; this is especially important when a child has high support needs.

The role of parents may be divided into three main categories:

(1) To support for their child's education,
(2) To make their home a good place for learning, and
(3) To help with home plan

The responsibilities of Parents in their child's growth and education processes

Responsibilities of parents can vary depending on various factors such as the child's disabling conditions; following suggestions may be helpful to ensure that their child's rights are being protected:

- Parents need to be a partner with the school and share relevant information about their child's condition and their style of learning.
- They need to know any and every aspect of the program implementing in the school and therapy centres, to ensure the growth and development of their child.
- Parents need to discuss with their child's teacher how their child might be included in the regular school activities program including lunch, recess, art, music, and physical education.
- Parents need to monitor their child's progress. If child is not progressing, discuss this with the teacher and see whether the program should be modified.
- If any problems occur with the child's assessment, placement, or educational program, then parents need to discuss it with the school. If they are uncertain about how to resolve then take guidance from other parents and professionals and should advocate the rights of their child.
- There may be many questions and comments about their child that they will want to discuss, for the clarity and continuity they need to keep records.

- To have a positive attitude to ensure the better learning and growth of their child. That means to have a well-supported home environment.

- Parents need to join a parent organization. In addition to giving parents an opportunity to share knowledge and gain support, a parent group can be an effective force on behalf of their child.

How they can be better equipped

- Parents need to learn as much as possible about the disability of their child.
- They need to observe their child's learning style to discern how he learns best. As parents are the best in position to tell as they observe their child every single day.
- Parents need to keep careful records of their child's education, and medical testing and education reports.
- Parents need to correspondence with teachers and other professional in writing as much as possible.

All these will help them to be better equipped to be part of the child's growth.

Involvement of parents also benefit them immensely

- When they give more time and interact more with child, they have more sensitive approach for the emotional and intellectual needs of the child.
- They will have more confidence in their parenting abilities.
- Have a better understanding of IEP, teacher's role and the curriculum their child is following.
- They will have a better understanding of development stages and they will be able to use more positive reinforcement.
- They will have realistic but higher opinion about their child and they will feel more committed.
- They will also have better understanding of educator's and schools' role.
- They will be active in school policy making and can influence schools to ensure growth and safety of their child as well as others in similar situation.

Summary

Parents develop wishes, expectations, and dreams for their children, even before the child is born. At a minimum, parents wish for a healthy baby ("We don't care whether it's a boy or a girl, just as long as it's healthy" is the cliché that is repeated over and over), and they assume that it will be so. The discovery that the wished-for child has a disability can be seen as destroying the hopes and dreams held by the parents. Parents need to grieve the loss of these hopes and dreams. Then, they can begin to "dream new dreams". It's said that 'A village is needed to raise child'. That is all the more true for child with disability and even truer for child with high support needs.

Check Your Progress

1. What is high support need?
2. Write defining factors for High Support Needs.
3. Write importance of peer support in inclusive education of High Support needs.
4. Write role of communication and use of assistive technology to access the education for High Support Need students.
5. Why transport and physical barrier plays and important role in education of High Support Need students.

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CHAPTER-5

CATERING TO NEEDS OF PARENTS OF YOUNG ADULTS

- ***Jubin Varghese***

Objectives

- To know about the needs of parents of young adults with HSN
- To develop good mental health of parents on handling their young adults with HSN
- Transition to adulthood and sexuality
- Support system for parents of HSN with young adult

Introduction

Families with children or adults with disabilities provide continuous care for many years, sometimes even till the time of death of the caregiver. With every change in life stage, the needs of the person with disability and the family changes. Over such a long period of providing care, parents and other family members face challenges to their identities, their family's structure and functioning, changing structure of their support networks, their capacities to face daily stressors and their ability to lead fulfilling lives outside their role of caregiving[i]. These changes go hand in hand with the changing needs of the person with disability. Recognizing these life course experiences and challenges have implications in providing support to families.

Young adulthood, while without the striking changes and angst of adolescence, is an important period of maturation. Physical changes continue to occur. Social, emotional and cognitive maturation occurs through this phase which moves the young adults towards taking on adult like responsibilities and slowly leads to reduction of behavioral risks. Most of the young adults move onto graduate, post-graduation studies and their first jobs. They deepen friendships and explore relationships that they may maintain for life. Persons with disabilities and their families identify various needs for a person going through young adulthood.

Physical needs

Physical needs can range from impairments acquired early in life like cerebral palsy to those acquired later in life like spinal cord injuries. The kind of care provided to help with the physical needs will vary depending on whether their abilities decrease or increase over time and whether the family has devices that help with independence. For example, whether families have hoists that help with transferring a young adult with quadriplegia from the bed to the wheelchair etc. Even if families manage to get assistive devices, these may need to be changed as the child's physical structure changes. This further adds to the financial burden of the family.

Complexity of care increases if the young person with disability has profound impairments. Care often revolves around the daily activities of eating, drinking, intimate personal care and getting dressed and undressed. What was simplistic in providing this care for a child with disability changes as the child grows and the degree of their need changes. The time required to provide this care becomes more as the child grows. Research shows that on average, 60% of parents with children and adults with profound disabilities spent more than ten hours per day on essential physical care.

During the period of transition from childhood to young adulthood, following are some of the health management skills that are required:

Health management	Self-care	Mobility
Nutrition	Feeding	Indoor
Exercise	Washing	Thresholds
Joint maintenance	Bath/shower	Outdoors
Skin care	Toilet	On foot
Medication	Sexual health	Transport public and private
Disease and disability management	Menstruation	
Use of health service resources		

Table 1: Health management skills needed by people with disabilities in transition. Chamberlain, M. A., Kent, R. M. (2005).

One of the mothers of a Community Based Rehabilitation (CBR) program in rural Dehradun, has 4 sons with profound disabilities. Their ages range from early twenties to late twenties. The father is a truck driver and so the mother is the only caregiver for all four of them. The mother’s day begins with helping each one of the sons in toileting, cooking breakfast, feeding them one by one, followed by bathing them one by one. By the time she is finished with these tasks, she cooks lunch and then feeds them one by one. This is followed by helping with toileting again and then tea for each of them. She then starts on dinner and feeds each of her sons, followed by helping each one with his toileting. And then getting them ready for bed. And the next day, the cycle starts again. Providing this level of care all the time can overwhelm the caregiver and is not really sustainable as the caregiver grows older.

It is not just the range and intensity of the needs that makes it difficult but also the fact that access to health care is hard for those with disabilities, especially for those with developmental disabilities. Individuals with intellectual disabilities are four times more likely to die of preventable causes than the general population[ii]. Although they experience a number of health problems through their life[iii], they are still less likely to access general health care as compared to general population and other vulnerable groups.

The barriers mentioned by the caregivers in accessing health care for their children have been grouped along 3 categories: financial, structural and cognitive. This approach is based on the Health Care Access Barrier model (Carrillo, et al., 2011). The HCAB model looks at three major barriers that have a causal relationship with poor health outcomes. The three categories of health care access barriers are financial which includes the cost of treatment, structural which includes physical barriers and cognitive barriers which include inadequate information, prejudices, communication distance etc. These barriers often reinforce each other, thus, leading to adverse health outcomes

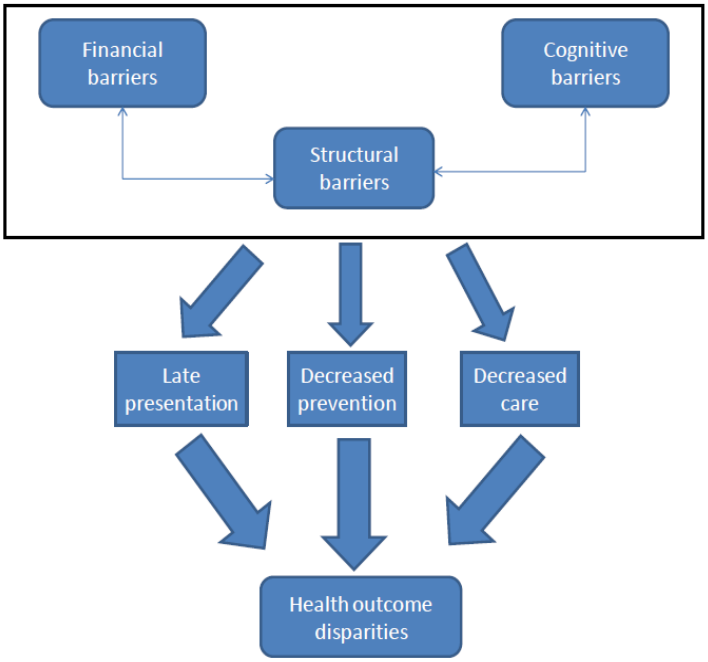


Figure 1: Health Care Access Barriers (HCAB) model suggested by Carrillo, et al., 2011[iv]

A plan for the young adult with disability and the family is required that considers the physical needs of the person and this involves collecting information about the following areas as a team:

- Present physical ability of the person
- Are the abilities likely to increase or decrease with time?
- Which family members provide this care? Is the person safe while being cared for by them?
- Is it possible to identify other members who might help with aspects of care to reduce the burden on the primary caregiver?
- Is there someone safe who may be trained in caregiving so as to take on the responsibility from aging parents?
- Does the family have resources to be able to access health care for the person with disability?

- Does the family have resources for modifications and devices that will aid in increasing independence for the person with disability?
- Does the family have a plan for finances that will be required in the future for the care of the person with disability?
- Is it possible to tap into community resources to pay for the services provided?
- Is there information available on other services in the area that could be tapped to help the family?
- **Social needs**
- This is the stage in life when consolidation of identity happens though achievement of independence, establishment of adult relationships and finding a vocation.
- For any of these to be achieved, the young person requires opportunity to explore, make mistakes and take decisions. Lack of opportunities for young persons with disabilities to develop these necessary milestones often comes from the lack of value placed on their life. They are not seen as people who can contribute and therefore are not in need of these life experiences.
- Research shows that the more we know people with disabilities, especially those with developmental disabilities, the better we can identify their desires, aspirations, values and pleasures and the more we recognise that their aspirations are no different from those of their peers. The tragedy, however, is that hardly anyone ever spends that kind of time with the young adult with disability. For many people with disabilities, social exclusion that they face was includes having no one to listen to them, having no friends, being made to feel like a burden, feeling unsafe and bullied etc.
- Young people with disabilities who attend special schools or live in rural areas experience isolation, having no friends where they live. Even if they are in mainstream schools, they are often unable keep pace with their peers. Bullying and abuse can occur. In fact, young people with disabilities may have more caregivers and professionals in their lives than friends. Research shows that they, especially women, confide primarily in their mothers as opposed to other adults or friends. This difficulty with making friends may also arise from lack of accessible transport and lack of opportunities to participate in fun activities that people their age have access to.
- Often young people with disabilities, especially developmental disabilities, are unable to achieve independence that enables them to take on adult roles in their family and community. Work opportunities often depend on ability to communicate effectively, relate in socially appropriate manner and navigate the physical abilities required for the job. Difficulties in these areas could mean that either the person with disability helps out at home or becomes self-employed. This further reduces their opportunities to interact with other young people of their age. Even if they do work in so-called inclusive work environments, there are studies that show that they may often find them working by themselves.

Social inclusion is a constantly evolving process where the level of community participation of the individual and the impact this has on their personal interactions contributes to their experience of social connectedness.

The difficulties in accessing opportunities for community participation often have to do with difficulties in physically accessing inaccessible locations, lack of transportation facilities to get to events, communication impairments that make it difficult to connect with people, negative attitudes towards them, especially those with developmental disabilities.

A study that reviewed activities that were shown to help with social inclusion identified the following as facilitators for social inclusion:

- Guided training program like sports where young people with and without disabilities train together, compete together
- Interventions that focus on social skills as they relate to task management or in preparation for the future
- Use of social media and online platforms

Another study offers the following recommendations:

- Build on knowledge, understanding, skills for socialization and integration among the young persons with disabilities
- Addressing dispositions as well as feelings towards them in whichever social context they are introduced
- Use of peers to provide much needed support of inclusion - this may prove to be the most effective resource for the implementation of the inclusion initiative.

Emotional needs

Resilience is the ability to recover from or to grow through challenges. Most people develop resilience by going through difficult times and developing coping strategies. Young people with disabilities are treated differently from their peers and parents try to shelter them from challenges which could be opportunities for them to develop resilience. Following the death of his father by suicide, the family felt that M would not understand the loss of his father. They maintained a ‘conspiracy of silence’ to the extent that they did not even let him be part of the funeral. Protecting young persons with disabilities from challenges is a disservice to them as they grow into adulthood without the skills required to face life, especially as their parents grow older and are no longer able to protect them.

They are primarily seen as vulnerable and dependent and hence it is understood that they need to be taken care of, looked after, provided for. However, if they are provided with opportunity to provide care it would tip the balance. They would develop confidence and self-esteem through their tasks of caring for the family. Reciprocity in relationships can empower young adults with disabilities.

In interviews with young people with disabilities, it has been seen that they would like to live life just like their peers, wanting to travel, 'hang out' with friends, go shopping, have fun, get a job etc. However, a number of them are denied these opportunities.

Young adulthood is also the time of transitions. Any kind of change or lack of stability can be hard. This is seen to be true in the case of a number of young people for whom transition from school can be a hard time, especially with no clear alternative for them after school. Moving out of school also implies that their peer groups change. In fact, they may begin to feel more and more isolated after becoming home bound. There are also expectations from them as they are seen as adults but have not had enough opportunities to develop skills to live as adults.

One parent talked about their son with intellectual disability who went to a special school but was let go with no transition plans once he turned 18. Since the parents could not find any other place their son could go to, they hired a caregiver to be with him through the day and the son became housebound. They were forced to seek help him for help when he had become extremely withdrawn. "We never saw it happening. The changes were so slow and we didn't pick it up. He slowly began to lose himself and we picked it up too late." The parents did not realise the impact it would have on their son who was limited to being at home all day while all of them had things to do, as he watched his sibling live his life, have fun with his friends and he could not even get in touch with friends he had made and the routine he had had when he went to school.

How to plan for transition:

- Take time to get to know them, what their days have looked like, who their friends are, what they like to do, what are they proud of
- Go out with them as friends
- Plan for changes that are coming up; help family think through what the future holds and help them communicate to the young person with disability
- Help plan for a new routine along with the young person; Facilitate making shift in routine and help the family and the young person to adjust to the new routine
- Find ways to help them express their feelings

Mental health needs among young adults with disabilities:

Study done on the mental health needs of young adults with learning disabilities and it was found that they have the same range of mental health problems as the general population. However, they were far more likely to develop depression and anxiety and these often went undiagnosed and thus untreated[v]. One study states that 1 in 4 persons with disabilities will have a mental health support need at some point during adolescence[vi].

These mental health problems seem to be connected with the lack of opportunities for work and leisure that leads to poor self-confidence and low self-esteem along with no opportunities to develop skills required to navigate social settings. This in turn affects their sense of hope[vii].

They also face other challenges in the form of caregivers who may not allow them the freedom to decide or choose, who think that they know best, thus disempowering the young persons with disabilities. They also have to deal with transitions during this phase of life. Generally most special schools or centers provide routine and support till they are 18 years of age. After this, a number of young people with disabilities especially developmental disabilities are forced to remain home bound. These add to their stressors making them vulnerable to mental health problems.

Mental health needs may be seen as part of their disability rather than as a need they need help for. For e.g., aggressive behaviours, being withdrawn, anxious behaviours are termed as either challenging behaviours or as a result of hormonal changes that occur during adolescence. In one study it was found that in every single person with learning disability, these difficulties had risen markedly at the time of transition or new problems had emerged[viii].

Things to do if the young person had mental health needs:

The young person needs to be seen by a specialist and often the help planned for them will follow a bio-psycho-social model. This model considers the biological, psychological and social factors that interact in health and disease. The following are some things one can do as a caregiver to help the young person with mental health needs:

Medication:

The medications that are given for mental health needs are called psychotropic drugs. If they have been started on medicines, it is good as a caregiver to know the following:

- What the medicines have been given for
- How will it help
- Will it have any side-effects, what are they and what can be done
- When the next follow up should be

Work with the family and the young person so that they understand these.

Therapies:

Provided by specialists, these often include:

- Counselling and
- Creative therapies like art, music, dance therapy

Social:

- Provide ways to help the young person with disability express their feelings in ways that the family can understand
- Work with the family so that they can understand and support the young person
- Work with the family to identify and develop a support network
- Train families to know when to seek help

- Facilitate setting up support groups for young people with disabilities and for the parents and siblings
- Focus also on the mental health of the parents. Allow for opportunities for them to express their feelings, worries about the future, plan etc.

When care plans are developed, plan with the life cycle approach. Plan keeping transitions in mind. Recognise that transitions are hard. Plan with a person-centered approach. This gives the young person some level of control over their lives. This is especially true for the families seen in the Indian context where most decisions are made by the elders of the families. Allowing some level of control to the young person helps them develop skills that they will need for later years.

Challenging behaviours

Behaviours that meet the following criteria are often termed as challenging:

- Age inappropriate and socially inappropriate behaviour
- Behaviours that lead to significant cost on the individual like physical harm, social rejection
- Behaviours that lead to significant cost on others like physical harm, property damage, emotional distress

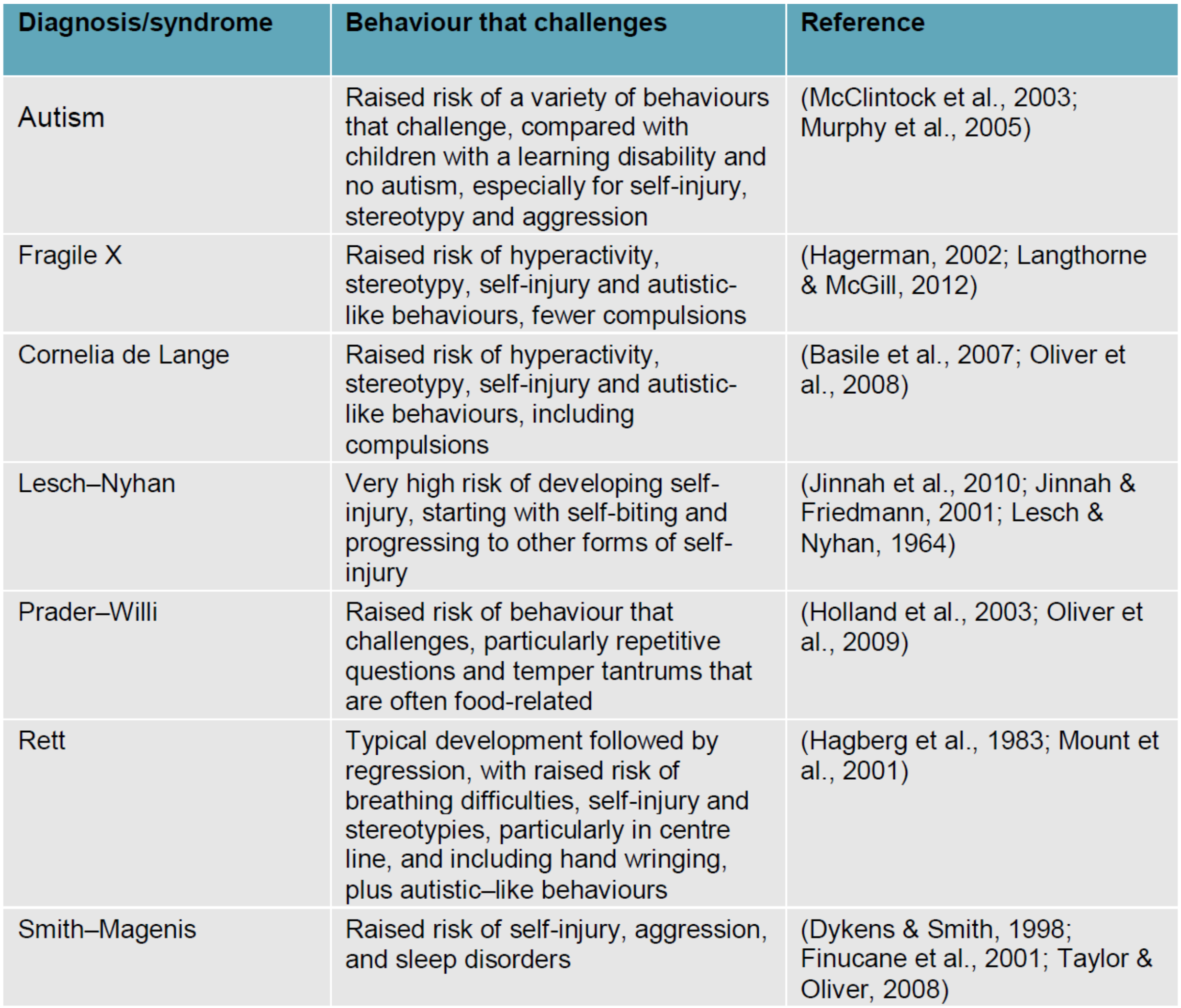
Challenging behaviours may be due to various reasons like life events, physical needs like being unwell, being in pain, emotional needs, mental health issues, experiencing abuse and environmental influences. A young adult with profound disability who screams and bites to escape being in a room could be doing so for a number of reasons. It could be that the person has had a traumatic experience in the room or the curtains in the room are too bright for them to handle or there is a sound in the room, may be the sound of the fan, that causes distress for them.

When young people with disabilities are forced to deal with increasing number of restrictions, they may express their frustrations in behaviours that we term challenging. Examples of restrictions could be limited social interaction, lack of meaningful occupation, lack of choice of sensory input, excessive noise, crowded areas, environment that is unresponsive or unpredictable and those characterized by neglect or abuse.

Identifying the function of the challenging behaviour, its frequency and designing interventions for the challenging behaviour with the parents becomes key. Therefore, adequate time must be spent gathering information to guide the process of intervention planning. Following are some of the areas to consider:

- Degree of disability: the higher the degree of disability, the greater are the chances of challenging behaviour that persist
- Communication skills: inability to communicate adequately their needs and feelings can lead to behaviours that may not be socially appropriate but are used by the person with disability to communicate their discontent or discomfort.
- Sensory impairment

- Attachment issue
- Traumatic events
- Mental health issues
- Sleep disturbances: People with developmental disabilities experience sleep problems at a higher rate than the general population and the prevalence rate varies from 34% to 86%. Creating a sleep diary will be essential while looking for reasons for challenging behaviours. Find out details such as
    - How many hours does the person sleep during the day and night time?
    - Is snoring present?
    - Does the person wakes up repeatedly at night?
    - Does the person complain of nightmares?
    - What is their bedtime routine?
- Behavioural phenotype: certain syndromes have as part of their phenotype specific challenging behaviour as seen in the table below:



Diagnosis/syndrome	**Behaviour that challenges**	**Reference**
Autism	Raised risk of a variety of behaviours that challenge, compared with children with a learning disability and no autism, especially for self-injury, stereotypy and aggression	(McClintock et al., 2003; Murphy et al., 2005)
Fragile X	Raised risk of hyperactivity, stereotypy, self-injury and autistic-like behaviours, fewer compulsions	(Hagerman, 2002; Langthorne & McGill, 2012)
Cornelia de Lange	Raised risk of hyperactivity, stereotypy, self-injury and autistic-like behaviours, including compulsions	(Basile et al., 2007; Oliver et al., 2008)
Lesch–Nyhan	Very high risk of developing self-injury, starting with self-biting and progressing to other forms of self-injury	(Jinnah et al., 2010; Jinnah & Friedmann, 2001; Lesch & Nyhan, 1964)
Prader–Willi	Raised risk of behaviour that challenges, particularly repetitive questions and temper tantrums that are often food-related	(Holland et al., 2003; Oliver et al., 2009)
Rett	Typical development followed by regression, with raised risk of breathing difficulties, self-injury and stereotypies, particularly in centre line, and including hand wringing, plus autistic–like behaviours	(Hagberg et al., 1983; Mount et al., 2001)
Smith–Magenis	Raised risk of self-injury, aggression, and sleep disorders	(Dykens & Smith, 1998; Finucane et al., 2001; Taylor & Oliver, 2008)

Table 2: Behavioural phenotypes in some common syndromes. NICE guideline (2015).

The interventions would need to be

- tailored specifically for the individual that looks at the all the pertinent factors based on the young person and his/her environment.
- evidence based and multifaceted: a multi-disciplinary team approach would need to be adopted and the focus would need to be on preventive strategies. Consideration would need to be given to what could be done before the behaviour manifests or ow to distract before the behaviour goes beyond control
- a list of strategies that parents can adopt at home with physical restraint and emergency medications as the last resort. The strategies would need to be used consistently and should be based on routine.
- Parents would also need to be trained on personal safety.

Sexuality

This is a topic that is often ignored or not talked about until the young adult with disability behaves in a manner that expresses their sexuality. However, because this has never been discussed and the aspects of sexuality that could have been taught never were, their behaviours often are socially inappropriate causing distress to the family members.

To begin with, learning about sexuality is a life-long process that includes:

- Acquiring knowledge, understanding and skills
- Developing attitudes, beliefs and values about sexual identity, intimacy, relationships

Learning about sexuality begins from in childhood where a lot of the learning happens informally through parents and caregivers. This is connected to developing a sense of self, developing value systems, learning about friendships and healthy relationships and behaviours towards others, learning about how to keep themselves safe and what to do when they feel unsafe etc.

Sexuality is more than sexual relationship. It is tied with being an adult. Being able to earn money, develop friendships etc contribute to our being seen as adults. Young adults with disabilities often are not seen as mature adults. And hence conversations that have to do with relationships, intimacy are not had with them.

One way that we express sexuality is in the way we present ourselves to the world- in the clothes we wear, the makeup we use, the accessories we use. Young adults with disabilities are often unable to participate in their sexuality this way. They may have no choice in the clothes they wear or in the social process of shopping, trying on jewellery etc.one young person described it as watching her siblings live their lives as though they were on TV and her life was spent watching them live theirs.

In rural communities where parents fear about what will happen to their children after their passing, often get their young adults married so that they will have someone to provide care. However, the young adult enters marriage without knowing what it means to be in a committed relationship, what intimacy can mean etc.

There is much talk about person centred approach for caring. This approach needs to consider sexuality and facilitating learning about sexuality for persons with disability, beginning in childhood. There are numerous resources that help caregivers guide learning about sexuality through childhood to adulthood There are numerous resources that help caregivers guide learning about sexuality through childhood to adulthood. An example is a collection of resources available at https://ccea.org.uk/search-api?search_api_fulltext=sexualityand at https://latikaroy.org/specialist-information/sexuality-and-disability-some-issues-to-consider/.
Caregivers need to use these resources and provide opportunities for young adults with disabilities to develop and express their sexuality in a socially appropriate manner.

Safeguarding against abuse

One of the main concerns of parents also is protecting their young adults from abuse. There is adequate evidence that shows the vulnerability of persons with disabilities to abuse. There are a number of disquieting facts about abuse in that they can happen anywhere, in the context of any relationship even close relatives and regular caregivers. Sometimes the government benefits they receive can be seen as payment for caring for them, making them vulnerable. It can happen in an ongoing relationship especially where power dynamics comes into play.

The question, therefore, to work with is how to manage relationships and risks rather than avoid relationships altogether.

Safeguarding from abuse requires interventions at three levels for:

- Primary prevention: this would include helping families define and set up safe environments; helping them work with the person with disability to regulate relationships, to help them identify and communicate when they feel unsafe
- Secondary prevention: this would include training family and professional caregivers on identifying signs and symptoms of concerns and detecting the causes for concerns so as to set in safeguards
- Tertiary prevention: when abuse is identified or reported, taking action to protect the individual while taking action against the perpetrator. When an adolescent girl with intellectual disability in one of the communities was sexually abused by a man from her village, tertiary prevention meant providing medical care for the girl, counselling for her and the family, working with the family to report to the police and working with them when the case went to court.

Needs of the family of the young adult with disability

During the course of caregiving, stages have been identified that seem to hint at major transitions within the family. Families begin at the novice caregiving stage as they live through diagnostic limbo during which they struggle to learn about what is 'wrong' with their child and what they are supposed to do in response. This is followed by taking on the direct caregiving of the child. Most families struggle with finding out what works best for their child and family. They struggle to work out routines that give a degree of order and predictability for the family. It helps if the disability has a fairly constant and predictable trajectory. However, there may still be surprises. During this stage, they are also working out through their own grief and having to deal with the societal responses to their child. However, every transition in the course of their lives reminds the family how different their child is from their siblings and other children. Their child with disability continues to grow physically and as adulthood looms, other issues being to crowd in such as their autonomy, capacity and legal rights[ix].

Life course trajectories:

Caregiving trajectory	Development/ disability trajectory	Life cycle
Overall description of the trajectory – effects of the 'stage' family carers have reached in moving from 'novice' to 'expert' carers	Overall description of the trajectory – Effects of seeing disability as an ongoing process with landmarks, transition points and changing demands	Overall description of the trajectory – Effects of shifts in support network membership and intergenerational ties
'Building on the past' – exposure to counseling; caregiving ethics and values; acting on known risk factors for disability while considering more children	Onset – Immediate or gradual; expected or unexpected	Family support network as: vehicle for transmitting values; opportunity structure for support; vehicle for substitute and complementary support; means of sustaining reciprocity
'Recognizing the need' – exposure to disclosure of disability; diagnostic limbo; disruption in the story of their lives; attachment formation; development of sense of coherence	Course – Progressive or constant, relapsing / episodic; these being precursors of predictability	Support network dynamics affected by death; incapacity or migration of family members; supportiveness of services
'Taking it on' – novice and improved caregiving; structures and routines for managing care; capacity to set limits on care	Outcome – Impairment; social and environmental barriers; shortened life expectancy; death	Potential of transfer of caregiving responsibility between family members

‘Working through it’ – managing care; realizing own identity needs; recognizing caregiving rewards; achieving reciprocity in relationship	Incapacity – Cognitive, sensory, mobility, energy and stigma; mediated by values, expectations and coping resources	Intergenerational ties, culture and ethnicity may be important in sustaining a commitment to family care
‘Reaching the end’ – maintaining care giving reciprocities; planning for the future; give up everyday care; making ethical end-of-life decisions		Work-life balance important during working-age years

Table 3: Adapted from Learning disability: a life cycle approach to valuing people (2005).[x]

As both the child with disability and the parents grow older, it becomes harder to plan ahead especially as families struggle with trying to decide as to what happens to the person with disability as the parents grow older and die. As parent age and their health gets affected, the siblings leave home pursuing higher studies or employment and other family members have conflicting priorities, there are major changes in the support system. Providing support to the family with the life cycle approach that helps them focus on where they are headed as members grow older is necessary. This provides a degree of support and protection to the person with disability and allows for the parents to feel a degree of control and relief about the future of their son/daughter.

What needs to be done for the family:

- Adopting a life cycle approach by the professional team; CBR approach works well in this context of journeying with the family from the ‘cradle to the grave’.
- Identifying the existing support network for the family and predicting what may remain or how they will change for the future
- Identifying family strengths and coping strategies

Check your progress

1. Define transition
2. Explain Health Care Access Barrier model
3. Write about mental health needs of adults with disabilities
4. Challenging behaviours during adulthood
5. Explain about sexuality
6. Needs of parents during young adult

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CHAPTER-6

CATERING TO THE NEEDS OF PARENTS OF YOUNG ADULTS

- *Jayashree L. V*

Learning Objectives

1. Describe the nature and extent of care giving burden on families supporting an adult person with High Support Needs.
2. List out the micro and macro factors of stressors that impact the nature of Caregiving provided for a person with High Support Needs within the context of Ecological Framework.
3. Classify both subjective and objective burden of care of families/caregiver/care-recipient.
4. Recognize the demographic characteristics of the Caregiver of an adult with High Support Needs**.**
5. Identify variables that support Family Centered Care Practices
6. Describe the various ways in which support for families can be enhanced to mitigate family burden of care by drawing on resources within and across the community.
7. Understand various ways of facilitating collaboration between and among families and professionals.

This chapter examines the multiple, complex and evolving roles of caregivers of older adults with "High Support Needs" (HSN) who need intensive long term support and services across all areas of life such as skills training, employment, family, community life, treatment and therapy. The person with HSN can be characterised by their profound intellectual and severe physical disabilities, resulting in limited or apparent understanding of spoken language (Nakken&Vlaskamp, 2007). Sensory impairments may co-occur along with health problems. Person with HSN on account of combination of disabilities requires pervasive support making heavy demands on families and especially primary caregiver. The nature of roles, responsibilities that a parent or primary caregiver undertakes while taking care of a persons with Long Term High Support Needs (LTSN) is complex, dynamic and intense which may change over time. Also parents have to engage in surrogate decision making in some situations due to which they may face ethical/moral dilemmas.

The nature and burden of Caregiving on families and person with HSN

In the field of disability there is a semantic difference in the way the community talks about providing care and support for a family member. The term "care giving" is used in the context of providing care for the aged. While the Intellectual Developmental Disabilities (IDD) field more often uses the term “family support.”. Simply put family support programs in field of disability targets providing support for the entire family.

The Family and other informal caregivers provide the vast majority of long-term care to adults with HSN. The family burden associated with care giving can be categorized into

subjective and objective nature of burden. Subjective forms of care giving burden are the psychological reactions families with Person with Disability (PwD) experience, including sadness, anxiety, embarrassment, frustration, grief, and stress of care giving.
Objective burdens relates to practical problems that arise from care giving such as financial due to heavy medical cost, loss of income, disruption in family relationships, lifestyle limitations (such as leisure, recreation, work or social activities) and negative impact on physical health. In sum, parental perspectives on care giving is more about their day- to -day experiences surrounding attitudes, relationships, social factors and support systems that has affected them more than a fragile health or body function challenges of the PwD with HSN. There is no prototypical family as structures of households are variable and interact in very complex manner with the key members (in-laws, other non-disabled children, and spouse) of the family. In a country like India diversity in people and families across North, South, East and West of India is influenced by nature of origin, geography, predominant occupations, and access to health/medical facilities/education. The cultural and sociological sensibilities are very different. The access to supports and services in rural versus urban is profoundly diverse with most programs available in urban areas.

Supporting families with adult HSN has to be explored in different contexts and levels:

a. Life course perspective both for the caregiver and care recipient.
b. Family roles, responsibilities and its impacts seen through the lens of Caregiving Trajectory
c. Economic impact of family caregiving
d. Programs and supports for family caregivers in the context of Individual, Organizational, Societal/Policy level ensuring pipeline of support for caregiving interventions
e. Enhancing the current Paradigm of Person-Family Centre Care as the basis of long term care and support

Family care-givers or informal supports rarely receive adequate preparation for their role (Bigby, 2002). We will in this chapter take a life course perspective as it helps us to understand and explore the experiences of individual with disability needing LTSS and their families. The well-being of person with HSN and their close family members have been shown to be closely intertwined. When we take a life course approach we can then appreciate the intensive, dynamic and complex factors that play into each other as both care recipient and caregiver are likely to experience activity or functional limitation as they grow older.

Demographic characteristics of Carers of HSN

Although there are no reliable statistics to rely on we can safely state most of the primary Care givers are female (65-70%) and the rest are male. Further there is literature to support that male caregivers report less stress (Mawani & Gilmour, 2010). A research carried out in United States by Braddock et al., (2015) 71% of persons IDD live with their families and of those living with family caregivers, 24% are living with caregivers aged above 60 years. In the absence statistics available in India, the demographics of people with HSN living with aged caregivers in India could be more as there are less services and support programs across India.

Most of the caregivers are the primary earners of the family are nearing retirement or retired or in part time employment post retirement. In rural areas they may work as daily wage workers on adhoc work taking up seasonal work or short work hours so that caregiving can take place without much disruption.

Factors that impact caregiver well-being

Caring for a person with HSN can have both positive and negative effect on parents. The positive aspects of care giving can include feelings of affection and closeness with their child and the sense of personal satisfaction and purpose in life that may be derived from it (Shah et al., 2010). Parents may report that they are chosen by God as they have the strength to provide for the child.

Quality of life of the carer may be impacted in the following areas depending on both contextual and individual factors. The areas that get affected are due to role strain, role overload and role conflict together impact on:

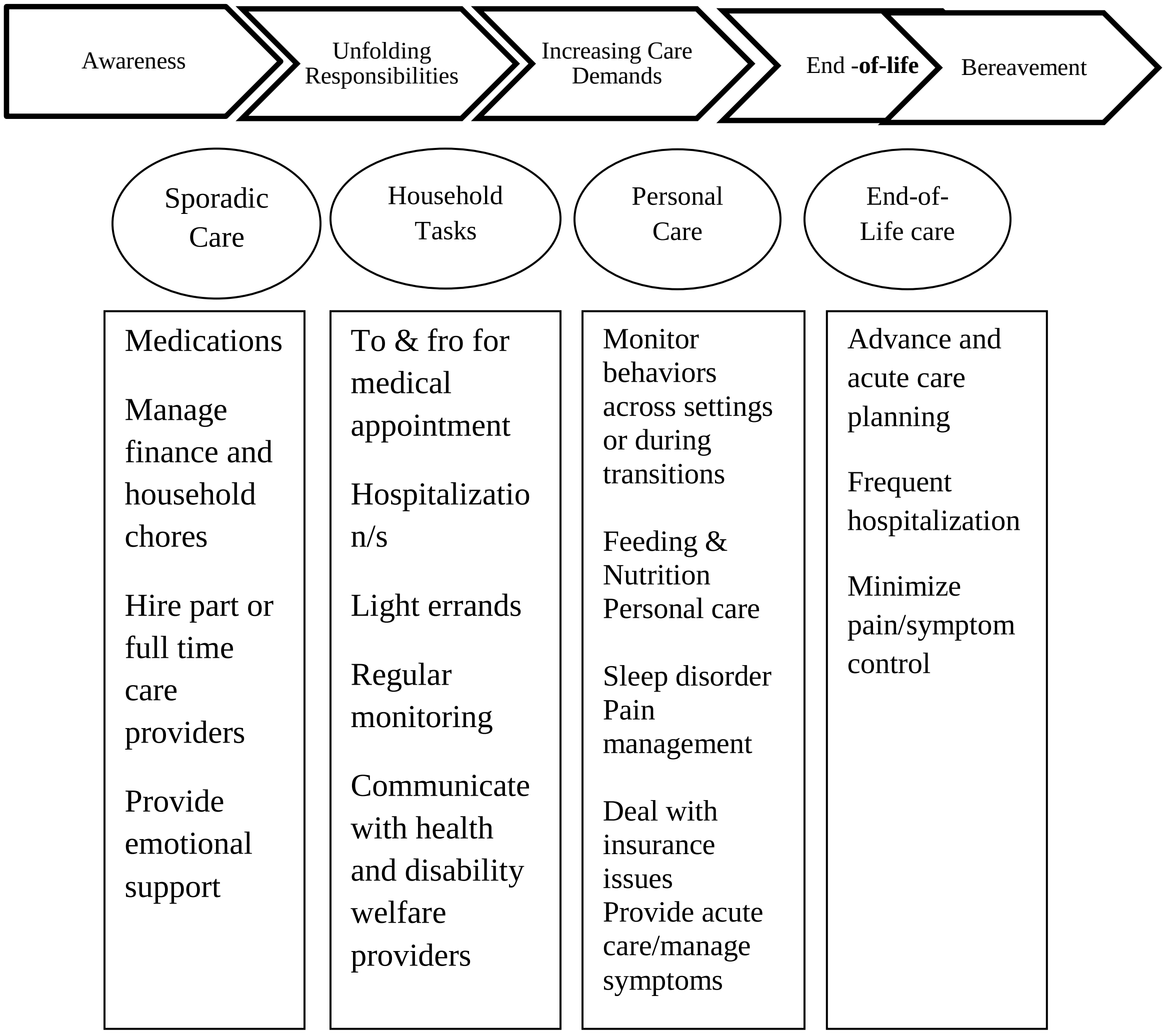
a. Physical health
b. Disrupted sleep
c. Difficulty maintaining social relationships
d. Pressure on marital relationships
e. Difficulty in taking family holidays
f. Difficulty in maintaining maternal employment
g. Financial burden
h. Difficulty in accessing or Unware of Schemes and Benefits provided by the State and Government of India;(if families not literate or living in remote areas not without proper access to public transport)
i. Chronic fatigue
j. Chronic depression

Families traditionally provide emotional support, provide personal care and attend to medical care at home. When caring for a child who needs frequent medical attention, families have to learn to navigate the complex and at times fragmented health care systems. A child with brittle bone condition once falls down that result in sub luxation or fractures has to be moved only in an ambulance. Families may struggle to find an ambulance on call. Not all medical sub specialities like X-ray, scan, laboratory facilities be available under one roof and easily accessible. A family in rural area for example may not get all medical services for complex /fragile health conditions in Primary Health Centre. So they have to go to a Peripheral or General Hospital in the peri/urban areas for medical care, surgery or other such critical care support. A rural family will have to manage the logistics of transport including cost of transport. Family caregivers report learning by trial and error and consistently fearing they will make some life-threatening mistakes. Despite the integral role that family caregivers play in the care of older adults with disabilities and complex health needs, they are often marginalized or ignored in the delivery of health care.

Impact of Caregiving Trajectories

As a society, we have always depended on families to provide emotional support, and to assist their older parents, grandparents, and other family members when they can no longer function independently. Parents of children with adult HSN in many ways evolve into 'career' caregivers, with extensive experience with providing supports and adapting to the ups and downs related to extended caregiving. Caregiving trajectories include both the intensity of HSN and the settings in which the care is provided nuclear-joint family.

This is very eloquently expressed in Care Trajectory shown below:



Awareness → Unfolding Responsibilities → Increasing Care Demands → End **-of-life** → Bereavement

Sporadic Care	Household Tasks	Personal Care	End-of-Life care
Medications Manage finance and household chores Hire part or full time care providers Provide emotional support	To & fro for medical appointment Hospitalization/s Light errands Regular monitoring Communicate with health and disability welfare providers	Monitor behaviors across settings or during transitions Feeding & Nutrition Personal care Sleep disorder Pain management Deal with insurance issues Provide acute care/manage symptoms	Advance and acute care planning Frequent hospitalization Minimize pain/symptom control

Retrieved from https://challenges.openideo.com/challenge/caregiving-dementia/ideas/caregiving-trajectories-1

Sporadic Care

From time to time families have to hire part-time help or request other family members to manage household chores, cash withdrawals, medications, payment of utility bills or carry out bank work etc. The nature of errands may be of low frequency but important for the family to run the household.

Household chores

Preparing meals, laundry, house cleaning, shopping for daily and monthly needs, transportation, etc can be major areas of both physical and emotional stress for parents.

Self-Care of HSN

Bathing, grooming, dressing, feeding, supervision, management of behavioral issues, toileting, transferring and getting around and outside can both time and effort intensive. In many families the burden of care falls on mothers. Managing issues related to menstruation, sexuality and personal hygiene for a person with HSN can result in intense emotional and physical burden with limited and non-existent support from the family or from service providers. Dressing of wound, use of medical equipment, and injections also make a caregiver a nursing aide.

Some of the medical problems a person with HSN may have and the intensity of care giving to which it is related are:

a. Increased pain;
b. Early arthritis;
c. Pressure sore or ulcer formation due to long time sitting in a given posture;
d. Progressive movement disorder;
e. Mental health issues;
f. Progressive loss of ambulation as the HSN grows older and transitions are difficult with attended medical issues;
g. Cervical or Lumbar spine problems including myelopathy;
h. Progressive Hydrocephalus in middle ages;
i. Worsening of dysphagia and inability to eat, requiring tube feeding;
j. Worsening dental care resulting in carries and abscesses.

Caregiver as provider of emotional and social support for HSN

Primary caregiver has to provide companionship to her adult child if he is profoundly disabled and is not going to any Intervention Centre, Day activity centres, or receives Home Based Program. Since the opportunity to interact with same age peers is limited or at times non-existent the primary caregiver and or families members become the social network. This can emotionally drain the caregiver as it limits their own social recreational choices. The primary caregiver becomes the key communication facilitator for her child with HSN. In the process of being the chief communicator and key advocate for her child the Mother or Caregiver in some ways “loses” her own “voice” and her own “needs”.

In many situations aging parents take the view that they alone can provide proper care for their adult-child with HSN. And this belief may be the direct result of their own experiences with low-quality services or institutionalization when their child was younger.

Psychological and Subjective Well-being Issues

A compelling body of evidence suggests that many caregivers experience negative psychological effects. There are ample evidence that many caregivers have reported lower self-ratings of physical health, elevated levels of stress hormones, higher rates of chronic disease like lumber-sacral or knee pain , and impaired health behaviors. Some caregivers are at higher risk than others, especially those who spend long hours caring for older HSN adults with advanced mental health problems such as dementia/schizophrenia. Raising an adult with disabilities including HSN not only changes *parental perspectives but also the parents themselves and not just their expectations and plan in life*. The particular mix of caregiving activities and time commitments varies. Families even though acknowledge that theirs will be a lifetime of exchanging care, many of them neither have the resources or the emotional strength to engage in formal future planning activities especially if they are from poor rural families. Primary caregivers often use up a lot of their physical and emotional energy in attending to the needs of HSN which *can significantly influence the dynamics of interactions within the family, often through the reduced availability of the primary carer to spend time with spouse, siblings, in-laws or other children.

Tensions in parent-adult child conflict

Young adults with HSN are increasingly faced with choices and decisions regarding identity, independence, self-care, and self-advocacy. This period of adulthood is largely stressful for parents due to tension in which with adult person with disabilities push for more independence and autonomous decision making while the parent may want to overprotect Carey, (2009). The key factors that matter here are Gender, Generation and Age of the PwD and care giver. Other structural/systemic factors like the socio-economic, literacy level of caregiver, family of origin, access to resources, single parent, availability of wheelchairs and other assistive devices also affect the relationship.

Person with HSN has positive feelings of bond of trust, emotional closeness, and respect with caregiver on one hand called the "affective solidarity". Research shows that the “affective solidarity” is more in parent than in the child (Shapiro, 2004). On the other hand there is a sense of ambivalence in parent-child bond where an adult with profound needs struggles for independence in regard to behaviors and choices. Parents due to their sense of responsibility towards caring for the person with HSN often tend not realise that the care recipient is an adult. The caregiver often times treats him/her as "perennial child" due to diffusion of boundaries both physical and psychological that takes place in personal care routines.

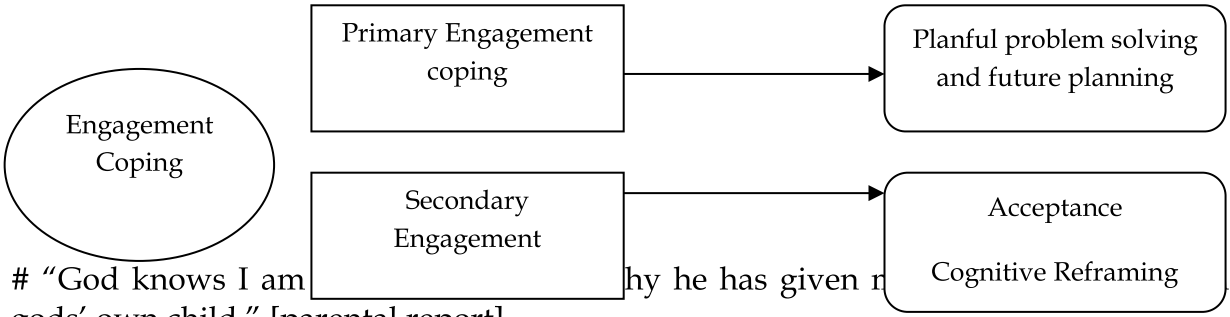
As parent grapples with problems such as deteriorating health due to menopause or back pain or other chronic health conditions they are also struggling how to "let go". For many families "Let go" is not a choice if it is single child family or their other children may be living and working elsewhere. With limited financial means families with a child with disability often live under one roof in small spaces. The absence of clear boundaries in physical and social space may give rise to conflicting thoughts and feelings as there are no clear understanding of interpersonal behaviours or relationships (Connidis & McMullin, 2002). The pattern of Parent-child interactions who live in constrained and small tenements often results in diffusion of physical and psychological boundaries among the members of the family. Older or grown up children leave the burden of care of the disabled sibling to the primary caregiver and move out when they have choices and the means. Currently across India family seems to the primary care available as provisions for fulltime residential care, assisted living, group home, supported living, or independent living with limited services are emerging sporadically across urban India.

Parents can feel chronically exhausted, physically, financially, and emotionally from years of direct caregiving and management of needs on multiple fronts with little or no avenues for self-care and adequate rest.

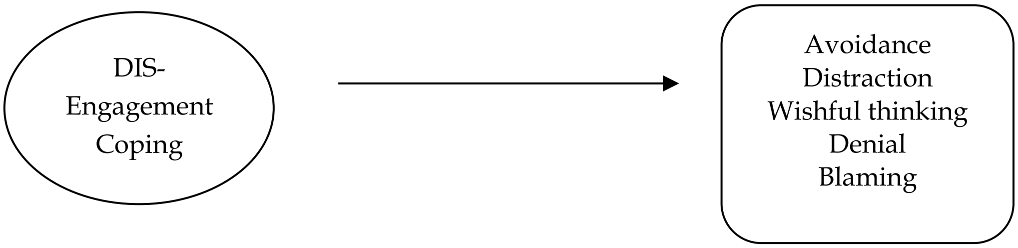
Even if families wish to move the child to other living arrangements many of them choose not to take it up for a number of reasons and among them the financial cost is paramount. Thus HSN adult continues to live at home until a big crisis unfolds or if the primary caregiver is no more or unable to take care due to major health reasons.

Positive side of caregiving has also been shared by them in regard to caregiving. Numerous anecdotal reporting and parental feedback suggest that, for some people, care giving instils confidence, provides lessons on dealing with difficult situations, brings them closer to the Person with Disability, and assures them that the care recipient is well cared for.

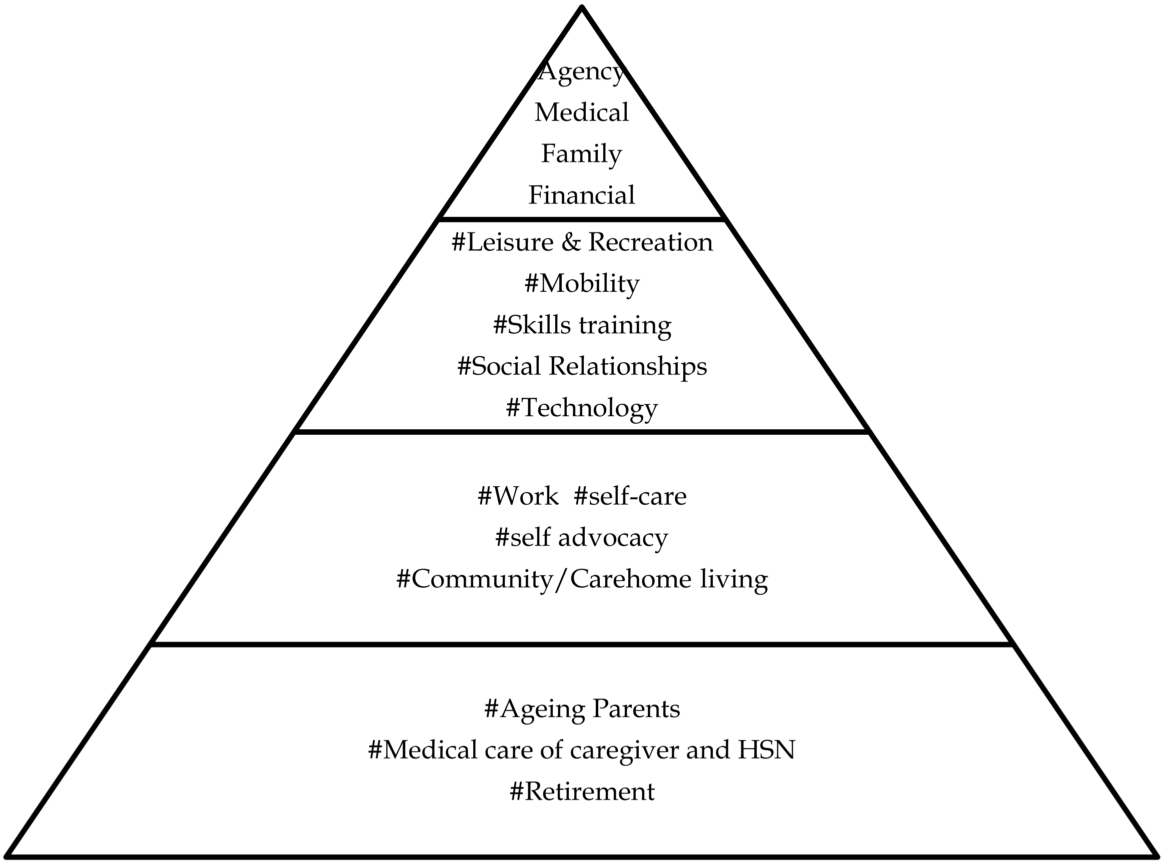
Common patters of coping mechanisms of Parents and Families



“God knows I am hy he has given r m gods’ own child.” [parental report]



There is a need to better understand how the meaning of child-related burden changes in different living circumstances. It is important for providing psycho-education to families including cognitive reframing and acceptance in reducing parental stress.



Agency
Medical
Family
Financial

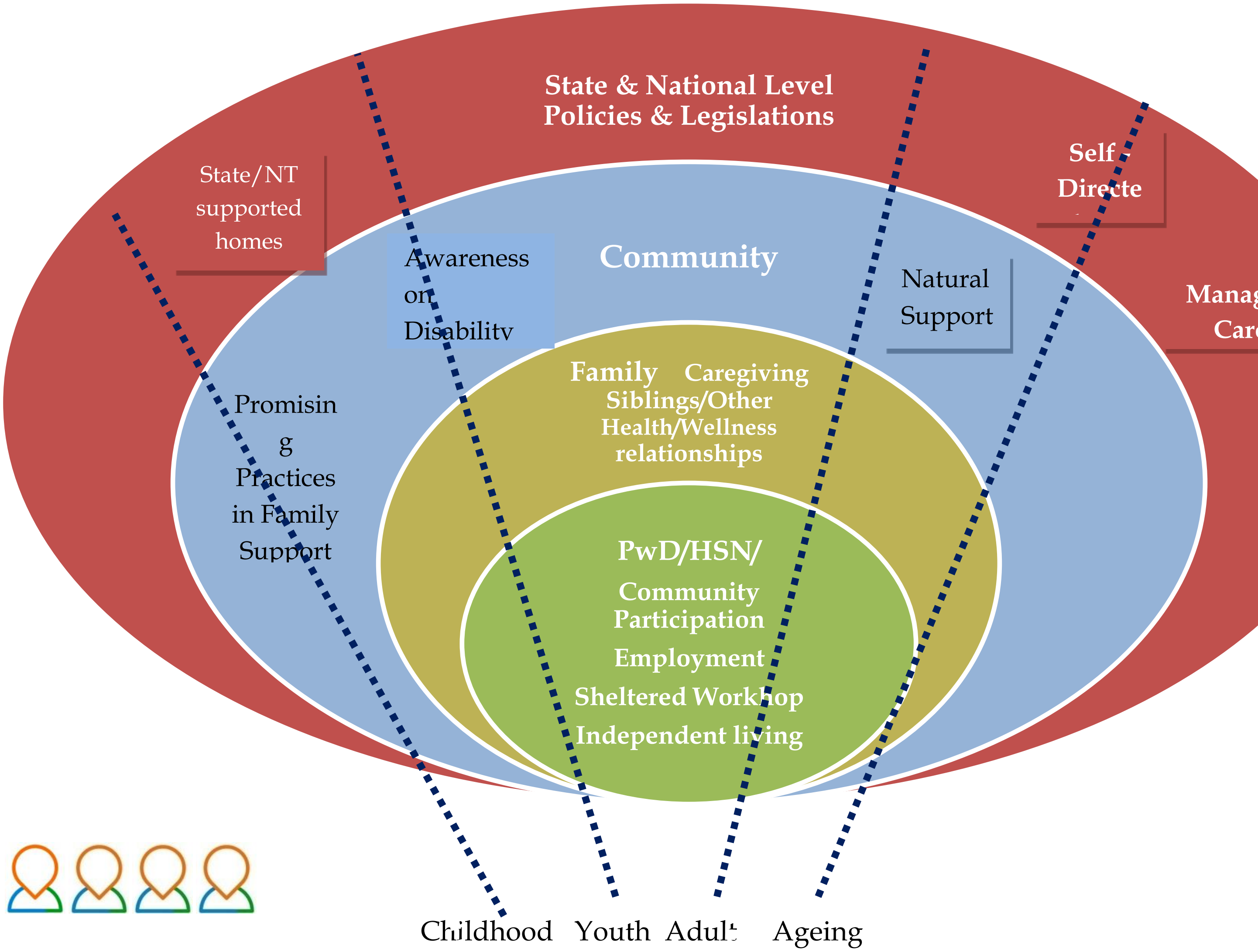
#Leisure & Recreation
#Mobility
#Skills training
#Social Relationships
#Technology

#Work #self-care
#self advocacy
#Community/Carehome living

#Ageing Parents
#Medical care of caregiver and HSN
#Retirement

Person with

High support needs


State & National Level
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relationships
PwD/HSN/
Community
Participation
Employment
Sheltered Workhop
Independent living
Childhood
Youth
Adult
Ageing

The use of ecological framework can help us understand the multiple levels of factors and stressors that interact and influences families/primary caregiver. This chapter builds on the work of Bronfenbrenner (1979) who conceptualized microsystem, mesosystem, and exosystem levels which interact with each other. Let us now look at:

a. Person with HSN needs
b. Family
c. Community
d. State & National Policy

Personal level

Dynamics of PwD and the individual caregiver often takes into account the Care Trajectory discussed earlier in the chapter. Gender and generation are important structural determinants which in some ways affects the way both the PwD and caregiver experience both positive and negative emotions about the same relationship.

When there are service provision such as Day Activity Community Centre where both the elderly and people with HSN can go to interact socially, do activities and also get rehabilitation care would go a long way in ensuring Caregiver gets respite and support.

Similarly a parent-to-parent support group can also provide a platform for caregivers to engage in activities that promote self-care. They can have access to activities like Bollywood/Kollywood dancing, Weaving, Meditation, Yoga, tailoring, Pilates, Karaoke, Television, visiting places of worship, participate in gram sabha etc. Having some "me time" to nurture and pamper the caregiver can go a long way in developing the emotional/physical resilience for a lifetime of "career caregiving" in parents.

Family: Families with HSN adult are often underserved and often face barriers in accessing formal services/programs and other challenges of practical nature such as barrier free access to free transport, programs such as day activity centre. Families often do not engage and involve their other adult children in interventions. Sometime given the family structure a caregiver has to also provide care for her aged parents or in-laws as the caregiver approaches mid-life;

Community Level: The scenario in peri-urban and rural areas in India there is dearth in the delivery and support facilities available for families. There is a dearth of individualized and family centred care for older adults even in Urban India and even if there are programs they are evolving and sporadic. The community looks at the families with prejudice, discrimination and low expectations which starts from the day the child is diagnosed as a PwD.

Person and Family Centred Care (PFCC): There has to be comprehensive and fundamental thrust to work as a “care team”. Care team consists of service providers, families, health and other supportive care workers who communicate and interact with each other by supporting both the family and the person with HSN, In person and family centred care the family is not seen as merely a “resource” but as individuals who themselves need information, training, and support. The defining features of PFCC are collaboration, co-ordination, communication, shared decision making and empowerment of both the family and the PwD. Families are seen as an "expert" who have the right to make decisions and not just as care recipient. PFCC approach can promote comprehensive care that address a wide range of preventive, promotive, chronic, behavioral, and rehabilitative services.

State and National Policy: India has recently passed the Rights of Person with Disability Act. The National Trust Act may need to be revisited and the scope of inclusion expanded in the light of provision for person with HSN. The programs essence has to capture and resonate with although there are number of Schemes and Benefits that varies from State to State the access to these programs are often tied to age, disability, category and entry requirements. State and National Policies need to evolve around developing programs that include Caregiver Support Program, Housing, Lifespan Respite Program, and family support activities either run by respective State or National or Non-governmental agencies. Many families often report that besides physical barriers that they also face a also lack of information about services and schemes that they can avail. Families that are less educated, from rural remote villages face the challenge of lack of awareness and information than urban middle class educated families. For urban lower middle class families their access to services and information is similar to those from rural areas.

Families with HSN can benefit from work place "Care giver" Care leave. State and Central Government employees on retirement and after their lifetime are now able to ensure their PwD can enjoy family pension when both parents pass away.

Summary

As parents and PwD age together there has to be an emphasis on fostering connections that could supplement or replace their care activities, particularly for aging parents facing their own physical decline and mortality. These connections need to ensure a "circle of support" involving with siblings and develop peer friendships, while also shifting care responsibilities to formal care providers and other community-based supports.

Families need support in the following areas:

a. Accessible low rent housing;
b. Parent to Parent Support Groups are essential both to provide for emotional support and for advocating for the collective needs of primary caregivers and their adult children with disabilities.
c. Health Services that includes Postural care to protect body shape, prevent deformities, eating and breathing. Epilepsy management, manage problems of swallowing, manage chest wall infections etc.
d. Availability and Access to customized multi-terrain wheel chairs. Many State Government issues free wheel chairs that are not customized and often becomes a source of further deformities and difficulty in moving across different surfaces/terrains. There also has to be service provision for "On Call" Wheelchair Repair services.

e. Persons with HSN need access to and knowledge on use of Communication Aids and assistive technology and this will reduce the presence of parent as the "primary physical voice" of the person with disability.
f. Services and programs such as Day Activity Centre that primarily caters to adult HSN and provides the activity and social space for interaction among adults and their families.
g. Short break Respite Centres which can pick up and drop the clients is aspirational (since India is low resource intensive country) but essential as many parents have difficulty in ensuring the logistics for availing Respite Care.
h. Training Pipeline: We need to have Caregiver Training Programs both for people who wish to pursue it as full time paid work and also for parents who need training in areas of managing critical medical care such as tube feeding or pressure sore management etc. The training curriculum and delivery has to involve both Health and Disability departments. Parents also need regular psycho education programs to enhance their social and emotional well-being. For parents the training should be free of charge borne by respective State Governments. Training provider can as value addition develop a directory of "caregiver assistants" available for State/District officials of the Welfare and Disability, NGO's and other individuals to avail for regular or sporadic care.

In sum by developing Policies, Programs and Services the community and State evolves service options that are generic, interlinked and transportable across the country like India thereby reducing the social, emotional and economic costs associated with caring that parents face when supporting a person with HSN. We need to focus on cross-over discussion and research on Ageing and people with HSN ageing. Both fields have a common agenda namely to reduce the negative impact of care giving on families, enable family support, enhance person and family centered care.

Also we need to encourage a Family/Parent to Family Networks that can play two primary roles. The first role is to become an Advocate for the child, and family. The second is to provide guidance, counselling and information to both new parents who enter the group and to provide guidance to existing parents. The family network also support parents if the person with disability passes away during the period of bereavement and post event options.

Unit Summary

a. Rights of Persons with Disability capture the nature of "high support":A person who requires intensive **support**, physical, psychological and otherwise, which to carry out daily activities, to take independent and informed decision, and to access facilities and participating in all areas of life including education, employment, family,

b. Two-way nature of interaction occurring during care-giving process can be self-perpetuating and can impact on both the Psychological and Subjective well-being of the primary caregiver and the person receiving the care-giving.
c. Objective burdens of care-giving includes financial burden but not limited to it as it includes quality of relationships, limitations in life-style, socialization etc.
d. The demographics of care-giving for persons with HSN largely falls on the woman than man due to several factors that may be attributed to social, cultural, economic nature by which family systems exists..
e. Care-giving Trajectory consists of four pathways of care which includes Sporadic Care, House-hold chores, Personal Care and End of Life Care, Each of these four areas are interlinked and always dynamic in nature.
f. The nature of tension between care-giver and care recipient is a natural unfolding of co-dependence between the two. Both struggle for autonomy and yet they realize that both need each other to ensure that person with HSN can enjoy quality of life that can minimize parental or caregiver burden. All these are further affected by the nature of micro and macro ecosystems that exists in a given context.
g. The nature of ecological framework can help us understand the multiple levels of factors and stressors that interact and influences families/primary caregiver. The work of Bronfenbrenner (1979) who conceptualized microsystem, mesosystem, and exosystem levels which interact with each other. These systems if strengthened can greatly support or mitigate the nature of care-giving burden and enhance the overall quality of life for families and HSNs..

h. Besides provisions in the Legislation actual schemes, programs, benefits and schemes have to be developed not just in urban context but also across rural context both at the National and State Levels.

Check Your Progress

1. Define the nature of High Support Needs
2. Describe the two way nature of interaction between the care giver and care – recipient that occurs during the care-giving process.
3. Write a short note on of both the caregiver and care-recipient:
4. Objective burdens
5. Subjective burdens
6. Psychological burdens
7. Describe the four pathways of care-giving trajectory across life span.
8. Both Care-giver and Care-recipient experiences tensions in their relationship. Describe the possible reasons for the same.
9. What are the protective factors in a family that can reduce the care-giving burden on the care-givers?.
10. What are the protective factors that can enhance the quality of life of person with HSN?
11. Describe the nature of Ecological Framework of Uri Bronfenbrenner

12. Explore the Ecological Framework and its impact on meeting the needs of a person with HSN.
13. Describe the nature of service delivery areas that are currently not available or available in very limited places and how they can be enhanced to provide support for families with HSN.

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CHAPTER- 7

CATERING TO THE NEEDS OF CARER OF GERIATRIC GROUPS

- *Dr. Himangshu Das*

Introduction

People with high-support needs in the category of multiple disabilities are not a homogenous group, apart from the inherent characteristics of varying combinations of disabilities and different severity levels of disability; there is considerable variation across age, ethnicity, health and social care needs, financial status and lifestyle.

Ageing is a natural process, which presents a unique challenge for all sections of the society. An ageing population tends to have a higher prevalence of chronic diseases, physical limitations, mental health concerns and other co-morbidities. And when it ageing is clubbed with the existing condition of multiple disability (MD) among the high-support need (HSN) population, there is a multi-fold impact on not just the individual but also her/his family.

Addressing the unmet care and support needs of geriatric group of high-support need individual with multiple disability; and designing services and planning solutions, is an urgent priority. And in order to address those needs effectively, it is important to identify and understand the care and support needs from the perspectives of older people with disabilities and their families. In this chapter, we aim to understand and gain this perspective, in order to better facilitate the services.

Geriatric Population with MD-HSN

In India, geriatric populace or the older adults or elderly individuals are people above the age of 60 years. When people with multiple disabilities & high-support needs grow older, many of their needs will be the same as that of any elderly person living in the community, but professionals who work for generic services for the elderly do not have the specialized knowledge and experience to relate to persons with Multiple-Disabilities having High-Support Needs (MD-HSN). At the same time professionals trained in multiple-disabilities who have been able to meet the needs of individuals in their earlier years, may not always feel confident when there are age-related health and social support needs when the individual gets older.

The life-expectancy of people with MD- HSN is increasing with the medical and social advances. And therefore, more people with multiple-disabilities now outlive their parents. The needs of an old person with multiple disability and an elderly parent may conflict. Therefore, the cooperation between the generic service providers for the elderly and disability-specific professionals is highly essential to cater to the needs of family.

Lifestyles: Adults with MD-HSN may be offered lifestyles that are passive and sedentary. This can present consequent risks of physical deconditioning and obesity-related diseases; and may also result in long-term risks through exposure to neglect and contagious diseases.

Physical Health& Safety: Inadequate personal skills, sensory and mobility impairments, morbid obesity, poor oral hygiene, sexual behaviour, and other lifestyle or personal attributes can also contribute to health, well-being and safety of the individual; more so if it is a woman with disability. Additionally, accessing services for physical restoration, sensory impairments (hearing/vision), dental care and other health-related services may be extremely challenging for elderly people with MD-HSN.

Obtaining Health Services: As people with MD-HSN grow older, as with other elderly people, mobility and access to transport can be a real hurdle to getting medical attention. Additionally, when their carer becomes elderly, frail and physically restricted; their access to healthcare professionals becomes very challenging. It is common practice, that general medical practitioners rely on the information given by family members to prescribe treatment; however, as parents become elderly they may become less observant to changes in the health and recognizing the signs and symptoms of illness. Access of persons with MD-HSN to health care provision may be restricted due to a variety of factors, like:

- Lack of training of healthcare professionals on MD-HSN
- Lack of training on health issues relative to geriatric population with MD-HSN
- Lack of pertinent information on the medical history of the individual
- Difficulties to administer medical examination due to communication or behavioural issues
- Lack of understanding by medical practitioner on concerns of informed consent etc.

Additionally, barriers due to stigma and negative attitude of the family/community, can influence the willingness of carers to pursue healthcare, especially if they have to undertake travel and financial costs beyond means.

Mental Health: Psychiatric disorders including depression, anxiety disorder, delusional disorders and affective disorders, are more common among elderly people with multiple-disabilities as compared to general elderly population. Dementia is also more frequently observed among people with multiple-disabilities, particularly those having intellectual disability; and the incidence rises as the longevity increases.

Women's Health Concerns: Because women with MD-HSN may have more sheltered lives, their exposure to available health care may be even more significantly limited. Also, very little is known about menopause, osteoporosis, amenorrhea etc in women with MD-HSN. Also, given their relative inability to defend themselves and/or lack of knowledge about their rights, women with MD-HSN are often victims of physical and sexual abuse. Also, those who take psychotropic medication and/or anti-epileptic drugs may see such medication interfere with hormonal and metabolic functions; which may have long-term effects on their health. Women with MD-HSN may be subjected to irreversible medical procedures such as endometrial ablation, hysterectomy, sterilization, without their consent. Such procedures raise important legal, ethical and bioethical issues.

Mobility and ADL Care: Difficulties with walking, changing body positions, lifting and carrying objects, hand and arm use, inability to change and maintain body positions like kneeling, bending, standing etc needed to perform activities of daily living (ADL) and self-care; pose challenges on individuals with MD-HSN. Challenges and dependence in dressing bathing, toileting, grooming, eating, drinking etc; pose an additional range of physical, social and psychological impacts on the person with MD-HSN.

Behavioural Management: Adults with MD-HSN may have difficulty in cooperating with receiving assistance for meeting self-care needs and also during medical examinations/interventions. They may face confusion, fear and frustration; when someone attempts to provide them health care services. Extra time may be necessary to reassure her/him in order to help acclimate to medical intervention or medical examination setting.

Bereavement: For almost everyone, the death of a parent will cause deep and enduring grief. For people with MD-HSN loss of a parent, especially a sole surviving parent, will not only be bereavement of a parent, but also of the person who cared the most for them throughout their lives. Also, the sudden change of care-provider may cause confusion, fear, unhappiness and result in behavioural symptoms including anxiety and depression.

Aids and Appliances: Assessing the need of and training on use of assistive or prosthetic devices such as canes, walkers, braces, dentures, eyeglasses and hearing aids; may require special intervention. Additionally, because communication and behavioural issues can play an important role in addressing these needs in case of elderly with MD-HSN. Therefore, training and exposure of family members and professionals to recognize early signs/symptoms of common geriatric problems is essential to effectively understand the special needs of aids and appliances; along with the existing inherent need of aids/appliances required as per the disability-specific necessity of the individual.

Services needed: Apart from therapeutic services like physiotherapy, occupational therapy, counselling, sensory integration etc; elderly with MD-HSN may need extensive intervention for medical needs, food and nutrition, self-care & hygiene, psycho-emotional, financial support, social welfare, legal-support, advocacy, guardianship, recreation and leisure, companionship, aids and appliances etc.

An ageing population tends to have a higher prevalence of chronic diseases, physical disabilities, mental illnesses and other co-morbidities. The health needs and health related problems of elderly cannot be viewed in isolation. A wide gamut of determinants such as family dynamics and family specific concerns, maltreatment towards elderly, poor knowledge and awareness about risks, psycho-emotional concerns, financial constraints etc determine the needs of services and its impact on the quality of life of the individual.

Prevention and control of health problems of elderly population with MD-HSN requires a multi-faceted approach that incorporates active collaboration of health care, social welfare, legal sector, rehabilitation service providers and family members. Measures such as improving the knowledge about health-care needs and potential risk factors, and developing social measures like culture that fosters siblings or other family members who voluntarily take responsibility of looking after their aged-siblings with MD-HSN can work effectively in the long run. Also, advocating for health insurance schemes to cover their health-care needs and construction of elderly-friendly homes can help build a strategic plan for achieving the improved services for the population with MD-HSN.

Understanding the needs of the Carers of an elderly with MD-HS

Parents who continue to care for a child with MD-HSN in their adulthood, will have their own health and social support needs due to aging. Many carers at this stage may have lost a spouse and may be the only surviving parent, which doubles their task of caring for their daughter or son with special needs. Aging carers and their adult children will have a complex set of individual and joint needs.

The caring parent may have their **own physical or mental health concerns** due to aging. Some common problems include decreased mobility which leading to difficulty in climbing stairs, cleaning the house, cooking, inability to go out to buy groceries, visit the doctor etc. Family and social networks tend to collapse, or become inactive, as people get older; and if the household has an elderly parent(s) having an aging daughter/son having MD-HSN, they are more likely to be cut-off from sources of informal support from family, friends and neighbours. The composition of the family may have also changed, not only through possible deaths, but also as other children leave home due to marriage.

Social isolation of elderly carers: Parents of children with MD-HSN and/or challenging behaviours, may become isolated from family and social networks much earlier in their lives, because of their all-pervasive caring role. In later years, their isolation may thus be even greater. Such isolation, especially of mothers, can result not only due to their own commitments as home-maker, but also because as their children grow they tend to have less in-common with their friends/ relatives who have children of the same age.

Planning for the future: Planning for the future for children with MD-HSN should ideally start long-before the problems associated with age and aging become relevant. However, as per research, parents who have cared for someone since they were born often wish to continue to look after them until some unspecified time in the future, and may refuse to contemplate letting them go into residential care. Also, as other children of the family leave home, parents tend to feel more responsible towards catering the needs of their child with special needs. This may also happen because of their lack of awareness of other options like residential facilities, co-living homes, care by sibling/relatives etc.

In order to pan future services for families, it is important to determine whether parents have continued to care for a child by choice, or because they do not consider that any alternative is appropriate or acceptable. It is always essential to facilitate continuing involvement of parents in care-planning, as they have intimate knowledge and understanding of their child's needs. Sensitive communication with families to properly understand and record the support needs of individuals is critical for professionals. Planning for the future should include recognizing inevitable separation by death, and the need to anticipate emotional as well as practical needs.

Division of labor with care-giving support: The predominance of traditional division of labour in household, even where women are working on full-time basis and combining other roles such as simultaneously taking care of their children with special needs is a common practice. This unequal division of care-giving responsibility needs to be relooked as both the child and her/his parents age.

Legal Guardianship: A guardian is a person who is appointed to look after another person or her/his property. She or he assumes the care and protection of the person for whom she/he is appointed as the guardian. The guardian takes all legal decisions on behalf of the person and her/his property when she/he is a minor (below 18 years of age). However, persons with MD-HSN even after they have acquired 18 years of agemay not always be capable of managing their own lives or taking legal decisions for their own betterment. Therefore, they may require someone to represent their interests in the legal areas throughout their lives. This need of appointment of a legal guardian for the individual at an earliest must be taken into consideration by the family.

Parental Psychological Health: The level of stress and its impact on psychological health of both parents is equal. And parents may face problems such as sleeping disorders, anxiety, depression etc which can impact their daily tasks of living and their overall sense of difficulty with respect to care-giving. Therefore, addressing the needs of maintaining parental psychological health is of extreme significance for the long-term wellbeing and quality of life of the family.

Most parents of children with disabilities demonstrate patterns of resilience and effective coping with their parenting responsibilities, even though they when they are posed with greater difficulties in psychosocial functioning than the general population. Therefore, as professionals we must have a holistic perspective while establishing the long-term outcomes for these parents through their midlife and into the early years of old age.

Understanding services for geriatric group

Different parts of the country vary in the **models of services** that are available for individuals with MD-HSN. And it is important to take note of the modifications needed in the various practices and service-delivery models for geriatric population with MD-HSN. Specific services providing physical and mental health care for persons with MD-HSN, regardless of their age, are not necessarily available throughout the country. Services that specifically provide care to older people with MD-HSN are extremely rare. Moreover, in some cases due to poverty and other issues, basic life necessities are also barely available for the general population; and persons with MD-HSN are often the last to benefit when basic health or mental health services are made available.

The goal in the development of **specialty services** is to include the maintenance of respect and dignity of the individual and her/his family, inclusion of the persons needs and wishes in any support plan, and development of support plans that are minimally restrictive, culturally sensitive, and which foster the growth and autonomy of the person. The aim of such services must include:

- Provision of meeting personal care needs
- Practical, leisure or life-enhancing skills
- Improved or maintained dietary and general health status
- A varied rhythm of life
- Productivity through old-age
- An increased and well-established social network
- Participation in community life, with friends and acquaintances

Many families rely on **institutional or residential settings** to provide care for the individual with MD-HSN, and as she/he ages they are under constant pressure maintain care over a longer period of time. Safety nets must be developed to ensure that in absence of family support, persons with MD-HSN do not find themselves abandoned to starve or condemned to poorly organized and inadequate services. Decisions about when to maintain in-home care or to plan for out-of-home living should be guided by considerations of services needed, consumer choice, service availability, current and future health needs and the potential consequences of transitions. Housing for the elderly people with MD-HSN must be viewed as more than a mere shelter, as it also holds a psychological and social significance. In India, life in a rural setting may be a more typical dwelling place, with conditions greatly conducive for inclusion in the community. However, even in isolated/segregated facilities inclusion and participation in community activities must be consistently targeted.

Families who continue to provide lifelong care require suitable support. **Long-term family care** support needed by such families depend on the services available in their locality as well as the cultural attitude and support available to them. The social and health-care needs of such families should be of high priority and met through appropriately focused services. Additionally, their social networks including family members, service providers and other families/peers with MD-HSN have an immense potential for enriching their lives by increasing opportunities of social participation for everyone involved.

Training of professionals in various service-delivery models to integrate aging-related issues and needs of elderly with MD-HSN, into their existing practices is highly essential. And, in case of progression toward integration of elderly with MD-

HSN into generic elderly services also require that professionals in those services receive training with respect to both MD-HSN and their age-related needs.

Promoting mental health through early identification and holistic assessment of behaviours attributed to life-stressors and mental-health disorders like depression, anxiety and dementia in older people with MD-HSN is highly essential. Increasing mental-health knowledge and skills in professionals, carers and families of elderly with MD-HSN must be targeted to improve their quality of life.

Palliative care is defined as the active, total care of people who are not responsive or have active participation in intervention/care being provided. Management of pain and other symptoms of social/psychological issues are the primary target of such services. However, adults with MD-HSN often have unique issues, challenges and circumstances that make it more difficult to meet those needs. Some of such challenges may include:

- Communication difficulties
- Unconventional ways of expressing signs and symptoms of ill health or distress
- Multiple co-morbidities
- Complex family and social circumstances
- Higher levels of behavioural or psychiatric problems
- Limited ability or inability to participate in decision making etc

Assessment and control of pain and other symptoms if the person in unable to communicate with words is highly essential to address the distress of elderly with MD-HSN. Pain is often the first indicator of injury and illness, and this warning sign could be easily missed in case of geriatric population having MD-HSN, along with other symptoms such as nausea, dysphagia, fatigue etc. as the individual may communicate them in a different way. Observation along with close knowledge of what is normal behaviour for the individual are needed along with close cooperation between health professionals and carers of the adult with MD-HSN in order to identify the possible causes of distress. Therefore, for healthcare professionals and carers, it is essential to note following behaviours and pick-up signs and symptoms related to illnesses:

- Vocal responses like crying or moaning
- Adaptive behaviours like rubbing of affected area or avoiding certain movements
- Self-distracting behavious like rocking, pacing, biting hand or gesturing
- Facial expressions such as frowning, scowling, smirking or grimacing
- Withdrawal or low mood
- Sleep disturbance
- Self-injurious behaviour
- Hyperactive behaviour
- Autonomic changes like increased/decreased pulse, BP, sweating etc

Paid carers also need attention and support, as they are often poorly trained and unprepared to work with elderly with MD-HSN who are ill, dying or bereaved. However, the bonds they form with people they support can be strong, and they too may be bereaved if someone with MD-HSN passes away. It is essential that paid carers must be given requisite training and support from both health-care and palliative care professionals and service providers.

Financial concerns and needs is a grey area that also needs attention for provision of services to geriatric population having MD-HSN. With the costs involved to meet the therapeutic, medical, aids and appliances, paid-carer, community participation, transport etc needs; and the eventuality of passing away of parents. Service providers need to identify and address the underlying worry of meeting finance related needs to care for the population.

Elderly with MD-HSN are no less deserving of high-quality palliative and health care than the general population. However, they along with their caregivers and professionals face considerable barriers, some of which are easier to overcome than others. However, planning for their care which is assisted with tools and strategies for communication and treatment, in collaboration with their family, professionals and community can help evolve an approach to ensure their long-term care, wellbeing and quality of life.

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CHAPTER - 8

RPWD ACT 2016 AND HIGH SUPPORT NEED

- *Alkananda Bandyopadhyay (Roy)*

Objectives

The objectives of this chapter are

1. Explain the definition of High Support Need with reference to RPWD Act 2016.
2. Define the criteria for level of high support needs.
3. Enumerate the special provisions for persons with disabilities along with the schemes and benefits for high support need.
4. Explain the various articles in reference to RPWD 2016 on HSN
5. Explain Legal Guardianship, Insurance and Special Medical Care for PHSN.

Introduction

The necessity to develop right based model of disability was endorsed in the Rights of Persons with Disabilities Act 2016 ever since India's ratification with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The paradigm shifts from the medical approach to the medical-social model and from social welfare concern to human rights issue is reflected in Rights of Persons with Disabilities (RPWD Act 2016) which replaced the Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act 1995.

The RPWD Act makes provision that "the Government shall ensure that persons with disabilities enjoy the right to equality, life with dignity and respect for his or her own integrity equally with others. The RPWD Act 2016 ensures right based model of disability from 7 to 21 conditions and it now includes persons with cerebral palsy, dwarfism, muscular dystrophy, acid attack victims, hard of hearing, speech and language disability, specific learning disabilities, autism spectrum disorders, chronic neurological disorders such as multiple sclerosis and Parkinson's disease, blood disorders such as haemophilia, thalassemia, and sickle cell anaemia, and multiple disabilities. Special provisions for persons with benchmark disabilities or persons with high support needs.

The RPWD 2016 has come out with new provisions which are applicable for persons with "high support needs category". High Support Need refers to people who need custodial care and assistance in day-to-day life and who are dependent on others.

RPWD 2016 defines persons with high support needs as those who need "an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision, and to access facilities and participating in all areas of life including education, employment, family, community life, treatment and therapy.

Daily Activities include activities of daily living like bathing, personal hygiene and grooming (including brushing/combing, dressing) toilet hygiene, walking, get in and out of bed, and get into and out of a chair; the broader definition (moving from one place to another while performing activities). In addition to this, High Support includes psychological support which means, support relating to the mind and management of emotions and moods etc. This support is required so that a person with disabilities can make decisions and make use of various facilities for education, employment, etc. As for example a sign language interpreter, for instance, enables a person with Hearing Impairment to work in a mainstream work environment. A personal assistant helps a person with Locomotor Disability who is wheelchair user to travel. A person with profound intellectual disability might require support on a day to day basis to develop his/her communication skills or to perform the activities of daily living.

The purpose of High Support is also to ensure that a person with disability gets equal opportunity to participate in family life and is included in the community life. It also ensures proactive participation of the person with high support need in his/her own therapeutic intervention sessions.

RPWD 2016 will allow people with 40% and more benchmark disability who meet the criteria of special needs to receive the benefit of schemes created for them. District level assessment boards will decide and recommend welfare and support benefits for them.

Definition

High Support Need and Benchmark Disabilities

As defined by Rights of Persons with Disabilities Act 2016 , "High Support" means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life including education, employment, family and community life and treatment and therapy.

RPWD 2016 defines "person with benchmark disability" means a person with not less than forty percent of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority.

The certified authorities may be district level assessment boards who will decide and recommend welfare and support benefits for them.

Criteria for Levels of High Support Needs

High Support means rigorous support, which may be required by a person with Benchmark Disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life including education, employment, family and community life and treatment and therapy.

A person with Benchmark Disabilities who needs High Support has to apply to an authority requesting them to provide High Support. Any other person or organization may also apply on behalf of the person who needs High Support. When such an application is received by the authority it will be referred to an Assessment Board, which after assessing the case should submit a report to the authority. The Assessment Board certifies the need for High Support and the nature of that support. As per this report the authority is required to provide support to the person with Benchmark Disability. (The authority to which such an application for High Support can be made is to be notified by the Government. Similarly, who shall constitute the Assessment Board is also notified by the Government)

Under the amended rules 2019 of RPWD Act the State Government shall constitute an assessment board at the district level or division level based on the number of persons identified with benchmark disabilities that require high support. The board must have a chairperson and eight members. A district medical officer, a civil surgeon or medical superintendent can be appointed as the chairperson of the assessment board. The state government may develop schemes to provide high support to eligible beneficiaries.

For implementation of the RPWD Act each state needs to frame rules. So far as per the data received with the department of empowerment of persons with disabilities only 11 states have framed rules. The state that has already framed rules include Arunachal Pradesh, Bihar, Delhi, Sikkim, Mizoram, Madhya Pradesh, Jharkhand, Telangana, Tamil Nadu and Uttar Pradesh. It may be noted that many states are still to implement the law.

It is stated in the rules that only persons with benchmark disabilities having permanent certificate of disability shall be eligible for applying for high support requirement. The board will assess the applicants based on different parameters.

Maximum weightage is assigned to the extent to which daily activities of a person are affected due to disability. Weightage is also assigned to severity of physical impairment and intellectual impairment that restricts any person form taking any informed decision.

The board will also assess the cognitive abilities, socio economic status and environmental barriers like access to health care or support system for rehabilitation of the applicants.

Special Provisions for Persons with Disabilities with High Support Needs

Section 38 and sub sections of RPWD Act 2016 states special provision for persons with disabilities. RPWD 2016 states that any person with benchmark disability having disability certificate and who considers himself to need high support, or any person or organisation on his or her behalf, may apply to an authority, to be notified by the appropriate Government, requesting to provide high support. On receipt of the application, the authority shall refer it to an Assessment Board consisting of such Members as may be prescribed by the Central Government. The Assessment Board shall assess the case in such manner as may be prescribed by the Central Government and shall send a report to the authority certifying the need of high support and its nature. On receipt of a report, the authority shall take steps to provide support in accordance with the report and subject to relevant schemes and orders of the appropriate Government in this behalf

Schemes and Benefits for Persons with High Support Needs

'Person with disability having High Support needs' means a person with Benchmark Disability who needs intense support - physical, psychological or otherwise, to carry out activities of daily living, access facilities/services and to take decisions. The rights and entitlements for persons with disabilities as well as HSN are as follows:

- ***Equality and Non-Discrimination:***

The appropriate Government shall ensure that the persons with disabilities including persons with HSN enjoy the right to equality of life with dignity and respect.

It is the responsibility of the Government to take steps to utilise the capacity of persons with disabilities by providing appropriate environment. No person with disability shall be discriminated on the ground of disability. No person shall be deprived of his or her personal liberty only on the ground of disability. The appropriate Government shall take necessary steps to ensure reasonable accommodation for persons with disabilities.

- ***Women and children with disabilities*:**

The appropriate Government and the local authorities shall take measures to ensure that the women and children with disabilities enjoy their rights equally with others. The appropriate Government and local authorities shall also ensure that all children with disabilities have right on an equal basis to freely express their views on all matters affecting them and provide them appropriate support keeping in view their age and disability.

- ***Community life***

The persons with disabilities shall have the right to live in the community. The appropriate Government shall endeavour that the persons with disabilities are not obliged to live in any fixed living arrangement; and given access to a range of in-house, residential and other community support services, including personal assistance necessary to support living with due regard to age and gender.

- ***Protection from cruelty and inhuman treatment:***

The appropriate Government shall take measures to protect persons with disabilities from being subjected to torture, cruel, inhuman or degrading treatment. No person with disability shall be a subject of any research without his or her free and informed consent obtained through accessible modes, means and formats of communication; and prior permission of a Committee for Research on Disability.

- ***Protection from abuse, violence and exploitation:***

The appropriate Government shall take measures to protect persons with disabilities from all forms of abuse, violence and exploitation and to prevent the same, shall
(a) take cognizance of incidents of abuse, violence and exploitation and provide legal remedies available against such incidents;

(b) take steps for avoiding such incidents and prescribe the procedure for its reporting;

(c) take steps to rescue, protect and rehabilitate victims of such incidents; and

(d) create awareness and make available information among the public.

Further any person or registered organisation who or which has reason to believe that an act of abuse, violence or exploitation has been, or is being, or is likely to be committed against any person with disability, may give information about it to the Executive Magistrate within the local limits of whose jurisdiction such incidents occur.

The Executive Magistrate on receipt of such information, shall take immediate steps to stop or prevent its occurrence, as the case may be, or pass such order as he deems fit for the protection of such person with disability including an order:

(a) to rescue the victim of such act, authorising the police or any organisation working for persons with disabilities to provide for the safe custody or rehabilitation of such person, or both, as the case may be;

(b) for providing protective custody to the person with disability, if such person so desires;

(c) to provide maintenance to such person with disability.

It is also notified that any police officer who receives a complaint or otherwise comes to know of abuse, violence or exploitation towards any person with disability shall inform the aggrieved person of

(a) his or her right to apply for protection under sub-section *(2)* and the particulars of the Executive Magistrate having jurisdiction to provide assistance;

(b) the particulars of the nearest organisation or institution working for the rehabilitation of persons with disabilities;

(c) the right to free legal aid; and

(d) the right to file a complaint under the provisions of this Act or any other law dealing with such offence:

Provided that nothing in this section shall be construed in any manner as to relieve the police officer from his duty to proceed in accordance with law upon receipt of information as to the commission of a cognizable offence.

If the Executive Magistrate finds that the alleged act or behaviour constitutes an offence under the Indian Penal Code (45 of 1860), or under any other law for the time being in force, he may forward the complaint to that effect to the Judicial or Metropolitan Magistrate having jurisdiction in the matter

- ***Protection and safety:***

(1) The persons with disabilities shall have equal protection and safety in situations of risk, armed conflict, humanitarian emergencies and natural disasters.

(2) The National Disaster Management Authority and the State Disaster Management Authority shall take appropriate measures to ensure inclusion of persons with disabilities in its disaster management activities as defined under clause *(e)* of section 2 of the Disaster Management Act, 2005 (53 of 2005) for the safety and protection of persons with disabilities.

(3) The District Disaster Management Authority constituted under section 25 of the Disaster Management Act, 2005 (53 of 2005) shall maintain record of details of persons with disabilities in the district and take suitable measures to inform such persons of any situations of risk to enhance disaster preparedness.

(4) The authorities engaged in reconstruction activities subsequent to any situation of risk, armed conflict or natural disasters shall undertake such activities, in consultation with the concerned State Commissioner, in accordance with the accessibility requirements of persons with disabilities

- ***Home and family:***

It is a mandate that no child with disability shall be separated from his or her parents on the ground of disability except on an order of competent court, if required, in the best interest of the child. Where the parents are unable to take care of a child with disability, the competent court shall place such child with his or her near relations and failing that within the community in a family setting or in exceptional cases in shelter home run by the appropriate Government or non-governmental organisation, as may be required.

- ***Reproductive right:***

The appropriate Government shall ensure that persons with disabilities have access to appropriate information regarding reproductive and family planning. No person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent

- ***Accessibility in voting:***

The Election Commission of India and the State Election Commissions shall ensure that all polling stations are accessible to persons with disabilities and all materials related to the electoral process are easily understandable by and accessible to them.

- ***Access to justice:***

(1) The appropriate Government shall ensure that persons with disabilities are able to exercise the right to access any court, tribunal, authority, commission or any other

body having judicial or quasi-judicial or investigative powers without discrimination based on disability.

(2) The appropriate Government shall take steps to put in place suitable support measures for persons with disabilities specially those living outside family and those disabled requiring high support for exercising legal rights.

(3) The National Legal Services Authority and the State Legal Services Authorities constituted under the Legal Services Authorities Act, 1987 (39 of 1987) shall make provisions including reasonable accommodation to ensure that persons with disabilities have access to any scheme, programme, facility or service offered by them equally with others.

(4) The appropriate Government shall take steps to—

(a) ensure that all their public documents are in accessible formats;

(b) ensure that the filing departments, registry or any other office of records are supplied with necessary equipment to enable filing, storing and referring to the documents and evidence in accessible formats; and

(c) make available all necessary facilities and equipment to facilitate recording of testimonies, arguments or opinion given by persons with disabilities in their preferred language and means of communication.

- ***Legal capacity:***

(1) The appropriate Government shall ensure that the persons with disabilities have right, equally with others, to own or inherit property, movable or immovable, control their financial affairs and have access to bank loans, mortgages and other forms of financial credit.

(2) The appropriate Government shall ensure that the persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life and have the right to equal recognition everywhere as any other person before the law.

(3) When a conflict of interest arises between a person providing support and a person with disability in a financial, property or other economic transaction, then such supporting person shall abstain from providing support to the person with disability in that transaction:

Provided that there shall not be a presumption of conflict of interest just on the basis that the supporting person is related to the person with disability by blood, affinity or adoption.

(4) A person with disability may alter, modify or dismantle any support arrangement and seek the support of another:

Provided that such alteration, modification or dismantling shall be prospective in nature and shall not nullify any third-party transaction entered into by the person with disability with the aforesaid support arrangement.

(5) Any person providing support to the person with disability shall not exercise undue influence and shall respect his or her autonomy, dignity and privacy.

- ***Specific measures to promote and facilitate inclusive education:***

The appropriate Government and the local authorities shall take the following measures for the purpose of section 16, namely:

(a) to conduct survey of school going children in every five years for identifying children with disabilities, ascertaining their special needs and the extent to which these are being met:

Provided that the first survey shall be conducted within a period of two years from the date of commencement of this Act;

(b) to establish adequate number of teacher training institutions;

(c) to train and employ teachers, including teachers with disability who are qualified in sign language and Braille and teachers who are trained in teaching children with intellectual disability;

(d) to train professionals and staff to support inclusive education at all levels of school education;

(e) to establish adequate number of resource centres to support educational institutions at all levels of school education;

(f) to promote the use of appropriate augmentative and alternative modes including means and formats of communication, Braille and sign language to supplement the use of one's own speech to fulfil the daily communication needs of persons with speech, communication or language disabilities and enables them to participate and contribute to their community and society;

(g) to provide books, other learning materials and appropriate assistive devices to students with benchmark disabilities free of cost up to the age of eighteen years;

(h) to provide scholarships in appropriate cases to students with benchmark disability;

(i) to make suitable modifications in the curriculum and examination system to meet the needs of students with disabilities such as extra time for completion of examination paper, facility of scribe or amanuensis, exemption from second and third language courses;

(j) to promote research to improve learning; and

(k) any other measures, as may be required.

- ***Adult education:***

The appropriate Government and the local authorities shall take measures to promote, protect and ensure participation of persons with disabilities in adult education and continuing education programmes equally with others.

- ***Duty of educational institutions:***

The appropriate Government and the local authorities shall endeavour that all educational institutions funded or recognised by them provide inclusive education to the children with disabilities and towards that end shall—

(i) admit them without discrimination and provide education and opportunities for sports and recreation activities equally with others;

(ii) make building, campus and various facilities accessible;

(iii) provide reasonable accommodation according to the individual's requirements;

(iv) provide necessary support individualised or otherwise in environments that maximise academic and social development consistent with the goal of full inclusion;

(v) ensure that the education to persons who are blind or deaf or both is imparted in the most appropriate languages and modes and means of communication;

(vi) detect specific learning disabilities in children at the earliest and take suitable pedagogical and other measures to overcome them;

(vii) monitor participation, progress in terms of attainment levels and completion of education in respect of every student with disability;

(viii) provide transportation facilities to the children with disabilities and the attendant of the children with disabilities having high support needs.

Additional **benefits** such as reservation in **higher** education (not less than 5%), government jobs (not less than 4 %), reservation in allocation of land, poverty alleviation **schemes** (5% allotment) etc. have been provided for **persons with benchmark disabilities** and those with **high support needs**.

- ***Employment:***

Section 34 (1) of the Act provides 4% reservation to people with benchmark disabilities - one per cent for each category, namely:

a) blindness and low vision;

b) deaf and hard of hearing;

c) locomotor disability including cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy;

d) autism, intellectual disability, specific learning disability, mental illness and multiple disabilities.

Various Articles in Reference to RPWD 2016 on High Support Need

- According to Section 31 of the act, a child with benchmark disability between the age of six to eighteen years shall have the right and access to free and compulsory education in a neighbourhood school,special school, or any school of his choice in an appropriate environment.
- Section 32 (1) of RPWD Act 2016 provides five percent reservation to persons with benchmark disabilities in all the Government and Government Aided higher educational institutions.

  They will also be given a relaxation of five years in upper age limit for the purpose of admission in such institutions.

- Section 34 (1) provides 4% reservation in Government jobs to the persons with benchmark disabilities such as blindness and low vision, deaf and hard of hearing; and loco motor disability including cerebral palsy, leprosy (cured) dwarfism, acid attack victims and muscular dystrophy.

  Also, 1% of the total strength of persons with benchmark disability shall be comprise of Autism, Intellectual Disability, Specific Learning Disability and Mental Illness, Persons having multiple disabilities.

- Sec 35 speaks of the appropriate Government providing incentives to private employers who ensure 5% of their workforce is comprised of people with benchmark disability.
- Sec 36 speaks about the establishment of special employment exchanges that keep a track of post and vacancies for persons with disability.
- Sec 37 states that the appropriate Government shall make schemes in favour of persons with benchmark disability by ensuring 5% reservation for allotment of agricultural land, housing related schemes, poverty alleviation and various other developmental schemes. Women find an express mention about getting priority regarding provisions under this section.
- Section - 45(1) directs authority to make all public building including schools accessible within a period of not exceeding five years of notification of rules for such purpose. Many schools in different parts of the country even lack basic amenities; therefore, due to inadequate funds and other practical reasons, the states and local bodies may not find it possible to achieve the target within the stipulated time frame.
- Section 47 directs competent authority to induct disability as a component for all education courses for schools, colleges and University teachers and conduct training programmes for sports teachers with the focus on sports, games, adventure activities for the persons with disabilities.

Legal Guardianship and Persons with High Support Need

This Act provides for the grant of guardianship by District Court. As per this act there will be a joint decision between the guardian and the person with disability. The Chief Commissioner for Persons with Disabilities and the State Commissioners will act as regulatory bodies and Grievance Redressal agencies and monitor implementation of the different sections of this Act. District level committees will be constituted by the State Governments to address local concerns of PwDs including guardianship. Details of their constitution and the functions of such committees would be prescribed by the State Governments.

Insurance and Special Medical Care for Children with HSN

- *Insurance schemes*

The health and medical needs of a person with disability/ HSN are different from others and vary based on their age, nature and severity of disability. Ageing might also bring changes in the nature of the disability. Hence support through the medical and assistive devices and techniques or other necessities of life becomes essential to make sure that a person with disability can sustain himself/ herself.

The Act provides that the Government must make insurance schemes specifically for people with disabilities.

The State Government shall, by notification, make insurance schemes for persons with disabilities or high support needs.

- ***Healthcare***

The Government and the local authorities shall take necessary measures for the persons with disabilities to provide free healthcare in the vicinity especially in rural area subject family income. The government will have to keep barrier-free access in all government and private hospitals and other healthcare institutions and centres. Persons with disabilities or persons with high support need should get priority in treatment.

The Government and the local authorities shall take measures and make schemes or programmes to promote healthcare and prevent the occurrence of disabilities and for the said purpose shall undertake surveys, investigations and research concerning the cause of occurrence of disabilities and the prevention. In addition, should promote different methods of prevention.

The government should take measures to screen all the children at least once in a year to identify at-risk children. The appropriate government shall take measures to provide facilities for training to staff of primary health centres, create awareness campaigns for disseminating information for general hygiene, health and sanitation. The government will also have to take measures for pre-natal, perinatal and post-natal care of mother and child. There should be public awareness programs through pre-schools, schools, primary health centres, village level workers and *anganwadi* workers. Mass media may be used to create awareness among the common people on the causes of disabilities and the preventive measures to be adopted. Other than this the government should ensure healthcare during the time of natural disasters and other situations of risk; essential medical facilities for life saving emergency treatment and procedures; and sexual and reproductive healthcare especially for women with disability.

Summary

The Rights of Persons with Disabilities Act 2016 is a piece of legislation happens to be a blessing to the PWDs. This Act deals with issues relating to the rights of persons with disabilities. It also mandates the Government to perform its duties in the most diligent manner and make schemes and programmes towards the welfare of the community. The implementation of the RPWD Act is to be carried out in addition to the other laws and not in place of them. In the event of a difficulty in the implementation of the RPWD Act, the Central Government has been given the power to give directions or make provisions in line with the Act or compatible with the Act, which are necessary to remove the difficulties.

Check Your Progress

1. Briefly answer the following questions.

(a)Who are Persons with high support needs?

(b)What are the health care benefits for Persons with High Support Needs?

(c) What are the Specific measures to promote and facilitate inclusive education?

(d) Write a note on Legal Guardianship and Persons with High Support Needs.

(e) Comment on the Employment opportunities for PWHSN's enumerated in RPWD Act 2016.

2. Interview five persons with high support needs above age 18 and list out their opinions about the benefits they get. Invite suggestions from them regarding the amendment and framing of new guidelines for them. Compile the opinion and suggestions in the form of an essay of 2000-2500 words.

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CHAPTER-9

GENERATING COMMUNITY SUPPORT TO MEET PARENTAL NEED

- *Benjamin Victor G*

Objectives

This unit will help you to understand

- What we know and what we still need to know on the needs of children with Multiple Disabilities
- Learning how to capitalise on their strengths.
- Importance of giving Children with Multiple Disabilities their chores and look for social opportunities.

Introduction

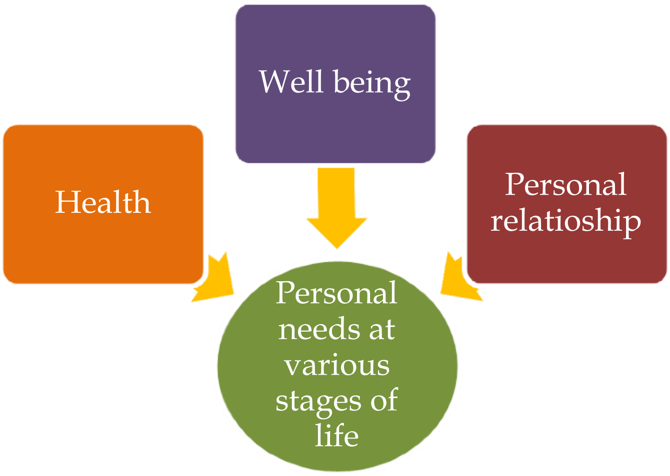
Children are not things to be moulded but are individuals to be unfolded. The education a child receives at a young age is designed to contribute to their overall development. As we all understand that Multiple Disability being a concomitant impairments (such as mental retardation-blindness, mental retardation-orthopedic impairment, etc.), unlike any other children, early childhood development and education for Children with Multiple Disabilities (CwMD) is much crucial and paramount important for minimising developmental delays and maximising their independency. Further as we know that often the impairments of CwMDs occurs in cognition, motor, and sensory functions and are present in combination with each other which combination of impairments further make them become more vulnerable and doubly disadvantaged in absence of holistic interventional services through multi-disciplinary team.

As young CwMD have unique abilities, needs and challenges which evolve/unfolds during their development process, we need to understand that an effective early childhood development program can provide the foundation for long-term physical and mental health as the intensity of their unaddressed needs means that delays are likely to have a pervasive impact on the child's development and likely to continue to impact the family and the child well beyond the early childhood years (Chen, 1997).

We further need to understand that holistic rehabilitation interventions will be the starting point for helping CwMD's successfully unfold/realize their optimal abilities. Despite, the wide heterogeneity of their characteristics, capabilities, and learning needs, these children share some common attributes besides possessing their own uniqueness as well. It would be pertinent to understand that the family members are involved in the process to help in identifying the children needs, strengths and opportunities for which mentoring parents to understand the needs of children with multiple disabilities in totality will be the first step for planning individual and family based interventions. further it will be pertinent to keep the fundamentals in mind while identifying and assessing needs of CwMDs - **Plan for**

extra time, Select appropriate assessment tools, Gather information about everyday life routine chores, **Do a "head to toe inventory" when assessing communication** and a**lways assess sensory and motor skills.**

Personal needs:



One of the most fundamental challenges that the parents and the caretaker of CwMD face is addressing to the personal needs of children across their different developmental stages (eg. Personal needs during childhood period, adolescence period and adult period). Further understanding to the personal needs of children with multiple disabilities will be the foundation for optimising the meaningful acquisition process of socio, emotional, communication, functional academics, and life skills health, wellbeing and personal relationship. The personal needs of CwMD's can be categorised into 2 level as follows,

a. Individual level
b. Family level and Community level

Individual level personal needs are those needs that are basic in nature to every individuals such as eating, drinking, brushing, bathing, toileting, grooming, dressing, etc.,. CwMDs due to their sensory-motor coordination difficulties and other limitations will exhibits diversified level of individual attention on the above personal needs which will have to be considered and carefully assessed while planning for their subsequent interventions. As we know that the fulfilment of these above fundamental needs are often driven by the family customs, belief, practices with a direct impact of their socio-economic status, it would be imperative for us to understand that the common thumb rule is create and built interest based upon the like and dislikes which will accelerate the learning and independency of CwMDs.

Family level and Community level personal needs are those needs those will facilitate and create platform for the child to be optimally independent, be accessible, feel secured and confident. An understanding to these needs will also help the families anticipate, and become sensitive to the child's personal needs besides helping family members and the community members to assertively help and assist CwMDs.

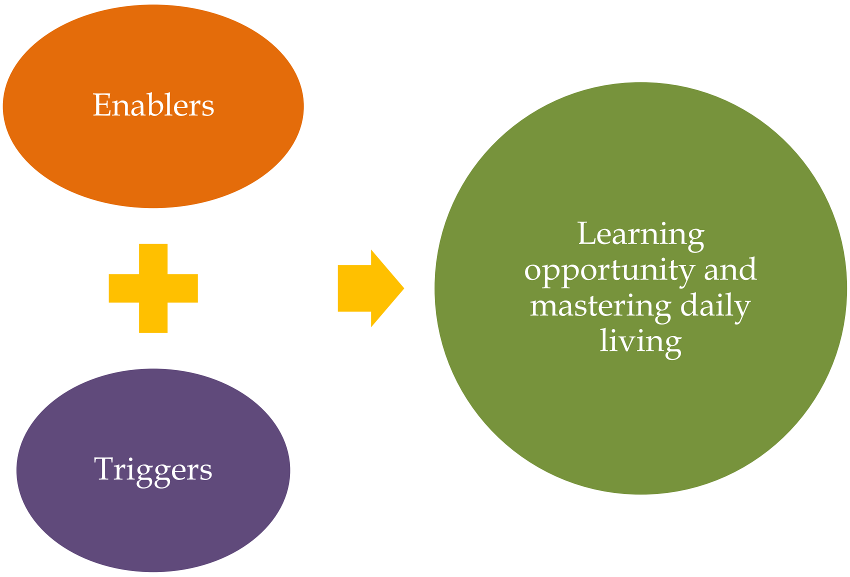
Indicative ready reckoner box

Due to the sensory motor deficits, impaired cognitive function, co-ordination difficulties, etc., the range of broad common needs of CwMDs in personal area based on the severity are as follows

Personal needs of CwMDs	*Needs/recruitment*
Eating	Inability to express like, dislikes and wants, difficulty in chewing, swallowing, sucking, licking, drooling with oral problems, hand-mouth coordination problem,
Brushing	Inability to express like, dislikes and wants, spitting and oral problems, co-ordination difficulties
Bathing	Inability to express like, dislikes and wants, planning and co-ordination difficulties for applying soap, water, wiping self, etc.,
Drinking	Inability to express like, dislikes and wants, swallowing, sucking, licking, drooling with oral problems, hand-mouth coordination problem,
Toileting	Inability to express wants, poor bowel and bladder control, utility of toilet, cleaning after defecation, washing hands after defecation,
Grooming	Inability to express like, dislikes and wants, poor fine motor coordination for combing (platting of hair*), applying powder, nail grooming, etc.,
Dressing	Inability to express like, dislikes and wants, identifying dress inner and outside, fine motor coordination for buttoning/zipping/hooking, etc.,
Menstrual health care*	Inability to express needs, difficulties to apply, remove sanitary pads, dispose, washing and self-care etc.,

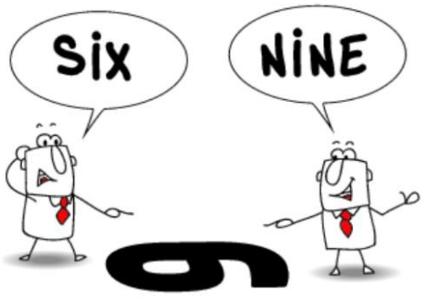
We know that as the intensity of the personal needs multiples with the severity level of CwMDs, it is further crucial for us to understand that, sensitivity and considerate to the emerging needs of CwMD's in their due course of development such as menstrual care and hygienic, adolescent behaviours, psycho-social needs, etc., and assisting parents/care takers to be sensitive to these personal needs will further make persons with multiple disabilities become more comfortable, independent and productive with age appropriate experiences of all the various strategies and approaches *Ecological based approach* will provide better learning opportunities and help the child to capitalise on their strengths. Further through this intervention CwMD may be provided opportunity for their personal daily chores which will be provide opportunity for social participation.

Ecological based interventions refer to the mapping the child ecosystem and identifying triggers and enablers that will help these children learning and achieve optimal independency. Given the present day of family life style context, ecology based intervention with child centric approaches for training and assisting CwMDs will help them to learn, integrate and master their daily living skills besides creating opportunity learning and sensitivity to the developmental and anticipated personal needs of CwMDs by family members.



Training CwMD's on expressing these basic needs and to cooperate appropriately for completing/fulfilling these needs will be the starting point for making them independent in their individual needs. One of the most crucial thing, often the care taker or special educator fails to understand on the needs perspective of CwMD is the like and dislikes of these children. It will be pertinent that the special educator/program planner includes the care taker, family members as partner in the special educational program to help families understand and comprehend the child overall interest while assisting the child

Further, we need to understand that, training CwMD's in their personal needs could possibility be achieved through *ecological based interventions* by involving all the household members which perhaps will be the starting point for planning and assisting CwMDs by giving opportunities for their daily chores and look for social opportunities towards mainstreaming. furthermore, the extend of helping parents /caretaker to effectively train their CwMDs in their personal needs lies in helping them in identifying child's personal needs, being sensitivity and building on existing strengths including families members support, creating opportunities and being persistent in daily chores built around reinforcements, etc.,



Language and Communication needs

There is a fine line that differentiates language and communication which we often fail to recognize this and hence it will be imperative that we understand the fundamentals of language and communication. While we refer to language, it means the communication modalities that depend on verbal and non-verbal methods through which information is shared and while referring to communication, it is the way two people or a group of people exchange information or messages. The subtle difference is that language is a tool while communication is the process of using that tool. Language focuses on words, symbols or signs while communication is centered on the message.

Now having understood the language and communication in a larger context, let us try to understand the language and communication needs of CwMDs which can be categorised as follows,

1. Cognitive and Sensory motor needs
2. Societal perception

Cognitive and sensory-motor needs- As we know that comprehension and expression are the fundamental upon which language and communication can be advantageously built, CwMDs due to their reinforcing nature of impairments exhibit both cognitive such as comprehending, associating, retention, etc., and sensory-motor deficits such as hearing, seeing, articulation, etc., which restrict/constraints them in their language and communication development. Further these deficits cascades as the child develops making them more vulnerable in their independent development.

It will be pertinent for us to understand that the cognition and

sensory-motor impairment deficits multiples as per the severity of the child and the child based on their impairments. Therefore it will be important for us to also know each CwMDs are unique and that there is no one individual blue print for helping children master their language and communication. Further Early interventions and an enabling ecosystem will facilitate development of language and communication to their optimal level which will vary from individual to individuals. and therefore a conscious effort to understanding the cognition and sensory motor needs of CwMDs will be imperative for assisting language and communication development of CwMDs.

Societal perception: Often the members in immediate neighbour due to their social perception either undermine and hinder the optimum development of the CwMDs which is mainly due to lack of awareness and understanding about the child and their conditions. Further, the overall attitude becomes as sympathetic rather an empathic perception which will stepping stone for helping CwMDs. The environment and ecosystem plays a major role in fostering language and communication development for a CwMDs. Needless to mention, the neighbouring and the family ecosystem are often the most significant factor that enables and triggers the child innate and incidental learning. Furthermore, making the households, family members and the immediate neighbour aware of the child need, limitation, interest, etc., will help building sensitivity, understanding and collective responsibility in helping the child in their language and communication development.

Indicative ready reckoner box

Due to the sensory motor deficits, impaired cognitive function, co-ordination difficulties, etc., the range of broad common needs of CwMDs in language and communication area based on the severity are as follows

Language & Communication needs of CwMDs	*Needs/recruitment*
Sensory functioning	Impaired sensory functioning of vision, hearing, proprioceptive, etc., cognitive deficits and sensory integration, etc.,

Oro-motor functioning	Primary function difficult of oral motor organs (lungs, vocal cord, tongue, nasal, etc., due to sensory motor coordination problem, Difficulty in chewing, swallowing, sucking, licking, blowing, drooling with oral problems, difficulties in articulation of sounds, oral problems, motor and co-ordination difficulties, etc.,
Receptive language/communication	Difficulties in comprehending processing simple instructions, gestures, directions, etc., co-ordination difficulties and inability to associate leaning experiences,
Expressive language/communication	Inability to express like, dislikes and wants through simple, gestures, verbal expression, etc.,

As we know that CwMDs due to their impairments exhibits both physical and cognition developmental delays which in the absence of an appropriate interventions cascades and results in severe conditions. Further the presence of Autism, Deaf-Blindness, Cerebral Palsy, Mental Retardation, etc., CwMDs exhibits both cognition and sensory-motor dysfunctions which impede the language and communication development to a greater extend and hence these children may develop need for *Augmentative and Alternative communication technology support*. Augmentative systems of communication are used by people who already have some speech but are either unintelligible or have limited abilities to use their speech and Alternative communication is the term used when a person has no speech. for our understanding the Augmentative and Alternative communication technology can be simply classified as follows,

- ✓ ***No-tech** communication* needs no extra equipment – it is sometimes called "unaided communication". Examples include body language, gestures, pointing, eye pointing, facial expressions, vocalisations and signing.
- ✓ *Low-tech communication* systems do not need power to function. They are sometimes called "aided communication" because they use basic equipment. Examples include: pen and paper to write or draw; alphabet and word boards; communication charts or books with pictures, photos and symbols; particular objects that represent what someone needs to understand or say.
- ✓ *High-tech communication systems* use batteries or mains power. Most gadgets or software speak and/or produce text. Some are based on familiar equipment such as mobile devices, tablets and laptops and may have simple buttons or pages that speak when touched and very sophisticated systems use equipment specially designed to support communication. Hi-tech communication is also sometimes called "aided communication" because it uses equipment.

Pre-academic and academic needs

The early years of a child's life are very important for their health and development. Healthy refers to the sequence of physical, language, thought and emotional changes that occur in a child from birth to the beginning of adulthood and development means that children are able to grow up where their social, emotional and educational needs are met. During this process a child progresses from dependency on their parents/guardians to increasing independence. Child development is strongly influenced by genetic factors, events during prenatal life and environmental factors which influences the child's learning capacity.

It is very important to recognize and address the signs of delays in the pre-academic and academic areas in young children. Being aware of milestones (and addressing any difficulties during the early years is likely to make a difference in CwMD learning and progress during their developmental period. A CwMD who does not receive help may be at risk for developing severe limitations. Given the myriad of educational, health, social, and emotional needs, CwMDs it is important that we collaborate and plan with every significant persons (both in the family and neighbourhood) for facilitating CwMDs learn and develop to their optimal level. Further, ensuring that young children with multiple disabilities are active participants in all aspects of their lives and that they make meaningful progress through collaborative family and team partnerships, the needs of CwMDs may be addressed and assist them in their independency in their overall development. As we all know that that early development of a child is more crucial and important. Needless to mention early infantile simulation program (EIS) for CwMDs will assist the child in their optimum development besides minimising their secondary developmental delays. The Pre-academic and academic needs of CwMDs may be broadly classified as follows,

- *Life Skills needs* – These are the most basic of functional needs which will be usually acquire in the first few years of life such as walking, self-feeding, self-toileting, and making simple requests. As we know that CwMDs often have these developmental delays and based upon their severity have difficulty in mastering these life skill, these life skills need are to be taught to CwMDs through combinations of strategies such as Task Analysis, Assistance (Physical, Modelling, Promoting, Cueing) and the use of Applied Behaviour Analysis, etc.,

- *Functional Skills needs* -Functional needs are those fundamental skills that will enable the independency. As we know that the goal of special education is to enable children with disabilities gain as much independence and autonomy as possible and thereby become independent. Further, as these skills are defined as functional skills as long as the outcome supports the individual independency (as for some individuals, these skills may be learning to feed themselves and for other individual, it may be learning to use a bus and read a bus schedule, etc). We can separate the functional skills as:

  - ✓ *Functional Academic Needs* - Few academics needs are pertinent for enabling independently living. These needs are fundamentally applied skills of academics such as functional Reading, Writing and Arithmetic. As we know that these needs will be crucial for enabling independent functional level, we need to understand that providing opportunity and individualised education training on functional Reading, Writing and Arithmetic will assist CwMDs become physically and economically independent and functional. further we need to know that the teaching learning materials for helping CwMDs should be age appropriate, cultural specific, etc which will support the child in their Activity Based Learning (ABL) and Self Learning Methods (SLM) for mastering functional academics making teaching learning materials as functional learning materials.
  - ✓ *Community-Based Learning Needs* - These are the needs that will assist CwMDs become independent in their community living which include needs such as using public transportation, shopping, making choices in restaurants, and crossing streets at crosswalks, etc., Further, we need we to understand that that too often parents, with the desire to protect their disabled children, over-function for their children and unknowingly stand in the way of allowing their children to acquire the skills they need.
  - ✓ *Social needs* – These are needs that will assist CwMDs to understand how to interact appropriately with different members of the community, not only family, peers, and teachers.

Indicative ready reckoner box

Due to the sensory motor deficits, impaired cognitive function, co-ordination difficulties, etc., the range of broad common needs of CwMDs in Pre academic and academic area based on the severity are as follows

Pre academic and academic needs of CwMDs	*Needs/recruitment*
Pre-requestic skill	Impaired sensory functioning of vision, hearing, proprioceptive, etc., cognitive deficits for developing readiness skills such as cooperation, listening,

	attention, on task on seat behaviours, etc.,
Life skill	Primary function, oral problems, motor and co-ordination difficulties, etc., for Daily Living Activities, inability to express needs, wants. like dislike, etc.,
Functional skills	Difficulties in comprehending processing simple instructions for functional reading writing arithmetic (sorting, matching/grouping, identifying, naming, etc.,) co-ordination difficulties and inability to associate leaning experiences through social and community learning, etc.,,

We know that as CwMDs have deficits in their cognitive function making it difficult for them in their learning process such as to communicate their wants, needs, and pains to those around them. These limitations can further lead to their hindrance in their social and emotional development besides making them more vulnerable and dependent on others. Therefore it will be imperative to have a Transdisclipinary team with child centred approach for assisting CwMDs in meaningfully assisting them in their functional life and independency. *Transdisclipinary approach* is a strategy that aims to provide more family-centered, coordinated, and integrated services to meet the complex needs of children with disabilities and their families (Carpenter, 2005). The family is considered to be the key team members who through the home visit, parent training, etc., by the professional team members are provided transfer of skills and knowledge for parents to meet the needs and assist CwMDs in their independency. This approach further enables the family members, neighbours in providing thematic spaces in the child ecosystem for a collectively contributing to the child functional learning and independency living.

Socio-emotional needs

Social health reflects a child’s developing ability to build on relationships with other familiar people in their lives such as parents, relatives and other nurturing caregivers and emotional development is closely tied to social development as a sensory process of learning experiences. As we know that the social and emotional development in CwMDs helps them in their independent living of CwMDs by capitalising on the relationships with family, peers community members, etc., and that social-emotional skills are developed in the context of relationships with their primary caregivers, families, and cultures. Further, family priorities affect the development of social-emotional competence and the early-childhood years are a critical time for the social and emotional development, we need to understand CwMDs take time in acquiring social emotional competencies as they have difficulties in expressing their feelings and experiences, difficulty to understand facial expressions of others, inability to recognizing social cues, etc., besides their limitations in their memory, motor planning, information and sensory processing, the use of language, the ability to plan and solve problems and the capability to think abstractly, etc.,.

We need to understand that social and emotional development are interrelated to each other and that addressing needs are the foundation for helping the child master his/her environment and therefore it is paramount important to create an ecosystem for CwMDs to experience and develop socio-emotional skills. Further understanding and identifying the socio-emotional needs of CwMDs and fostering them as integrated learning experiences will be the starting point for effectively assisting the child towards their independency. The socio-emotional needs of CwMDs can be broadly classified as

- *Inter and Intra relationship needs*--CwMDs due to mobility impairments, communication deficits, poor socialisation, etc., are often unable to express themselves and thereby have challenges in their socialisation and emotional development. Further due to the sensory motor deficits these children have problem in expressing their need which often are perceived by parents/caretakers as behavioural problems. The interpersonal relation needs of CwMDs includes needs such as cooperating with others, ability to follow simple instructions, etc., relating to develop socio-emotional relationship with parents/care takers, neighbours and while the intrapersonal needs includes such as those needs to comprehend of simple instructions, ability to gesture or communicate wants and needs etc.,
- *Safety and Security needs*- As we know that due to impaired cognitive functioning and sensory motor deficits, CwMDs often have problems in taking care which many times becomes hazardous/injurious to self or others which affects their socio-emotional development to a larger extend.

Indicative ready reckoner box

Due to the sensory motor deficits, impaired cognitive function, co-ordination difficulties, etc., the range of broad common needs of CwMDs in Socio-emotional area based on the severity are as follows

Socio-emotional needs of CwMDs	*Needs/recruitment*
Inter and Intra personal needs	Poor self-awareness, personal spacing, difficulty to communicate need, wants, like, dislike, etc., difficulty in socialisation, understanding simple instructions, sign boards, etc.,

Safety and Security needs	Difficulty in understanding/anticipate hazardous, inability to request for help/support, etc.,

As we know that ecology based training will be more beneficial and assist CwMDs, in developing their socio-emotional development, it would be pertinent to plan inclusive interventions that will provide opportunity and learning life time experience to CwMDs by involving their families and neighbourhood members.

5. Non-academic needs

Non academics learning includes both the intended learning and the incidental learning where the former refers to the planned instruction/learning of the child in a simulated environment and the latter refers to the incidental or accidental learning that happens during the process of the intended learning. We all know that besides various needs for imparting academic skills there is an equal amount of non-academic needs those are to be addressed for effective facilitating of learning and independency. Further we know that the generally say the 4As (Availability, Accessibility, Affordability, and Appropriateness) for imparting skills and knowledge to CwMDs will be only made as a fruitful learning only when cohesive and facilitating environment is enabled. Many times, parents and care taker of CwMDs also have to overcome the vulnerability of being stigmatised and marginalised besides supporting the disabled child and other siblings. It would be pertinent for us to understand the process of helping parents/care takers understand the non-academic needs of CwMDs for supporting them to bring in community support for assisting their child become functionally independent. The non-academic needs of CwMDs can be broadly categorised as follows,

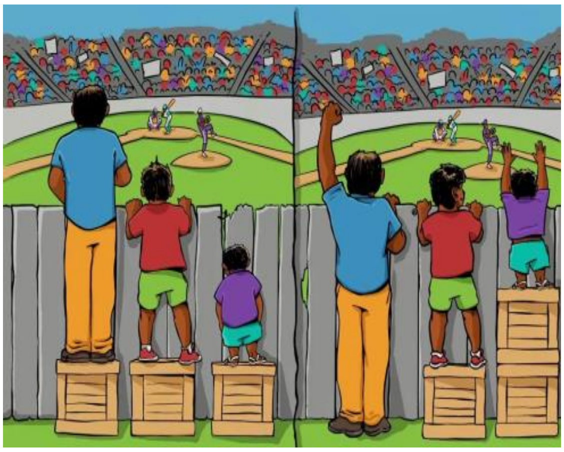
- *Recreational needs* – These needs includes such as giving choices to CwMDs for identifying, naming their activity that would are interest to them such as drawing, playing games, etc.,
- *Leisure needs*- These are needs such as expressing willingness, interest/wants for involving CwMDs in activities such as art music dance, drama, swimming, etc.,
- *Community living* – These needs includes such as travelling, gonging to neighbourhood houses, taking part in family/community functions, etc.,

Indicative ready reckoner box

Due to the sensory motor deficits, impaired cognitive function, co-ordination difficulties, etc., the range of broad common needs of CwMDs in Non-academic area based on the severity are as follows

Non-academic needs of CwMDs	*Needs/recruitment*
Recreational Needs	Poor self-awareness, personal spacing, difficulty to communicate need, wants, like, dislike, etc., difficulty in socialisation, understanding simple instructions, sign boards, etc.,
Leisure Needs	Difficulty in understanding/anticipate hazardous, inability to request for help/support, etc.,

Community living	Difficulty to get along with others, difficulty in adaptation to new environment, Inability to maintain relationship, seek assistance/support from other, etc.,



As we know that schools are increasingly implementing policies not only to educate children, but to deliver programs that meet the non-academic needs of students including health and mental health conditions, low levels of social competence, and prevention of risky behaviors. further these non-academic needs triggers the child latent potential by creating opportunity to learn their daily chores, develop readiness skills such as giving/taking, cooperating, participating, turn taking, etc., CwMDs will also help them to develop socio-emotional skills but also enable them develop pre requestic skill which can in future become the base for their vocational activities (music, art, dance, etc.,).Hence it will be pertinent to capitalise on the ecology based interventions which will advantageously assist in identifying and assisting CwMDs to support them in their choices (identifying, naming, etc.) for involving themselves in their selected activity made through these choices.

Summary

Assisting young CwMDs in all aspects of their lives and enabling them become independent to optimal level can be a daunting endeavour for families and educators. Given the dynamic needs and myriad of educational, health, social, and emotional needs of these children, a successful outcome requires collaboration and planning among large numbers of individuals for providing individualized instruction within high-quality programs for ensuring young CwMDs learn and develop to their optimal level. Individualization--or put another way--ensuring a match between what is offered and what is needed is a critical component of quality program. Through collaborative family and team partnerships, young children with multiple disabilities can achieve meaningful outcomes. Educators have to come to the understanding that although these children may present substantial educational challenges, they deserve the right to grow, learn, and prosper, like everyone else.

Further as we understanding that deficits in motor development can impact independence in self-care areas besides leading to limitations on mobility and access to the environment. Therefore while planning it would be pertinent to understand the importance of appropriate assistive devices and adaptive device for optimal benefit and independency of CwMDs in their self help activities such as eating, bathing, cooking, dressing, toileting, home maintenance, etc. will include modified eating utensils, adapted books, pencil holders, page turners, dressing aids, adapted personal hygiene aids, etc.

Check your progress

- What are the fundamentals we need to keep in mind while assessing the needs of CwMDs?
- How ecology based intervention will be a facilitating strategy for identification of needs and supporting CwMDs in their needs?
- Prepare an simple indicative ready reckoner of need mapping of CwMDs in your classroom?

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CHAPTER-10
REDRESSAL OF GRIEVANCE

Mahesh Kumar Choudhary

Objectives

1. Understand the concept and meaning of grievance.
2. Describe constitutional rights of individual in India.
3. Discus special rights of persons with special needs in India.
4. Discuss types of grievance redressal mechanisms.
5. Explain the needs of special legal mechanism of grievance redressal for persons with disabilities.
6. Describe special legal mechanism of grievance redressal for persons with special needs.
7. Explain various functions of chief commissioner for persons with disabilities.
8. Describe grievance redressal procedure in the special court for persons with disability.
9. Explain appeal procedure for grievance redressal process in special court.

Introduction

The constitution of India provided right to education to the every Indians, which needs to be ensured by everyone. The same fundamental rule is equally applicable to the children with special needs also. Families considered being the first agencies of educating their children. In case of children with high support needs families play more crucial role for education and rehabilitation of their children. Families are the decision maker for placing their children in appropriate and needed educational and rehabilitation services. They are considered to be the more driving force behind many of the services provided to their children. In the process of education and rehabilitation of children with high support need these children and their families come across a number of grievances which need to be redress in a sensible manner and proper way. The central government as well as state government made effort to systematize the nature of grievance redressal through various legislations. As per the present policies grievance redressal mechanism is mandatory in each and every government agencies and department those are directly involved with serving to the organizations and citizens. When minor grievances are not expressed by the individual and their families then they accumulated and lead to major conflicts and collective disputes. Thus, proper mechanism of grievances redressal is necessary in order to safe guard the fundamental rights and to optimize the education and rehabilitation of children with high support need and minimize the dissatisfaction among their families. As per the present policies central government as well as concern state government developed some special mechanisms of grievance redressal for persons with special needs and their families in addition to general grievance redressal mechanism.

Concept and meaning of grievance

In general grievance arises if any dissatisfaction or sense of injustice felt by an individual related to their rights in the system. In other word, grievances are those dissatisfactions that adversely affect the individuals as well as the concerned system.

In case of children with high support need and their families the grievance arises when they feel that something's happening or going to be happening unfair and unjust to them or their child. Some grievances may be beneficial for the child with high support need, as it may direct the attention of system towards improving the services, facilities, and conditions related to education and rehabilitation of the child. When grievances are minor one and not expressed by the individual and their families they just accumulate and lead to major conflicts collective disputes. Therefore, proper mechanism of grievances redressal is necessary in order to safe guard the fundamental rights and to optimize the education and rehabilitation of child with high support need and minimize the dissatisfaction among their families. It is also important to make aware to the people and other stake holders regarding the constitutional and special rights of persons with special needs. This will help to minimize the grievances of persons with special needs and also to redress their grievances in more effective way. Thus it important to know the constitutional and special rights of persons with special needs before discussing the grievances redressal mechanism.

Constitutional rights

The Indian constitution is applies uniformly to every legal citizen of India irrespective of their ability or disability. Various fundamental rights are guaranteed to the Indian citizens by the constitution of India. The constitution secure rights of every citizen including persons with special needs. As per our constitution every citizens of India ha s right of justice, liberty of thought, expression, belief, faith & worship, equality of status & of opportunity and for the promotion of fraternity. The article 15(1) the constitution prevent form discrimination against any citizen of India including persons with special needs on the basis of religion, cast, sex or place of birth. At the same time article 15(2) of our constitution focus accessibility for every citizen including the persons with special needs to all public places, all entertainment places, all religious and worship places maintained by private or government system. In this article it is also mentioned that women and children belonging to any socially and educationally disadvantage group or the schedule cast and schedule tribe, persons with special needs and other disadvantage group can be given the benefit of special law. The freedom of life and liberty to every citizen of India is guaranteed under article 21 of our constitution. As per the constitution human traffic including persons with special needs and beggars and other form of forced labour are punishable under article 23 of the constitution. Article 24 prohibits from public or private any type of employment of children including the children with special needs below the age of 14 years. Article 25 of our constitution guaranteed the freedom of religion to every citizen including the persons with special needs. Every person with special needs (like non-disabled) has freedom to practice and propagate his religion. Every person with special needs can move to the supreme court of India to enforce their fundamental rights and the right to move to the Supreme Court is itself guaranteed by article 32 of the constitution of India. In additions to these constitutional fundamental rights persons with disabilities had some other special rights.

Special rights of persons with special needs

In addition to the constitutional rights provided to the citizen of India persons with special needs also had some additional rights provided through various special acts. These special acts include Rehabilitation Council of India Act (RCI Act-1992), National Trust Act (NTA-1999) and Rights of Persons with Disability Act RPWD Act-2016). All these special acts and policies are related to various aspect of person with special needs. These include prevention, early detection, early intervention, education, vocational training, employment, non-discrimination, social security grievance redressal and so on. All these general and special rights of persons with special need help to promote their education and rehabilitation and also promote their quality life. If any dissatisfaction and sense of injustice felt by persons with special needs related to their right need to be redressed properly.

Grievance redressal mechanisms

Grievance redressal refers to a process used for receiving and processing of any complaints received from consumer or citizens. In other word it includes all actions taken by the system on any complaint received by them related to benefits and services provided by them. In our country each and every government and private departments and organizations that may be big or small had their own grievances redressal unit which had their own grievances redressal mechanism. This grievance redressal unit redresses all the types of grievances including the grievances of persons with high support need. In our country in general we see two types of grievance redressal mechanism. First one is administrative mechanism which is also called as quasi judicial mechanism and second one is legal mechanism. In addition to this there are some Special legal mechanisms of grievance redressal for central government employees, defense personnel, women, children, for persons with disabilities and so on. In this chapter we will discuss the administrative, legal and special grievance redressal mechanisms for persons with disabilities.

Administrative mechanism of grievance redressal

The administrative grievance redressal mechanism is also known as non-judicial mechanism. It is one of the most important mechanisms which provide cheap, easy, prompt and effective mechanism of grievance redressal to the public including the persons with special need. The grievance redressal mechanism in government and private organization is not same. Each and every organization has their own process of grievance redressal but more or less they follow the guidelines issued by the government of India, department of administrative reforms and public grievances. Time to time the department of administrative reforms and public grievance issued the guidelines to the various departments and ministries of government of India for prompt and effective redressal of public grievances including the persons with special needs. All the ministries and departments of government of India are required to put in place an internal machinery to redress the grievance as per these guidelines of government of India. All these guidelines help in strengthening grievance redressal mechanism of the concern departments and ministries.

As per the guidelines of the department of administrative reforms and public grievances, government of India, each and every departments and ministries should display the name, designation, room number, telephone number of the director of grievances at reception and other convenient places for effective redressal of public grievances. According to these guidelines there should be locked complaint box at the reception of the each and every department and ministries. It is also advised that to declare one day in the week as a meeting and also observe a weekly meeting for redressal of the public grievances including the persons with special needs.

Further these guide lines also suggests that all the departments and ministries should fix the timeframe for disposal of staff and public grievances and strictly follow that timeframe. According to the guidelines after receipt each grievance should be acknowledged. Acknowledgement should clearly indicate the name, designation and telephone number of the concerned official processing the concerned case. As per the guidelines reasoned and speaking reply for each and every grievance rejected must be issued.

The guide lines further suggests that Lokadalats should be constituted for easy public access to the grievance redressal mechanism. Lokadalat to be held in every quarter for quicker disposal of public grievances. Furthermore this guide lines also suggest that in order to ensure sensitivity of government towards public concerned ministries and departments should pick up grievances appearing in the newspaper pertaining to their jurisdiction and take remedial action on them in the time bound and also issue rejoinders to be issued to the newspaper after investigation in the case. It will help to build up public trust in the organization.

The guidelines also state that each ministries and department should deal with every grievance in a fair and objective manner. There should be monitoring system for the grievances received and disposed of in each and every ministries and departments by the director of public grievances on monthly basis and quarterly progress reports to be prepared regarding the receipts and disposal of grievances in the concerned ministries and departments. There should be measurement of level of public satisfaction on a regular basis. The guideline also suggests that annual action plan and annual administrative report should include the statistics related to receipt, disposal and redressal of public grievances.

Appeal procedure in administrative mechanism of grievance redressal

Every Ministries/ Departments / Organizations has provisions to appeal against the decisions of grievances redressal to the higher authorities. These higher authorities are called first and second authority and are notified by the concerned Ministries/ Departments / Organizations. If the complainants are not satisfied with the decisions taken by the designated officer or committee then they can appeal their issues to the higher authority who is called first appellate authority and if not satisfied with the decisions of the first appellate authority then appeal can be done to the second appellate authority.

As per the act there are provisions of three appellate authorities related to different areas. In this act it is mentioned that if in a certain circumstances suitable and satisfactory support provided to a persons with special needs and still he/she is not able to make legally binding decisions, then to care for the personal and property interests of the person with special need, he/she may be provided the support of another person who has the legal authority. If a person with special need is not satisfied with the decision of the authority which appoints the legal guardian then he/ she may approach to the higher authority for their problems. This higher authority is called appellate authority. This authority is required to look into the matter and if required he/ she may change or alter the decisions taken by the previous authority. As per the act if any person wants to start and maintain an institution for persons with disabilities then they will be allowed to do so only if they will obtained a certificate from the concern authority appointed by the concerned state government. In certain cases this authority can also revoke the license. If this authority refused to issue a license or any person is not satisfied with the decision of this authority then the concerned person may approach to the higher authority and request them to look into the matter. Based on the fact this authority may hold or reverse the decision of previous authority. This higher authority is also called as an appellate authority. According to this act person having specific disability (as per the act) can apply for the disability certificate to a certifying authority. In case of persons with disability is not satisfied with the decision of certifying authority then he/she may approach to the higher authority to look into the matter. This higher authority is also called as appellate authority. The appellate authority may hold or reverse the decision of the previous authority based on the merits.

In addition to this there is a legal mechanism for the redressal of public grievances including the persons with special need. So if any one of the party is not satisfied with the administrative decisions the can approach to the court of law.

Legal mechanism of grievance redressal

Legal mechanism of grievances redressal is a formal mechanism. It also called as judicial mechanism. This mechanism is available for everyone including the persons with disabilities. In this process they can go to the concern special court or to the general court. In general court the process is started at lower court or district court or the particular designated court and then it goes to high court or state level and then to the supreme court or national level. In other words they can go to the district court and if not satisfied with the decision of lower or district court then any party can appeal in the high court and still not satisfied with the decision of high court then at last any party can appeal in the Supreme Court. In these court every things dealt with as per the set procedure and court of law. As this mechanism is for every citizen, so there are number of grievances are pending in the court of law.

Needs of special legal mechanism of grievance redressal for persons with disabilities:

I most of the Indian courts there is delay due to systemic problems that include delay, pendency, increasing costs and limited legal aid for persons with special need. This is also reflected in one of the study done in 2007 by the Indian centre for Human rights & Law and the Maharashtra State Legal Services Authority. The various massive problems faced by the persons with disabilities in the justice system clearly mentioned in this report. This report also reflects that persons with disabilities faced barriers at three levels. These are physical barrier, procedural barrier and attitudinal barrier. Though at present the right of persons with disabilities act-2016 makes it obligatory upon the concern government and local authorities to provide accessibility to the persons with disabilities for full participation. This includes ramp in public buildings, adaptation of toilets for wheel chair users, brail and auditory sign in lifts and elevators. All these facilities are not available in all the courts of India even today. Thus even today it is impossible for persons with disabilities to approach to the general court.

Among all the barrier attitudinal barrier is very important. The court of India is even not more friendly to the common man and utterly fails to accommodate the persons with disabilities. Even today if we see the websites of many courts in India they are not accessible to the persons with disabilities and the court do not have facilities to provide legal texts and documents in accessible format to them. Even most of the legal and judicial professionals are not trained in disability rights issues. They are not aware of particular rights persons with disability.

In view of these attitudinal, physical and procedural barriers, it is important to create structure and procedure that are friendly to the persons with disability and also cater their specific needs. Many researches show that when the grievance redressal mechanism is effective then people become more assertive about their rights. Thus it is important to develop a strong and effective individual grievance redressal system that will encourage the persons with disabilities to move away from their reluctance to approach the justice system. Keeping in view all the above points it is suggested to develop a special legal mechanism at district, state and national level that will help in realization of rights of persons with disabilities mentioned in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and in the Right of Persons with Disabilities (RPWD) act.

Special legal mechanism of grievance redressal for persons with disabilities

As per the provision of right of persons with disabilities act-2016 it is necessary to make easy, cheap and timely redressal of grievances of persons with disability. According to the section 74 of this act chief commissioner and two commissioners for persons with disability appointed by the central government. Out these two commissioners one must be persons with disability. Person must have special practical knowledge and experience in the area of disability and rehabilitation to be appointed as chef commissioner or commissioner for persons with disability. Salaries, allowances and other benefits of service of chief commissioner and commissioner for persons with disability and any employees working under their supervision are decided by the central government. Similarly as per the section 75 of this act state commissioner and district commissioner for persons with disability are appointed by the each concerned state government. The chief commissioner, state commissioner and district commissioner for persons with disability perform various functions. Some of their important functions are mentioned below.

Functions of Chief Commissioner for Persons with Disability

The important functions performed by the chief commissioner for persons with disability related to grievances redressal are listed below.

i. To identify the provisions of any law or policy, programme and procedure as per this act and recommend for necessary corrective steps.
ii. To inquire into issues related to right of persons with disabilities.

iii. Safeguard the rights of persons with disabilities and take up the matter to the appropriate authorities for corrective action.
iv. To review and recommend the suitable measure for the effective implementation under this act.
v. To review the factors inhibits enjoyment of rights of persons with disabilities and recommend suitable remedial measures.
vi. To study and recommend the treaties and other international instruments for persons with disabilities.
vii. To undertake and promote research related to persons with disabilities.
viii. To create awareness related to rights of persons with disabilities.
ix. To create awareness related to safeguards measures available for persons with disabilities.
x. To monitor implementation of provisions, programmes and schemes of this act meant for persons with disabilities.
xi. To monitor the utilization of funds disbursed by the central government for the benefit of persons with disabilities.
xii. To perform any other functions assign by the central government.
xiii. In order to redress the grievances of persons with disabilities they may utilize any one or more of their powers in the special court.

Functions of State Commissioner for Persons with Disability

The important functions of state commissioner for persons with disability related to grievances redressal are listed below.

i. To identify the provision of other law, policies, programme and procedure those are in consistent with this act to recommend for corrective steps.
ii. To inquire into the matter related to deprivation of rights of persons with disabilities.
iii. Safe guard the rights of persons with disabilities and take up the matter to the concerned authorities for corrective action.
iv. Time to time review the safeguard provided to the persons with disabilities under this act.
v. To recommend the concern authorities regarding the measures to be taken for the effective implementation of act.
vi. Time to time review the barriers that inhibit the enjoyment of rights of persons with disabilities and also recommend the remedial measure to be taken to overcome these.
vii. To undertake and promote research related to rights of persons with disabilities.
viii. To create awareness related to rights of persons with disabilities and their protection
ix. To create awareness related to safeguards measures available for persons with disabilities.
x. To monitor implementation of provisions, programmes and schemes of this act meant for persons with disabilities.
xi. To monitor the utilization of funds disbursed by the concerned state government for the benefit of persons with disabilities.

xii. To perform any other duties and responsibilities assigned by the concerned state government.

Functions of District Commissioner for Persons with Disability

As per the provision of this act each state government established a District Commissioner for Persons with Disabilities in each district of the state. Some of the important functions of district commissioner for persons with disability related to safeguard the rights persons with disabilities and their grievances redressal are listed below.

i. To summon the concern persons related to grievances and enforce their attendance.
ii. To ask for discovery and production of documents related to matter.
iii. To receive evidences of affidavits.
iv. May be requisitioning any record and document and their copies form any department and offices.
v. To issue order for examination of witnesses and documents.
vi. To review its decisions.
vii. To dismiss an application for default or decided it ex parte.
viii. To set aside any order of dismissal of any application for default or any order passed on ex parte investigation.
ix. To deal any other matter prescribed by the concerned government.

Grievance redressal process in special court for persons with disabilities

To make easy, cheap and timely redressal of grievances of persons with disabilities special provisions are made in the new act that is Rights of Persons with Disabilities Act-2016. According to this act concerned state government shall have to establish a State Commission as well as District Commission in each district for Persons with Disabilities. As per provisions of this act any person with disability may approach to the district commission related to their rights. This is the first point for redressal of problem. Any persons with disability aggrieved regarding their right can approach to this office. It is the responsibility of the district commissioner to decide the every case or complain after providing reasonable opportunity to hear from all the concerned parties. The powers of district commissioner are same as vested in the Civil Court and hence the proceeding of district commissioner is a judicial process.

A laid down procedure followed as per the concerned acts, policies and programme as well as the need of the grievances followed in the special court to redress the grievances of persons with disabilities. As per the section 82 of this act the commissioner for the persons with disabilities have the same powers as that of the civil court. During the redressal of grievances they can summon and enforce the attendance of the witnesses, can receive evidence on affidavits and issue commissions for the examination of witnesses or documents. Depending upon the provisions of the section 76 of the acts & policies and available facts in the case chief commissioner for persons with disabilities send recommendations to the concern authority. After receiving the recommendations concerned authority take necessary action within three month and informed the same to the chief commissioner of persons with disabilities. If the concerned authorities do not accept recommendation made by the state commissioner then they have to convey the reasons for their non-acceptance within three month to the aggrieved persons as well as to the concerned state commissioner for persons with disabilities.

Appeal procedure in special legal mechanism of grievance redressal

The persons with disabilities can approached to the office of district commissioner for persons with disabilities with grievances related to their rights. If the aggrieved persons are not satisfied with the decisions made by the district commission then they may appeal to the state commission of the concerned state against that order. In view of natural and timely justice appeal need to be made within the specified period of time from the date of order. Even after the expiry of specified period state commission may entertain the appeal if there are sufficient and reasonable reasons for not appealing within the specified period of time. Parties may satisfy with the decisions of state commission or may not be. If any of the party is not satisfied with the decisions of state commission then there is no provision to appeal in the national commission like other bodies in India. In fact he or she may appeal against this order to the high court of the concerned state within the specified period of time from the date of order. If still any of the party is not satisfied with the decision of the high court then within the specified period of time from the date of order they can appeal to the supreme court of India.

Summary

The roles and responsibilities of parents of children with high support need are more complex and challenging than the roles and responsibilities of other parents as they have to take decisions about each and every thing for their special children. Families are the decision maker for placing their children in appropriate and needed educational and rehabilitation services. They are considered to be the more driving force behind many of the services provided to their children. In the process of education and rehabilitation of children with high support need these children and their families come across a number of grievances which need to be redress in a sensible manner and proper way. Grievance redressal includes all actions taken by the system on the grievances related to their rights. There are two types of grievance redressal mechanism. First one is administrative mechanism and second one is legal mechanism. In addition to this two special legal mechanism there is also special legal mechanism for persons with disabilities. Persons with disabilities and their parents had choice to register their complaint in any of the system. This special legal mechanism specially developed for persons with disabilities helps to provide natural and timely justice to them as per the provisions of these acts and policies.

Check your progress

1. What is expanded form of UNCRPD?
2. When Rights of Persons with Disability Act become effective?
3. Which Article of our constitution guaranteed life and liberty to every citizens of India?
4. Administrative grievance redressal mechanism is also known as-----------.
5. Legal mechanism of grievances redressal is a ------------mechanism.

6. Central Governments appoint a Chief Commissioner for Persons with Disabilities under which section of RPWD-Act?
7. Functions of the Chief Commissioner for Persons with Disabilities are mentioned under which section of RPWD-Act?
8. Appeal against the order of the State Commission for Persons with Disabilities will be done to --------------.

Questions

1. Discuss the role of parents in education and rehabilitation of their children with high support need.
2. What do you understand by the term grievance?
3. Describe the special rights of persons with disabilities in India..
4. What do you understand by administrative mechanism of grievance redressal? How it is differ from legal mechanisms?
5. Discus special legal mechanism of grievance redressal for persons with disabilities.
6. Enumerate the functions of Chief Commissioner for Persons with Disabilities.
7. Describe grievance redressal procedure in the special court for persons with disability.
8. Discuss the appeal procedure for grievance redressal process for persons with disability in special court.

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GLOSSARY

Person with disabilities High Support Needs: Refers to a person requiring an intense support, physical, psychological and otherwise which may be required by a person with benchmark disability for daily activities, to take independent and informed decision and to access facilities and participating in all areas of life including education, employment, family, community life, treatment and therapy.

Parental Support Groups: Parent Support Groups are peer groups primarily formed by the parents of disabled children as a platform for sharing, learning and supporting mutually one another. Further these peer groups can also advantageously contribute in voicing the interest of parents for policy formulation, argue in the role of advocacy for enforcing safeguard measures etc.,

Quality of Life (QoL): Refers the general wellbeing of an individual. WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

Multi-disciplinary approach - Team of specialists/experts extending their services to C-HSN, however the experts/specialist may not be interacting with each other. Most of the time they will be working in isolation and are independent to one another.

Trans-disciplinary approach – The team of professionals/specialist/experts come together, assess and evaluate C-HSN, work on a common agenda by providing transfer of skills and knowledge to a person (nodal person) who receives it and in turn provides these services and support to C-HSN/their parents.

Inter-disciplinary approach - The team of professional/specialist/expert come together, assess and evaluate C-HSN, work on a common agenda by providing services and assistance to the child/their parents.

Developmental disabilities and delay: Delay is said to exist when a child is performing like a typically developing child of a much younger age.

At-risk: Many infants and young children are said to be at-risk or at high-risk. This means there is reason to believe serious problems are likely to develop. Infants that are born with low birth weight are likely to be considered at high-risk; they are in grave developmental danger.

Special Education: Special education defined as specially designed instruction that meets the unique needs of the child with disability. It includes special methods of teaching, special teaching- learning materials, use of assistive devices and specially designed physical environments- classroom or playrooms for children.

Social: Refers mostly to the ability to form attachments, play with others, cooperates, share, and create lasting relationships.

Communication: It is referred to one's ability to understand others and make oneself understood. It is most important as far as our ability to understand concepts and form relationships with people is concerned.

Individualized Family Support Plan (IFSP). This is a plan of the actual inputs that will be provided to the child to foster her development in different areas. It is called an individualized plan/programme because the plan is specifically worked out for each child depending upon the needs of each child and their family.

Aesthetic development: Experience in art and music should be available every day in preschool classrooms. Emphasis is on exploration, spontaneity, self-expression, and appreciation rather than on completing a specific product or learning a particular tune. Art and music activities should represent the cultures of the children and staff in the classroom.

The **Right of Children to Free and Compulsory Education Act** or **Right to Education Act** (**RTE**) is provides the education as mandate for children from 6-14 years. As per article 21 section 3(2) of Right To Education Act elementary education of children with disabilities and support the severe and multiple disabilities can opt the education as per their needs whether general education or special education or home based education.

Multiple disabilities: Multiple disabilities is a condition when two or more disabilities occur at the same time in the child.

Intellectual impairment: It refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more following applicable adaptive skills areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and home work.

Cerebral Palsy: Cerebral palsy is a non-progressive brain damage occurs in the child before, during, and after birth. The result of the insult affects the child coordinated movements, maintain posture and balance. The child also face difficulty in learning to do his activities of daily living, participate effective social, express emotional, communication and cognitive skills.

Autism Spectrum Disorder: It is a neurodevelopmental disorder characterized by impairment in social interaction, social communication and restricted pattern of interest and repetitive behaviour. Its affects information processing in the brain by altering how nerve cells and their synapses connect and organized; how this occurs in not well understood.

Specific Learning Disabilities: Difficulty in reading, writing, and doing arithmetic's. Children having trouble in reading, which accounts for the majority of children with learning disabilities is referred to as dyslexia. Dysgraphia is the term sometimes used to describe problems in printing and writing the spelling. Dyscalculia is the term used to describe the child difficulty in doing mathematic calculation and solving arithmetic problems. Some may have problem in motor planning is called apraxia.

Speech Impaired: The impairment of speech articulation, voice, fluency, or the impairment language comprehension and oral expression or the impairments of the use of a spoken or other symbol system.

Hearing disabilities: Deafness is a hearing loss so severe that individuals cannot process spoken language, even with hearing aids or other forms of amplification.

Hard of hearing refers to a loss that has a negative effect on a child's education, but not to the same degree as it does on children who are deaf.

Locomotor disabilities: It is defined as a person ability to execute distinctive activities associated with moving both himself and objects, from place to place and such inability resulting from affliction of musculoskeletal and /or nervous system.

Neurological disability: A neurological disorder is a disorder of the body's nervous system. Structural, biochemical or electrical abnormalities in the brain, spinal cord, or in the nerves leading to or from them, can result in symptoms such as paralysis, muscle weakness, poor coordination, and loss of sensation, seizures, confusion, pain and altered level of consciousness.

Behavioural and Emotional Disorder: Behavioural and emotional is a broad category which is used commonly in educational settings, to group a range of more specific perceived difficulties of children and adolescents.

Visual impairment: Is vision loss of a person to such a degree as to qualify as an additional support need through a significant limitation of visual capability resulting conditions that cannot be corrected by conventional means, such as refractive correction, medication, or surgery. Visual acuity of less than 20/60.

Deaf-blindness: Dual sensory impairment, it affects the child whole perspective and image. The child with dual sensory impairment learns through tactile mode, and compromise with other senses. The child considered as multiple disabilities.

Adaptive behaviour needs: Adaptive behaviour refers to the abilities or skills needed by people in order to cope in their everyday lives and to adapt with one's environment. Personal needs or self-care skills like, eating, toileting, bathing, brushing, dressing and grooming.

Socio Economic Needs: A Socio economic need does not mean only the income but also the educational achievement and financial security. It is also a subjective perception of society about social status and social class. It also encompasses the opportunities and privileges afforded to families and children with disabilities within that society.

Bronfenbrenner (1979) who conceptualized microsystem, mesosystem, and exosystem levels which interact with each other. These systems if strengthened can greatly support or mitigate the nature of care-giving burden and enhance the overall quality of life for families and HSNs..

Activities of daily living (ADLs). The actions a person must do by themselves to engage independently in everyday life, including bathing, dressing, eating, being mobile, moving from bed to a chair and using the toilet.

Assistive technology devices. Products that improve a person's ability to live and function independently. Low-tech assistive devices include canes

	and pill organizers, and high-tech items include electric wheelchairs, hearing aids and smartphones.
Comorbidity.	The presence, or coexistence, of more than one disorder in the same person. They can occur at the same time or one after the other. Interactions between the illnesses can worsen the course of both.
Bereavement:	It is the response to a loss of a person and includes the process of healing from the loss. Each person will grieve and 'recover' in their own way
Family:	A family is defined as those who are closest to the person in knowledge, care and affection. The family may include the biological family, the close relatives, and the family of choice and friends (including neighbors, pets).
Holistic Care:	The principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspect.
Home Care:	Services provided in the home, such as nursing and physical therapy.
Informed consent:	The process of making decisions about medical care based on open and honest communication among the health care provider, the patient and the patient's family.
Multidisciplinary Team:	This team typically includes disability rehabilitation professionals, doctors, nurses, social workers, care-assistants, palliative care specialists, occupational therapist, physiotherapist, dieticians, volunteers etc.
Long-term care:	Care that supports individuals with HSN for an indefinite period of time; it is provided in nursing facilities, at home, institution or in the community.
Palliative Care:	The medical specialty focused on relief of the pain, symptoms and stress of a serious illness. The goal is to improve quality of life.
Primary Carer:	The primary carer is generally the person who is closest to the elderly with MD-HSN, this can be usually be her/his mother, father, sibling, another relative, or friend.
High Support":	means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life

including education, employment, family and community life and treatment and therapy.

“**person with benchmark disability”:** means a person with not less than forty percent of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority.

Publications of NIEPMD

Title	Cost
1. Resilience Headway Youth with Intellectual Disability: A Manual	Rs.400/-
2. Resilience Headway Siblings of Children with Special Needs:A Manual.	Rs.400/-
3. Resilience Headway Youth with Multiple Disabilities: A Manual	Rs.400/-
4. Acceptance &Coping : Families of Persons with Multiple Disabilities	Rs 300/-
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8. Parental Wellbeing in Raising a child with Special Needs	Rs 400/-
9. Individuals with deaf blindness: Perception Analysis	Rs.350/-
10. Specific Learning Disabilities: An Introduction	Rs.500/-

High Support Need: Parents Need

About this book

As per RPwD Act 2016, High Support means an intensive support, physical, psychological and otherwise, which may be required by a person with benchmark disability for daily activities, to take independent and informed decision to access facilities and participating in all areas of life. This book provides information about the needs of parents having children with high support need from early childhood to geriatric based on various socio economic group.

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