

ACCEPTANCE & COPING :
FAMILIES OF PERSONS WITH
MULTIPLE DISABILITIES



*"Exploring
Diversity"*



Developed & Published by

**NATIONAL INSTITUTE FOR EMPOWERMENT OF
PERSONS WITH MULTIPLE DISABILITIES (DIVYANGJAN)**

*(Dept. of Empowerment of Persons with Disabilities (Divyangjan),
Ministry of Social Justice & Empowerment, Govt. of India)*

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Preface

For any person, family serves as the support system during the ups and down of life. A person with supportive family members feels empowered even during the toughest phase of life. When a family has a person with multiple disabilities, the other members of the family faces additional responsibility, especially it takes a heavy toll on the primary caregivers, mainly the parents. Over the period of time, during the rehabilitation process of the person with disability, the family members face stress in various dimensions and only when they reach the level of acceptance, they could function well and dedicate their time and efforts for that person to learn, grow and to achieve new heights.

It is hence realized that it is important to help these families to cope with the stress that results from the caregiving process and to enhance their acceptance of disability. This book emphasizes the unique needs and stress faced by the family members of various family systems, having a person with multiple disabilities and provides research based data on what facilitates and inhibits their coping and the level of acceptance observed in various family structures. It also indicates the need for intervention for these families and some of the best practices followed in NIEPMD to empower the families of persons with multiple disabilities.

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CHAPTER-1

INTRODUCTION

- P. Kalaivani

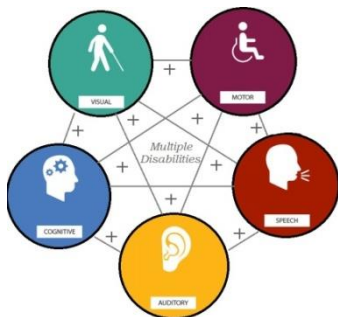
“People with disabilities are vulnerable because of the many barriers we face: attitudinal, physical, and financial. Addressing these barriers is within our reach and we have a moral duty to do so.....

But most important, addressing these barriers will unlock the potential of so many people with so much to contribute to the world”
-Stephen Hawking

What is Disability?

According to WHO, Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Multiple Disabilities is the simultaneous occurrence of **two or more disabling conditions** that affect learning or other important life functions. These disabilities could be a combination of both motor and sensory nature. Some **examples of multiple disabilities are:**

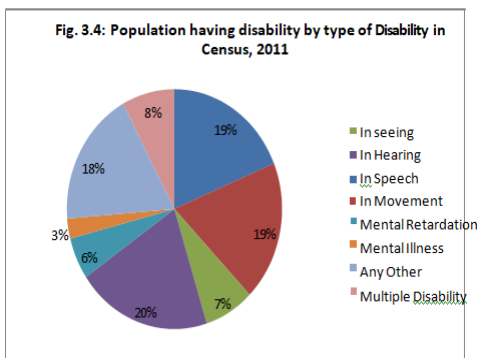
- Deaf blind (Visual Impairment + Hearing Impairment)
- Visual Impairment + Hearing Impairment + Intellectual Disability
- Visual Impairment + Intellectual Disability
- Cerebral Palsy + Intellectual Disability / Hearing/ Speech/ Visual problems



The Census 2011 done by Ministry of Statistics and Programme Implementation revealed that In India out of the 121 Cr population, 2.68 Cr persons are with disability which is about 2.21% of the total population.

Population, India 2011			Persons with disability, India 2011		
Persons	Males	Females	Persons	Males	Females
121.08 Cr	62.32 Cr	58.76Cr	2.68 Cr	1.5 Cr	1.18 Cr

In India, 20% of the persons with disability are having disability in movement, 19% are with disability in seeing, and another 19 % are with disability in hearing. 8% has multiple disabilities.



Source: Persons with Disability in India, A Statistical profile 2016.

Multiple Disabilities: A familial experience

Families are dynamic functioning units which constantly strive for balance to the development and changes. A family is a functional unit of society (Sooryamoorthy, 2012) and all its members are interconnected and interdependent.

Family system in India is very peculiar and the bonding is very strong where it helps the individual to have safety, procreation,

personal gratification, and indeed the personality of an individual evolves.

The family is the first line of defense especially for children and it serves as a major factor in their survival, health, education, development, and protection. It is a major source of nurturance, emotional bonding and socialization. It has the major potential to provide stability and support when there are problems (Desai, 1995a).



Figure 2: Interconnections in Family group
Image source:
www.schoolevolutionarystages.net

According to the Family Systems Theory (Broderick, 1993) the experiences and needs of each family member affects all the other members of the family. So, when one person has a disability, the emotional and psychological effect of that disability is felt by the whole family as well. Especially the mothers experience more stress when their children with disabilities have lower functional status. In case of elderly caregivers, physical strain becomes a limiting factor in how much or how long the assistance can be provided.

A child's disability or multiple disabilities is a *triadic experience* as it involves a three-way interaction between the child with disability, the family of the child, and the external environment (Falik,1995).

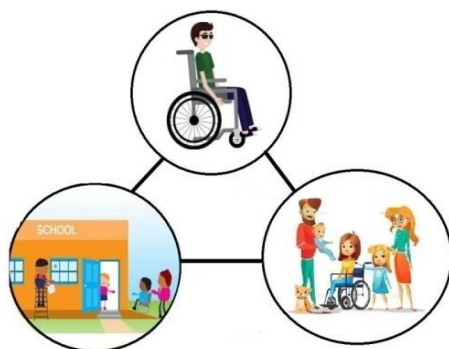


Figure 3: Triadic experience of a child with multiple disabilities.

Image source: edited content from www.photobucket.com

Emotional Impact on the Family

The birth of a new child is a dream and cherished by the whole family. Birth of a child with disability creates shock and shatters the hope of the parents. It is not easy for the family to accept the disability of their loved one. They have to come along through a difficult path from accepting their child to the process of rehabilitation. They initially undergo a grief reaction which Olshansky, S. (1962) describes as a lifelong “chronic sorrow” and it is a normal reaction to the crisis which has the following stages:



Change Crisis: Immediately after the diagnosis

Ideological Crisis: It is the stage of ambivalence wherein they have to love and protect their child with disability and on the other hand experience inability to accept and feels guilty, frustrated, shame, and grief.

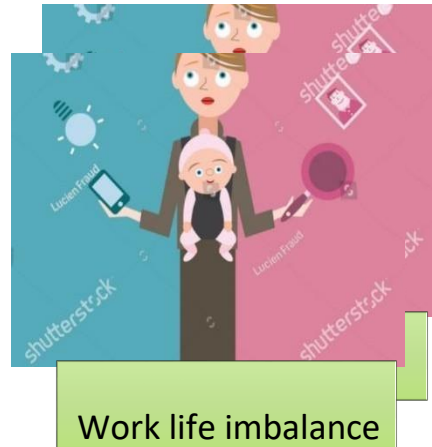
Reality Crisis: Has to face the real difficult conditions in bringing up a child with disability like financial expenses, time etc.

Although the intensity of emotional reactions varies from

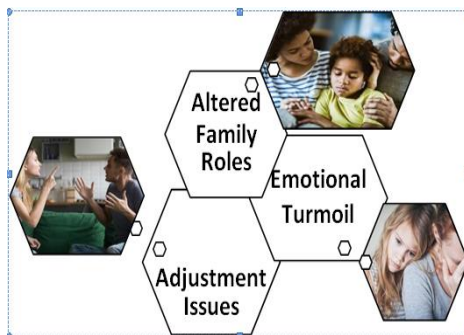
one to another, all parents experience grief starting from immediately after the diagnosis to changes that happen every day. They face severe emotional reactions like shock, mourning, shame, guilt, anxiety, etc. They blame themselves and feel embarrassed in facing the society. Some culture perceive it as bad luck and sin they have done in their past. They are excluded and they withdraw themselves. They avoid social gatherings and meeting relatives to avoid remarks of them. The impact is severe in all the dimensions of their life.



Families, caring for a person with disability have increased stress and it affects their own mental and physical health. They have difficulty to find appropriate and affordable care for their child including education, and training. It affects their work leading to financial difficulty. They constantly think about their special child where they ignore their personal life and the life of the other beloved ones. They have to spend more time in taking care of their child, travelling, education etc. It may be associated with guilt blaming them or directing towards other family members like spouse, in-laws. They carry the guilt most of their life time and have constant worry and anxiety about their child's future.

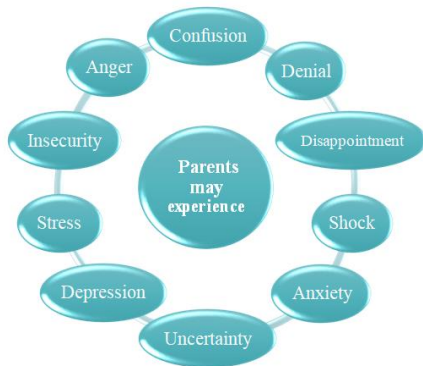


The reaction of the relatives, neighbors towards the child also add on to their difficulty. Hence, their social interaction minimizes and makes them withdrawn. They were often anxious and on guard to allow their child to socialize with others fearing their critical comments or the unpredictable behaviour of their own child itself. They have difficulty to take them to social situations feeling embarrassed that they have to face questions related to their child. The gestures and facial reactions of others towards their child creates angry and they dumb their emotions within themselves. Blaming the mother for the child's disability is also widely prevalent which is more distressful to the parents, especially the mother.



Challenges of the Family having Persons with Multiple Disabilities The birth of a child with disabilities creates a severe breach of balance and places extra demands or challenges on the family system which

lasts for a long time. Family has to make many adjustments related to their work and other responsibilities at home. The stress associated could be multifold and it can be a physically and mentally tasking job depending on the type of disability resulting in compromised quality of life (QOL) of the families too.



Mothers especially have to leave off their jobs to take care of the children with disability. Fathers take the extra burden, have no time and restrict other activities. Recreational activities are often limited in their families. The scenario when having children with multiple disabilities is

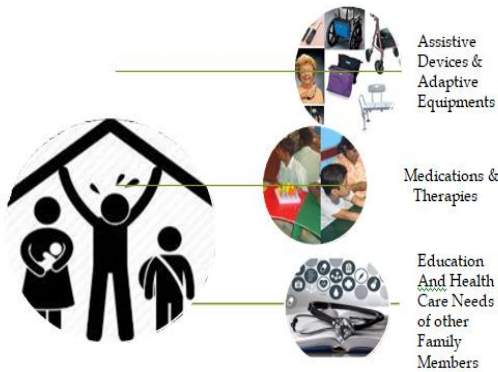
worse. They have to adapt changes in their physical environment, daily routines etc. Taking care of the children like lifting and doing personal activities also become essential in case of multiple disabilities and hence the burden and stress become much more significant.

Many of these challenges also depends upon the disability type, age of the person with the disability, family support, behavioural and emotional problems, functional impairment, prognosis, etc..

The problems they encounter are associated with:

- Getting adequate health care services
- Getting necessary therapeutic aids.
- Education and social services.
- Financial constraints
- Getting access to professional services.

- Making accommodations to the home.
- Transportation



Impact on other Family Members:

The wellbeing of the family members may get affected while having children with multiple disabilities. It intrudes the functioning of the whole family. It

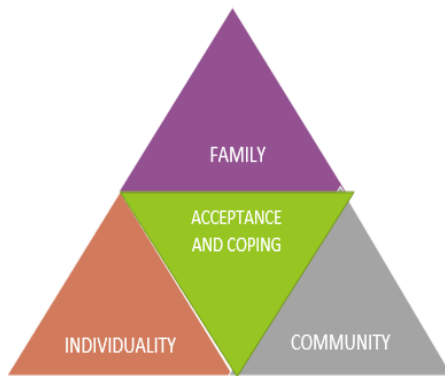
disrupts the marital relationship and affects the other children in the family

The attitude towards the child's disability and opinion in different methods of taking care may lead to conflict and it affects the marital integration between the couple. Many of the studies have revealed poor marital functioning among the couple having Persons with Disability. The personal space itself gets disintegrated as most of the time are involved in taking care of the child. The financial constraints and extra burden fuel the conflicts between the couple.

The stress created by the disability of the person may directly influence the siblings or indirectly through parenting style. They were affected with more emotional and behavioural problems which remains unnoticed sometimes. They tend to externalize or internalize their emotional problems. Most of time, their needs were ignored as the parents are more involved in taking care of their sibling with disabilities. The behavioural problems of the children with multiple disabilities are unpredictable and may be sometimes severe which cause the

siblings to have constant worries and anxiety. They tend to adjust at very early younger age and feel embarrassed in facing their own peers. They tend to withdraw from the social situations, which affects their attitude towards self and others. They also have trouble in concentrating studies due to lack of adequate time, support, and environment.

Acceptance and coping during the Rehabilitation Process:



The acceptance and coping of the family members plays a major role in the rehabilitation process. The commitment and compliance to the treatment/rehabilitation process also comes from the nutshells of the level of

acceptance and coping of the family members. Some try to succeed and some lose hope in rehabilitating their child. This may be due to the various factors, their individual traits, environmental and social factors etc.

Individual factors: Perception, attitude, knowledge, self-efficacy etc.

Family Factors: Support from the family members like sharing responsibilities, providing emotional support etc.

Community Factors: Government services, professional services, accessibility, infrastructure, lack of discrimination, providing opportunities etc.

- Low acceptance and coping will cause severe emotional problems like depression or anxiety.
- Positive perception and appraisal like perceiving it is an extra responsibility given by God, can help others with similar conditions, to develop self as a

person will help them to have better coping.

The Recovery of Persons with Disability involves the commitment of the family members of persons with disability, professionals, and the community. While treating and rehabilitating Persons with Multiple Disabilities the needs of the family are not often thought about. Hence, studying the acceptance and coping factors of the family members that facilitate and inhibits the rehabilitation process of having Persons with Multiple Disabilities would be very significant at current scenario.

CHAPTER-2

ACCEPTANCE AMONG FAMILIES OF PERSONS WITH MULTIPLE DISABILITIES

- *Darshini*

“Real acceptance is discovering the clarity to face our complexities and challenges”

-*Larissa*

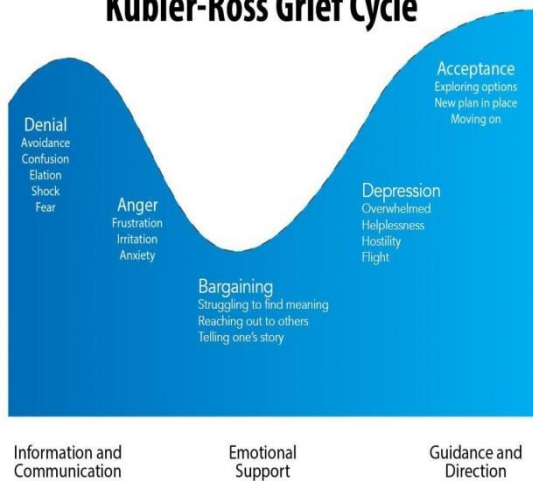
The word acceptance literally means to take / receive whatever is offered. Acceptance is typically acknowledging a negative experience by an individual that is unchangeable. In case of families having persons with disability, acknowledging negative event may lead them to have preoccupation about the condition of the loved ones which in turn affects the wellbeing of the whole family members including persons with disability. Acceptance generally influences an individual's adaptation and support psychological wellbeing. To increase adaptive nature, one should accept the unchangeable / uncontrollable situation by giving up or striving to control the situation.

Acceptance as a Process

In 1969, a psychiatrist Elisabeth Kübler-Ross described five popular stages of grief. This model showing the stages of grief is also applicable to families of people with multiple disabilities (Calandra et al, 1992). The five stages are 1) denial, 2) anger, 3) bargaining, 4) depression, and 5) acceptance.

Denial: Immediately after the diagnosis, the mourning starts and denial sets in first. The family refuses to believe that their loved one has multiple disabilities and they might dispute the diagnosis. Sometimes they might refuse to accept that the condition is permanent.

Kübler-Ross Grief Cycle



Anger: When the family of individuals with disability realize that their loved one has disability, they have feelings of frustration and anger. This anger might be shown towards the person with disability and often it is even directed towards fate or God.

Bargaining: During this stage family members might try to bargain with fate or God and say statements such as, "I would give up anything for my child to be like other children"

Depression: After bargaining, depression begins. There is a level of acceptance however the acceptance comes with sadness.

Acceptance: The sadness becomes less as time goes on and the individual moves into the final stage of acceptance. However, it does not mean that if one has accepted there is no sadness.

Acceptance is the only possible way to deal with any negative events and to get over it. It is acceptance that influences adaptation and well-being in one's life. There are two major types of acceptance: active and resigning acceptance.

Active acceptance: Acknowledging the difficult situation and deal with it constructively with many fruitless attempts to control the unchangeable situation. However, the individual finds meaning in life and travel towards his/her goals balancing life in all its aspect peacefully. **For instance,** after knowing the unchanging condition of the child, the mother makes many efforts which never results in any improvements, but still she accepts the reality and continues the journey without dropping her attempts.

Resigning acceptance: In simple words giving up all efforts. There will be negative expectations about future and hopelessness that influences the attempts as it is known that there is no control over the situation and finally being inactive in other areas of life (passive). **For instance**, understanding the facts of an individual with disability will push the families in fear of who will replace their role as caregiver in their absence and when their efforts doesn't provide their expected results ultimately they end up giving away. The following table explains it's cognitive, emotional and behaviour aspects.

Types of acceptance	Cognitive aspect	Emotional aspect	Behavioural aspect
Active acceptance	Accepting the reality of an event, dealing with any new situation constructively, finding meaningfulness in the new situation	Calmness, confidence	Activities towards personal goals are retained, and work towards new goals that would help the child to attain independent living eventually.
Resigning Acceptance	Resignative thoughts, disappointment, negative future expectations	Hopelessness, avoidance	Passiveness in other areas of life, leading to isolation and depression.
Non-Acceptance	Denial – not accepting the event or not want to fight with it, searching for strategies	Anger, rage towards the situation/ or the person responsible for the situation.	Reactance, blaming, thinking what went wrong and where, which are not fruitful.

Acceptance of Multiple Disabilities by the family having Persons with Disability

Acceptance of disability was considered as acceptance of loss for the affected person and the family (Wright, 1960). This is especially true when limitations of a person with disability is compared to normal population. The families of people with disabilities have to adjust and accept changes in their everyday life and social routines along with the additional stigma of having a family member with multiple disabilities. These prevent full acceptance of the conditions of multiple disabilities among family members.

The acceptance process involves:

- Parental perception and appraisal of the disability.
- Realistic view of the child's condition and not putting extra demands or not over protecting the child.
- Logical way of thinking like seeking support, acquiring knowledge about the child's condition, and seeking support.
- Able to provide adequate care with no feelings of rejection or overprotection and attend activities of other members in the family.



Figure 6: Social support is crucial to acceptance of multiple disabilities among families

Acceptance of disability involves the role of various factors such as person's individual characteristics, family, social support etc.

Coping factors also depend on the level of acceptance. High acceptance will lead to impart positive coping strategies like taking necessary action. Positive perception and appraisal like it is extra responsibility given by God can help others with similar conditions, to develop self as a person will help them to have better acceptance and enhance their coping. Low acceptance and coping will cause severe emotional problems like depression or anxiety.



High acceptance is the core part in rehabilitation process of individuals having Multiple Disabilities. The families having high acceptance tends to have hope in the treatment and provide proper treatment services. They do not regret about having the child. Having low acceptance will lead to frustration, anger, guilt, and feels embarrassed. They also frequently change the professional help. This increases the emotional problems of the family which affects the mental wellbeing of the individual and finally affects the outcome of the rehabilitation process.

Hence, focusing on acceptance level of the family of the disability and enhancing it by increasing the coping mechanism, increasing the formal and informal support systems, and other necessary interventions would help the family.

CHAPTER- 3

COPING AMONG FAMILIES OF PERSONS WITH MULTIPLE DISABILITIES

-C. Sylvia

“The mystery of life isn’t a problem to solve, but a reality to experience”

-Frank Herbert

The way a person responds / reacts to a negative experience / situation with a conscious effort in order to master / tolerate the conflict that pressures him/her is called as coping. They are the different ways of approaching the problems that distress a person with sense of optimism and acceptance. It is defined by the experts as “the constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” – Lazarus and Folk man (1984). In simple terms it is referred as an individual’s attempt to tolerate and / or minimize the effect of the stressors / negative experiences.

FACTS ABOUT COPING

- Coping needs mental efforts that can reduce stress.
- The only aim of coping is to solve the problem and bring back to state of normalcy (homeostasis) either consciously or sub consciously.
- The strategies that are used by a person depend on their personality and experiences in the past and it can be either positive or negative.
- The strategy that has been used by a person is highly individualized and is mixture of how an individual perceive the source of stress, optimistic and pessimistic outlook in finding a solution.

- It also depends on individual's locus of control. Internal locus of control makes an individual to believe that their *successes and failures are determined by their own choices and they are responsible for it and believe that they can control it. Whereas on the other hand, external locus of control* makes an individual to believe that their success and failure purely depends on their fate, luck or by external forces which they can't control.
- The sense of coherence plays a vital role in coping. It is a mixture of optimism and control with three components such as **Comprehensibility**- where events are perceived as ordered, consistent and structured as they make logical sense; **Manageability**- where the person feels that s/he can handle the situation; **Meaningfulness**- how a person feels that his/her life makes sense to them and facing the challenges are worthy by providing meaning to their life.
- Never two people can choose same type of coping mechanism for same situations and the strategy which earlier worked may not work all the times for a particular situation.

In precise coping is a complex process that varies due to many variables such as the situation, negative experience, its intensity and how an individual estimate the particular situation that is demanding, and the availability of resources.

COPING STRATEGIES AND ITS FORMS

A coping strategy is defined as group of cognitive processes, behaviours and skills that are employed by an

individual / group while experiencing stressful / negative situation or at times when looks ahead of such situation (Latack & Havlovic, 1992). These cognitive and behavioural efforts can vary and are of many forms.

Coping happens in a sequence (systematic order) of various strategies for an individual when facing negative situation. It is proved that one stressful situation can be handled by applying several coping strategies either simultaneously or sequentially in response to the stress. The systematic order of these coping strategies depends upon individual differences such as their appraisal processes, personality traits, socio- demographic characteristics such as age, gender, education, marital status etc., and adequacy of the situation that is encountered (predictability, controllability and complexity) also matters.

Coping strategies can be adaptive and maladaptive:

- **Adaptive strategies:** They are healthier and is constructive like seeking social support, gaining knowledge, trying to improve wellness etc.
- **Maladaptive strategies:** They are temporary, unhealthy like trying to avoid the stress temporarily like avoidance, numbing out, dissociation etc.

The strategies are used by the people consciously in order to face negative situation or experiences and to manage them effectively by reducing the pain or distressing emotions attached to that particular event. This would help individuals to adjust with the situation and support them in maintaining their mental well-being. There are three sub-divisions of coping mechanisms:

- **Physiological Coping:** Includes yoga, breathing exercises, muscle relaxation, art, and naturopathy.
- **Cognitive Coping:** Meditation, mindfulness (state of being

in the present moment), thought restructuring (learn to identify illogical thoughts and alternate with logical thoughts).

- **Environmental Coping:** includes nature walk, bonding with pets etc.

Types of coping strategies are:

- Problem focused coping.
- Emotion focused coping.
- Approach coping
- Avoidance coping.

Problem focused coping: The stressor is considered as to be under some degree of personal control. The behaviour attempts to either remove the stressor or alter its impact. This is most effective and adaptive type of coping.

Emotion focused coping: It involves emotional reactions. This strategy is effective as it focuses on altering the emotional experiences of stressor/ negative experience rather than changing the situation / source itself.

Approach coping (cognitive and behavioral aspects) – cognitive approach is positive reappraisal or reframing. This helps in restructuring the problem in a positive way. In terms of behaviour approach, it involves problem solving like making plans to either remove the stressor or minimize the effects of stressor.

Avoidance Coping: Involves withdrawal from the problem. In the cognitive level denying the negative event i.e., attempts are made to forget about the problems. Whereas in the behavioural approach avoidance, denial catharsis- expressing pity / fear about the problems or in simple term, it's dispersing the negative emotions.

In long term of any negative experiences, the effectiveness of these coping strategies depends on the individual differences such as persons' personality and the situation itself. Therefore it's

essential to develop different coping strategies with regards to the demanding situation.

Table 1. Coping Strategies and Types of Responses	
Coping Strategies:	Type of Responses:
<i>Problem Solving or Active Strategies</i>	<ul style="list-style-type: none"> • Work on solving the problem in the situation • Make a plan for action and follow up
<i>Emotional Expression and Emotional Regulation Strategies</i>	<ul style="list-style-type: none"> • Let emotion out; get in touch with feelings and let them out • Let someone know about my feelings • Keep emotions under control by performing appeasing activities • Cognitive restructuring; reorganizing the way I look at the situation
<i>Seeking Understanding Strategies</i>	<ul style="list-style-type: none"> • Try to understand or find meaning of the situation; looking for learning
<i>Help-seeking Strategies and Support-seeking Strategies</i>	<ul style="list-style-type: none"> • Seeking instrumental aid or advice from others • Seeking comfort or understanding from others
<i>Problem Avoidance Strategies and Distraction Strategies</i>	<ul style="list-style-type: none"> • Acting like nothing had happened • Avoid thinking or doing anything about the problem • Leaving the scenario and staying away from the stressful situation • Efforts to avoid thinking about the problem situation by using distractions or entertainment activities

FACILITATORS AND INHIBITORS OF COPING AMONG CAREGIVERS

Coping of family members having Persons with Multiple Disabilities depends upon various individual factors such as personality dimensions, perception, attitude, knowledge, accessibility, etc. Support from the family and the community also plays a major role in mediating the coping process.



Faith in God
Working
Self-determination
Inspiration
Mutual
Physical/
Loss of support
Lack of acceptance
Poor Physical Health of the Family Members
Family Problems
Over indulgence by others/outsideers
Financial constraints
Problems related to professionals
Lack of information

Caregiving persons with multiple disabilities are highly challenging and have greater impact on the process of rehabilitation as well as on the entire families too. The significance of cooperation among family members including primary caretaker influences the rehabilitation of an individual with multiple disabilities. The role of the parents will be demanding on daily basis. They will be focusing on their loved ones round the

clock by attending their health care services / activities of daily living and find little time for their own self-care. On the long run, family members find it difficult to balance their feelings, which is necessary for their well-being as well as for the rehabilitation of their loved ones. They would have lost themselves in the midst of daily demands as a caregiver hence it is significant to refocus on themselves and reflect the reality through coping strategies. This would have impact on their loved ones' rehabilitation process also.

It is also well reported in the researches that the disability in the family also create positive impact to the individual and the family like increasing the family cohesiveness and tapping the potentials of the individuals. Some of the family members were able to cope up well the stressors using problem solving strategies like gathering knowledge, seeking social and professional support, making decisions, performing task-oriented actions, planning, and resolving conflicts (Gupta & Singhal, 2004) . Focusing on positive aspects and reappraisal of the situation also helps to cope up their stressors (Abery, 2006). Emotion focused strategies like believing in God, engaging in pleasurable activities helps them to reduce the negative emotions related to their daily stressors. The maladaptive coping strategies like avoidance, withdrawal, blaming, and self -destructive behaviours inhibits the rehabilitation process and in turn affects the mental wellbeing of the care taker.

Some of the examples of internal and external facilitators are:

External facilitators:

- Physical support
- Emotional support
- Professional support and proper guidance in providing knowledge about disability and treatment procedure.

Internal facilitators:

- Faith in God
- Cognitive reappraisal
- Finding out the meaning out of situation and life
- Being grateful
- Working on problems
- Self-determination etc.,

Other factors like institutional support, access to services and Government benefits also facilitate coping in caregivers which would bring progress in rehabilitation process of person with multiple disabilities.

The most significant inhibitors for coping in families which hinders the rehabilitation process are:

- Lack of acceptance by other family members
- Poor health of the members in the family
- Loss of support from family due to someone's death (spouse, elder persons or somebody who is financially supporting)
- Uncooperative or alcoholic spouse
- Lack of time for caring
- Financial constraints like loss of job / unemployment, debts, lack of income tax benefits & other government benefits
- Lack of accessible to professional services and misguidance from the professionals
- Behaviour problems in individual with disabilities,
- Comparison of their own child with other normal children
- Misconception about the problem.

In **conclusion**, the increased stress and poor coping will always have negative impact on the well-being of the caregivers. Rehabilitation is a process that ranges from interventions for the individuals which also include the caregiver and family members as they play a vital role in it. Hence, it should pay attention to the needs of the family as well. The severity of disability and other factors such as socioeconomic status, education, culture, support network, personality as well as individual's coping ability of caregivers have direct or indirect impact on the process of rehabilitation. There is no doubt that situational factors significantly impact the quality of life of the person with disability and as well with their caregivers which ultimately in turn rehabilitation.

CHAPTER- 4

EXPLORING DIVERSITY

-P. Kalavani

The recovery of persons with disability involves the commitment of the family members of persons with disability, professionals, and the community. While treating and rehabilitating the persons with disability, the needs of the family are not often thought about. Hence, understanding the role of the family, it's diversity, and its impact in the rehabilitation process of persons having disabilities would be very significant at current scenario.

This paved way to explore more about their coping facilitators and inhibitors during process of recovery of the children having multiple disabilities. Hence, the parents of Multiple Disabilities attending various services from NIEPMD and parents from two special schools from Chennai were studied. A special school from Mizoram was also included in the study. Total number of samples included in the study was 91.

The parents of children having multiple disabilities were only included in the study. The parents having any other comorbid chronic physical or mental illness were excluded. After given the written informed consent and explaining about the purpose of the research, the parents were interviewed and were administered a questionnaire to assess their level of acceptance and coping factors that inhibits and facilitates the rehabilitation process of their child having Multiple Disabilities. The samples included were Autism with Intellectual disability, Cerebral Palsy with Intellectual Disability, Hearing Impairment with Intellectual Disability, Visual Impairment with Intellectual disability, locomotor disability with speech impairment after traumatic brain injury.

The distribution of the samples are as follows:

Categories	No. Of Samples	Percentage
Joint Family	19	24.05
Nuclear Family	60	76.00
Single Parent	12	15.19
Rural	28	35.44
Urban	51	64.55
Tribal	6	6.88
High Economic strata	66	83.54
Low Economic strata	13	16.46
Minority	16	20.25

Procedure

All the interviews were conducted by the investigator and the research staff. It is an exploratory study. The semi-structured interview was conducted individually to elicit the factors that inhibits and facilitate their rehabilitation process. The open ended question asked was: “What were the factors that facilitated and inhibited you to cope during the rehabilitation process of your child’?

The acceptance level of the parents was assessed by administering a questionnaire which was constructed having 25 questions. The questions were constructed and finalized after the peer review. The parents were asked the questions and were asked to rate accordingly. The acceptance scale constructed has four subscales like feeling embarrassed or self-pity about having the child, perception of child skills and limitations, rejection of the child, overprotection of the child, accepting the reality, and taking solutions. The results of the study among different family systems were explored and discussed in detail in the following chapters.

4.1 FAMILY SYSTEMS

-E. Subashini

"Families are the compass that guide us. They are the inspiration to reach great heights, and our comfort when we occasionally falter"

-Brad Henry

Introduction

A Family is a group of people related either by consanguinity and/or affinity (by marriage or other relationship). It offers the safety and maintains the well-being of its members and eventually forms a healthy society. Additionally family meets the basic needs of its members and provides a sense of boundaries for performing tasks in a safe environment. It ideally builds a person, transmits culture, and ensures continuity of humankind.

Nuclear family

The nuclear family consists of two parents and children. Children in nuclear families can have more opportunities due to the independence and financial ease of two adults. They have autonomy in their decisions and can follow their own customs. Nuclear families can be strong and



successful; however, like any family nuclear families have their struggles to face.

For example, their support system will not be strong and getting through hard times can be challenging.

Single parent

The single parent family consists of one parent raising one or more children on his/her own. This family may include a single mother with her children, a single dad with his kids or a single person with their kids which may be due to separation or death of the one parent. The support system is poor and hence the single parent has to face more stress.

Joint family /Extended family

The joint family structure is the traditional type of family system wherein two or more adults who are related either by blood or marriage live in the same home. The family system



includes relatives like grandparents, aunts or uncles and cousins living together. More physical and psychological support present in this family system is more healthier for the development. However, more number of people present under same roof may lead to financial difficulties because earning is

made by one or few for the whole family and it may also add on the burden if in need to take care of elderly persons.

The most common challenges faced by parents in different family structures in bringing up a child with disability are as follows:

- Financial constraints
- Additional burden of looking after a special child
- Lack of enough time for the special child's sibling, if any
- Lack of social support and acceptance
- Lack of information on child's condition
- Lack of understanding/support from spouse

- Behaviour problems of the special child

Strengths and Challenges in Joint Family system

In joint family, the burden of taking care of child with Multiple Disabilities can be mitigated by splitting up the work and financial expenditures among different adults in the family. The physical and emotional support is more in Joint Family systems compared to Nuclear Family system. The need of physical support like carrying the child, helping in toilet and other self-care activities can be shared by other family members. They have the opportunity to assign the task of caregiving of special child to another adult in the family and can have a little break from caregiving role which would serve as major coping strategy. Most of the researches have concluded that increased social and family support helps to reduce their stress. Skills of the child can also be facilitated in the Joint Family System where the interaction and learning process is more. So, the strengths are:

- Physical support
- Emotional support
- Financial support
- Facilitating the skills of the child with disabilities

Challenges: Especially the mother of child with disability faces the burden of taking care of ailing or bedridden elderly people and also the other family members. Difference in opinion on disability among different families' members hinders the care taking and rehabilitation process. There might exist lot of misconceptions about the child's condition among the members, especially grandparents and other old people that might mislead the parents eventually affecting the special child's rehabilitation process. Such opinion difference might also give rise to conflicts among different family members that might become a barrier for child's rehabilitation.

- Burden while taking care of the other elderly members
- Misconceptions and difference in opinions
- Lack of acceptance among other family members

Strengths and Challenges in the Nuclear Family System

In Nuclear family, the family has autonomy to take decisions on their own. The stigma and remarks of the other family members is less which reduces their grief and helps them to accept the disability and move on to the rehabilitation process. The spouse being the only support, bonding is increased among themselves and they consider it as a common goal to provide better rehabilitation to their special child. Their relationship gets stronger which serves a factor that would facilitate coping to care giving stress. The strengths are:

- Autonomy and Freedom
- Less misconceptions

Challenges: A child with multiple disabilities usually needs constant physical and psychological support. Parents being the sole person to support the child experience greater burden and stress because of this. Nuclear families faces this problem often wherein most cases, the mother is the only person to take care of the child and this restricts her from going for a job or even spending time for herself pursuing hobbies of preference which all together adds up to the stress of the mother. The family might also have to fix their expenses earned by one of the parents alone as the other would be busy being with the child round the clock. This may also lead to financial constraints that would affect the child's rehabilitation process.

Challenges:

- Lack of personal and leisure time
- Financial and care taking burden
- Less emotional and physical support

The parents in nuclear family having a child with multiple disabilities have to manage other works single handedly especially mothers have to concentrate on her other child, if any and have to do with the chores too. This division of attention and time spent among all the works, may decrease the time spending with the child with disability who needs more guidance and home therapy. As a result, more behaviour problems can also be perceived by the mothers and this would make them to lose their temper affecting the mental health of both the mother and the children. The emotional and physical support provided by other elders of the family will also be not available on daily basis. If the husband is not supportive in bringing up the child with disability or if there is difference in opinion between both the parents, it might create a lot of friction eventually affecting the child's rehabilitation process.

Strengths and challenges in the Single Parent Family

For single parents, wherein their child is their only point of focus, the hope they pin on their child's treatment/therapy is high and their positive attitude towards child rehabilitation is also high. Similarly, higher gratitude towards life is common among single parents than the other two family structures. Social stigma and rejection affect them less as they can attribute it not only to the disability of their child but also to their single parent status. Hence, they start learning to live without paying much attention to any prejudice on disability. This is little hard to observe in joint family, wherein more elderly people with conservative thought process holds more prejudice and stigma towards disability.

Challenges: The stress experienced will be even more, since the same person has to take care of the child, home and also the financial needs. Overwhelming responsibility might sometimes create negative reaction towards the child. The challenges are more being the single parent such as:

- Less family and community support
- Lack of emotional and physical support
- Financial constraints

ACCEPTANCE AMONG THE DIFFERENT FAMILY SYSTEMS

Acceptance of disability varies between different family structures and depends upon the social support, availability of information and accessibility to services. Soon after the disability of the child has been revealed to the parents by a professional, the parents enter into utter shock. During this stage family support, with people having more positive attitude is important to move on to consequent stages. In this case, joint family might be helpful if it consists of more understanding members. However, parents from joint family might get stuck in the next stage, denial, for a longer time than single or nuclear parents if elders in the joint family deny the diagnosis of professionals and convince the parents to not to take the child for further services.

While single and nuclear parents might have difficulty in overcoming the next stage anger, especially single parents who single-handedly has to handle the child might be getting into the attitude of “why me” as they would already be facing challenges to break the social stigma of being a single parent and lead a normal life. But, most of the single parents may reach the final stage of acceptance and put their fullest effort on their child especially if they have only one child.

Nuclear family especially from urban and higher socio economic strata might stay in the third stage, bargaining, for a longer period of time where they will never be easily convinced with services provided by any particular institute and would like to reiterate the diagnosis every now and then by different professionals. Eventually, parents from nuclear family structure get into depression stage and might also stay in that stage longer because of the extra efforts they have expended in their bargaining. On the other hand, acceptance level may also be high depending upon education, awareness, and cooperation from other family members.

Our studies shows, overall 63.16% of joint family parents have reported that they are affected by their comparison of normal children with their special child compared to 35% from nuclear and 33.33% from single family. This may be because in joint family, more cousin children will be present in the same home with special child and also the occasions of meeting them would be more. Hence the parent may get the inferior feeling as just their special child couldn't go about doing normal activities or playing as the other normal children does. Few even reported that they compare the achievements in terms of academic success of other normal children to their special child's.

Whereas, 28.33 percent of the parents from nuclear family has reported that they are experiencing threats regarding other family member's future especially their other child compared to 21.05% among joint family and 25% among single family. This might be because they usually lack time for their normal child and presence of special child in a family affects the educational opportunities, job and even marriage for their siblings. Many of them have reported that they keep changing the professional help to have changes in their child indicates low acceptance among the nuclear family who belong mostly from urban area.

66.67% of the single parents reported financial constraint as their major coping inhibitors compared to 51.67% by nuclear and 36.84% by joint family parents for the reason that has been discussed above. Also 66.67% of single parents reported behaviour problems by special child as major stressor compared to 53.33% by nuclear and 26.32% by joint family parents. This could be attributed to the reason that gradient support system observed in these family structures affects the temperament and eventually changes the perception of problem behaviours of the special child. Similarly 66.67% of single parent reported lack of social support for their special child compared to 47.37% and 40% by joint and nuclear family parents respectively. This might be because of the reason that the stigma associated with single parents affects their special child and they get even lesser support from their family and community.

50% of the single parents reported lack of time for their special child compared to 35% and 26.32% by nuclear and joint family parents respectively. This might be because of the reason that single parents has to meet the financial needs going for a job and also take care of the home along with the special child. But in joint family, sharing of responsibility would be the reason that they reported comparatively less in this aspect.

Our studies shows that 78.95% and 73.33% of joint and nuclear family parents reported that they believe that their child will get better , while 100% of the single parents believes that their child will get better. 52.63% of the parents from joint family reported that getting help from other family members to help with chores and tasks at work facilitates their coping while 33.33% and 26.67% of nuclear and single parents has reported that this factor helps them to cope.

Similarly, 94.97% of joint family parents told that talking to someone about how they feel enables their coping, while 71.67%

and 66.67% of nuclear and single parents has reported that this factor helps them to cope. This might be because of the fact that joint family parents have more opportunity for talking to people at home than the nuclear and single parents. While 67% of the single parents have told that reading about disability and success stories of persons with disability motivates them in their journey of bringing up the child, but the same factor has been reported by 47.37% and 46.67% of joint and nuclear parents respectively. This might be because of the reason that because of perceived social isolation, the single parents opt to read and motivate themselves than to talking to others to vent out their stress.

It can be well understood that enough social support, knowledge building on disability and attitude enhancement would build up more positivity and enhance the acceptance and coping among the families.

4.2 DOMICILEFACTORS

- K. Priyadharshini

“No Pessimist ever discovered the secret of the stars, or sailed to an uncharted land, or opened a new doorway for the human spirit”
-Helen Keller

Disability in Rural Areas

According to the World Health Organization (WHO), about 15% of the world's population are with disability and the occurrence of disability is found to be higher in developing countries such as India, with the majority of them residing in rural areas.

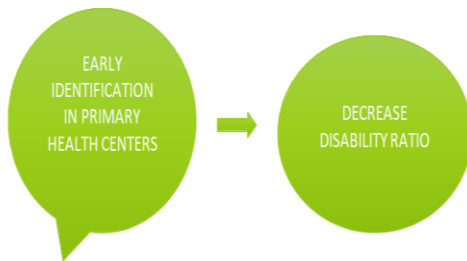


The census of 2011 indicates that 2.2% or 27 million people are Persons with Disabilities out of which 70% live in rural India. Uttar Pradesh ranks first, Bihar is next on the list with 2.90 lakh children with disabilities and Maharashtra has 2.17 lakh children with disabilities. In the south, undivided Andhra Pradesh has 1.27 lakh children, followed by Karnataka - 92,853 - Tamil Nadu - 62,538 - and Kerala - 26,242.

Causal Factors

The causal factors can be attributed to:

- Poverty
- Poor nutrition and lack of care of pregnant mothers
- Lack of awareness
- Lack of access to medical facilities and health care services
- Lack of professionals
- Pregnancies happened by midwives



Early detection and medical intervention of disabilities is very essential which is lagging in most of primary health centres and hospitals in rural areas due to lack of professionals.

Challenges in Rural areas

Even though Government has been implementing various policies for the empowerment of Persons with Multiple Disabilities, integrating and inclusion of them in the economic mainstream has not been fully met. Especially women, youth and those in rural areas, remain disproportionately undereducated, untrained, unemployed, underemployed and poor. (Economic and Social Commission for Asia and the Pacific, 2002, p. 5).

Challenges are:

- Housing
- Enrolling in schools
- Transportation
- Employment
- Limited awareness of entitlements and services available
- Appropriate healthcare and rehabilitation services



Source:Pixabay 1

Most of the people are not sensitized about disability schemes and programs, and available services for rehabilitation. Lack of education, negative perception, and stigma also makes them inhibited limiting the opportunities and involvement of people with disability in social and financial life often even within their own families.

Acceptance and coping in rural areas

A number of studies have concentrated on the degree to which families having persons with disability and families feel stressed, how they manage, what factors support them, and what coping strategies they use. The family members are hesitant to accept the disability or pass on to it as a physical illness and treatable condition. The burden of stigma is more in rural areas especially they are concerned about the marriage of their other children. The pseudo-stigma attached to such disability makes them hide the fact of having a member with disability at home ultimately leading to social isolation and restrictive behaviours. Claiming to cure the impact leading to acquiring disability, families often lock or chain their children with behavioural issues due to helplessness, ignorance or under social pressure. Sometimes, misconception about the disability is also prevalent like attributing to other factors like black magic, sin etc.,

There is also a necessity to be more advanced in understanding the diversity and heterogeneity of Persons with Multiple Disabilities in relation to planning livelihood ways. In India receiving maximum social-emotional support from the spouse, family members, relatives, and friends are facilitators for

effective coping. The bodily support from within and outside the family is one of the greatest facilitators in coping. The support from the family and the relatives is better in rural areas compared to the urban areas; hence it also helps in reducing the burden of the caregivers and helps them to reduce their stress. The natural environment from the rural areas also helps in cognitive stimulation and improve their social and communication skills.

In our study conducted, about 28 samples (35.44%) belonged to the rural areas. 17 of them had moderate level of acceptance and 11 of them had high level of acceptance. The main inhibitors of their coping were reported as problem as lack of acceptance from the community and the family, difficulty in accessing services, cannot afford the cost for the treatment, do not have awareness about the Govt. Services and schemes available. Poor knowledge about the condition and appropriate treatment, lack of professional help and services were reported as the major inhibitors as reported from the tribal area from Mizoram. The coping facilitators were reported as believing that their child will get better and believing in the treatment.

Mass awareness through media on general health, hygiene, and sanitation should be promoted. Better health policies should be framed to reduce the burden of the condition. Early detection and medical intervention of disabilities in the rural population are the most important measures to be focused. Community organizations, healthcare services, local governments and other rural entities can help people with disabilities by collaborating and productively using limited resources to provide needed service.

Disability in urban areas



According to World Health Organization and the World Bank, 15% of the world's population live with some type of impairment or disability. By 2050, 6.25 billion people will live in urban centres. India is experiencing rapid urbanization from being a predominantly rural country to more people aspiring to live incites.

Urbanization is defined as the rise in the number of cities and urban population and it is not only a demographic movement but also includes social, economic, psychological changes that constitute the demographic movement. Urbanization address necessary development domains such as education, employment and decent work, social protection, resilience to and improvement of disasters, sanitation, transport, and non-discrimination.

Although disability is as old as the human race, the issue of disability and the experiences of people with disability have received little consideration even in urban areas. Despite improvement in the health care system, the situation of people with disability remains terrible.

Urban areas focus on inclusion and participation of persons with disability in profitable and social development. The inclusion and exclusion of Persons with Multiple Disabilities depends upon the infrastructure, facilities, services, and accessibility. It is a known fact that the awareness, education facilities, therapy facilities, and accessibility to other services is more in urban areas,

but still the Persons with Multiple Disabilities face dramatic

Challenges in the following areas:

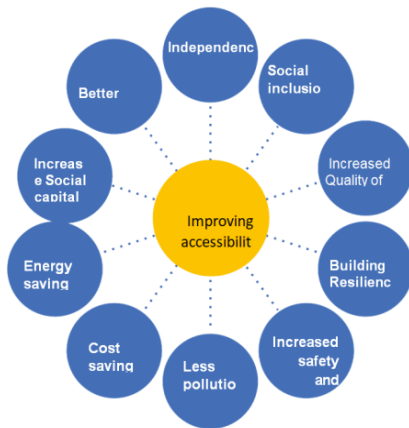
- Poor infrastructure
- Poor accessibility
- Restriction in leisure and social activities
- Education
- Limited employment opportunities

Challenges in Infrastructures

Disability affects different facets of life of a person irrespective of age, gender etc.. Persons with disability continue to face considerable discrimination regarding mobility and accessing urban infrastructures and services due to the lack of accessible transportation options, pavement ways, and poor building structures. Their needs are not fulfilled because of inaccessible or poorly designed services and it remains a barrier for their development. Children with disability are denied and excluded from the play and recreational activities the normal kids do mainly because of poor accessibility to the environment. Basic facilities like toilet access and other necessary provisions also remains challenging for them and hence they restrict themselves from most of the recreational activities like going to park, theatres, shops etc. Poor infrastructure remains a barrier in most of the buildings including houses, public areas, and education settings. Housing accessibility and accommodating the house especially for Persons with Multiple Disabilities becomes very difficult of the family.

Poor infrastructure remains barrier in the rehabilitation process also. Transportation facilities like travelling in buses, poor accessibility, and distance of the available services makes the

rehabilitation process a difficult one. Improving the accessibility and barrier free environment is very significant to provide equal opportunities for Persons with Disability.



Challenges in Education Facilities

Getting basic education and admitting in schools remain difficult, which is more worse for Persons with Multiple Disabilities. They are excluded even though they are admitted in the main stream. Lack of adequate professional help in the inclusive school setting is

the scenario in many schools. Getting appropriate rehabilitation services and admission in special school remains difficult for majority of the population in urban areas because of the extra cost and poor accessibility.

They have to undergo frequent assessments, availability of the professionals and cost for the services remains a problem for most of the families in urban areas especially people from middle class or lower income group.

Challenges in Employment opportunities:

Poverty rates are considerably higher for individuals with disability on a world-wide basis (WHO, 2011). Financial burden, lack of employment is another major challenge for Persons with Multiple Disabilities. The involvement of Persons with Multiple Disabilities is very important not only for their financial independence, but it also helps to improve their social and

cognitive skills. The employment opportunities and vocational training centres are very limited even in urban areas and do not meet the demands required. Hence, most of the Persons with Multiple Disabilities remain unemployed. Even though they are employed, the restriction of environment in the work place and the attitude, stereotype of the employer and the co-workers is also a major barrier. Most of the time, they are underpaid or have problem in mobility access because of poor accommodations in their job areas. Discrimination of Persons with Disability who are even qualified makes them to lose hope and remains dormant. The Disability act 2016 emphasizes on providing equal opportunities, lack of discrimination, provide barrier free environment, it should be implemented vigorously for the betterment of the community.

Acceptance, Coping Facilitators and Inhibitors in Urban areas

The presence of problems in Persons with Multiple Disabilities is known to produce greater stress for parents. Controlling such problems requires more effort and skills in handling them, and hence such support would be considered as important facilitator.



Even though, there are facilities available in the urban areas, the burden of the families having Persons with Multiple Disabilities still remains the same.

Poor social support and sharing responsibility by other family members is not present in urban area as compared to rural areas which would add on the burden of the caretaker and inhibits their coping

process. Accessing housing facilities, especially accommodation for Persons with Multiple Disabilities remains a challenge. Unable to meet the financial demands and meeting extra costs for the services available is another stressor and inhibitor.

Persons with Disability (PwD) who live in urban areas seldom face difficulties as people live in rural areas as necessary facilities are available. The sharing of knowledge and awareness is more in urban areas which is important facilitator during the recovery process. Accessing Government aids and schemes is also much more better in urban areas. The attitude and less stigmatization towards disability play a significant facilitator during the recovery process in urban areas.

In our study conducted, number of samples from urban area were 51 (64.55%). The acceptance level was reported to be moderate among 36 samples and high among 19 samples. The common inhibiting factors affecting coping of the families having Persons with Multiple Disabilities during the rehabilitation process were reported as behaviour problems, getting admissions to schools, and lack of time for the child. Some of them have reported about uncooperative spouse, financial constraints, and lack of acceptance of their child particularly by other members in family as the other inhibiting factors. Devoting enough time for the personal growth, spending leisure time, and talking with other parents who have similar problems were reported as facilitators of coping. Many of them have reported as believing in God has helped them in coping. They are not much concerned about the remarks of others. Most of them have reported about the professional help and guidance as the major facilitator, but they also have difficulty in accessing because of transportation and costs.

People with disabilities may require access to specific

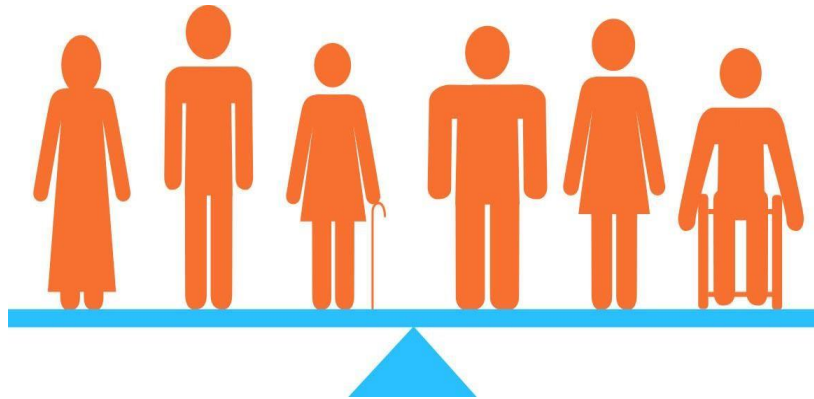
measures, support services, and training. In this process, involvement of persons with disability is of paramount importance. Monitoring and evaluation of the service should be strengthened with information related to impact on disabled, community mobilization, opportunity for education, opportunity for work, transfer skills to community level, program activities, and involvement of disabled people in all set ups.

4.3 ECONOMIC DIVERSITY

- Amanda Fernades

"A person who is severely impaired never knows his hidden sources of strength until he is treated like a normal human being and encouraged to shape his own life'-

-Helen Keller



Introduction

Diversity can be broadly conceptualized as a power which includes respect, acceptance and recognizing one's unique individual differences. It encompasses concepts such as gender, socio economic status, ethnicity, ideologies etc. Diversity within an economy largely points towards nurturing the differences between individuals and providing a safe environment by harnessing tolerance and moving towards celebration of differences within each individual.

Economic diversity can be defined as a multidimensional concept that includes the products, workforce skills and capabilities in a local **economy**, in addition to how well that **economy** is able to compete in the global marketplace, according to **Economic Modeling Specialists Intl**. While there are several ways to segment an Indian society, in terms of language, community etc.,

categorization in terms of economic background can highlight major aspects of an individual's life.

In a country like India, with such an assorted population economic diversity plays a major role in deciding the wellbeing of almost all individuals. Till date the socio economic status of an individual dictates and governs the whole life of an individual encompassing the individuals' status, education, work, income etc. The socioeconomic status of the society goes further to even affect the individual's physical and mental resources. The effect of low socioeconomic status ultimately affects the economic makeup of the society. Ideas on diversity have focused mostly towards gender and religious beliefs leaving in the shadows the very existence of disability and mainly the impact of economic diversity on this minority group.



The Indian Government has undertaken measures to safeguard the rights of Persons with Disability by enabling several acts to ensure equality in work, education and prohibiting discrimination.

Economic Diversity in India and its impact

People with disability are largely denied access to economic resources such as job opportunities, sustainable wages and are not given chance for self-employment. Yeo has reported that "50,000 people, including 10,000 people with disability die every day as a result of extreme poverty" (Yeo, 2005, p.1). Attempts to include Persons with Disability into the society of India prioritizing equality among all has not yet normalized. This in turn creates a

huge disparity among Persons with Disability and the general public leading individuals with disability and their families to live a life of poverty. The exclusion of such a huge population which inhabits necessary working potential viciously hampers growth within Indian economy and globally.

Focusing mainly on the interaction between economic background and opportunities for Persons with Disability in India, Government has taken several measures to improve the economic condition of Persons with Disability. In Disability act of 1995, 3% reservations for differently able in all public sector jobs was implemented. In 2016, Disability act raised it to 4% reservation in job vacancy and implemented several measures for equal opportunity in higher education. Self-employment schemes were also initiated for empowerment of Persons with Disability. In spite of all these measures, the employment opportunity is very limited and it remains hard for this population to be economically independent.

Hence steps to include these diverse and well capable individuals into the society should be prioritized not only for personal growth and inclusion of Person with Disability, but also adding to the stability of the Indian economy.

Economic Diversity and Acceptance among families of Persons with Multiple Disabilities

It is very obvious that poverty is one of the major causal factors for the disability as they have poor access to healthcare facilities and proper nutrition. It is also clear that disability would lead to poverty because of lack of opportunities in education system and employment. This is mainly due to lack of awareness among families of Persons with Multiple Disabilities and the condition can be viewed as worse if the family is economically challenged.

Lack of awareness about Government Acts and schemes for Persons with Disability, societal exclusion, poverty and economic factors interfere with families' acceptance of Persons with Disability. In India, coming from a lower socioeconomic status creates many challenges for family members to better manage the circumstance of having individual with multiple disabilities.

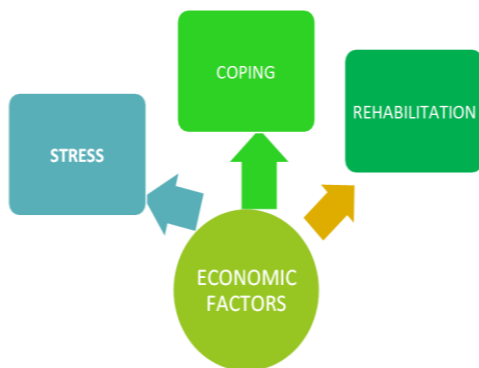
The Family Stress Model developed by Conger (Conger et al., 1992) proposes that poor child health outcomes are directly associated with factors such as poor family financial status, psychological distress, and poor parenting (e.g., ineffective parenting). Low income surpasses the expected cost of taking care of the needs of the family members of the Persons with Multiple Disabilities. This cost burden plays a negative role and puts abundant pressure on the family members.

Families are often ridiculed and become victims of discrimination due to the stigma associated with disability. When economic factors such as these (social exclusion, low socioeconomic status, physical neglect) cross paths it has very detrimental effects on Persons with Multiple Disabilities and their families. They are often hidden in the shadows of their homes away from society, denied basic rights of education, and job opportunities. Overall, they fit under the category of being 'dependent'. Such stigmatization begins from family members due to their negative acceptance of disability. This harsh discrimination leads to health issues, economic burden and violence against the differently- able individuals. The acceptance level of families from higher economic strata tends to be low as they do not get satisfied with the professional services. This in turn increases their stress and it affects their attitude towards their child.

Economic Diversity and Coping among family of Persons with Multiple Disabilities

Having a disability in a family creates a major impact and it leads to adjustment in various aspects in life of the family members and caregivers. Caring for Person with Disability can lead to physical and mental stress which in turn leads to decreased quality of life among the family. Family members resort to coping mechanism to help deal with the emotional, mental and physical stress of caring for a family member with disability.

Having a family member with a disability leads to a great stress and change within the dynamic functioning of a family. Studies have shown that coping with physically or intellectual disability is highly individual process and families may never adjust fully (Koller, Richardson & Katz 1992). This does not



suggest that every family is affected in a negative way, several resorts to healthy appraisal of the situations and cope well despite the difficulty. While several factors can influence coping behaviour, economic diversity plays a major role

among others. The high economy may reduce the stress of the family members as they can avail the facilities easily, procure necessary aids, and can afford all the available services for the rehabilitation whereas this does not happens in families with low income and it increases their stress.

Research in India has suggested that receiving social-emotional support from family and friends are facilitators of effective coping (Peshwaria, 1989). Such support seems to decrease as we move down the ladder of economic class. They often compromise with wellbeing due to their limited resources. Persons with Multiple Disabilities belonging to lower economic class are regarded as burden without rights. Due to lack of support and understanding, caregivers chose unhealthy coping mechanisms such as avoidance of the situation and living in isolation. Caregivers and family members may also engage in unhealthy behaviours such as substance abuse or abusing the Person with Disability and other family members. This eventually makes it worse to look at the crises in a positive light.

The coping mechanism is difficult in individuals who come from lower socio economic status because of limited financial resources, lack of support, unawareness etc., which leads to negative attitude and poor coping which overall impacts Persons with Multiple Disabilities. Due to financial constraints, the families have problems in:

- Getting equipment and aids
- Difficulty to access services because of extra cost
- Modifying infrastructures
- Transportation costs

This make them to constantly worry about the future of the child with Multiple Disabilities and also about the other family members as they have to meet the other demands like education and marriage for the other children. Sometimes they have to leave the jobs to look after the child which increases their financial burden and the stress is more as they are not able to meet the demands of the family.

On the other hand, families from higher economic class tend to resort to healthier ways of perceiving the situation, they provide opportunities for the Persons with Disability to grow, focus on cultivating optimism and having a more positive attitude. For example parents of a child with disability from a higher economic strata will enroll their child in a special school, nurture his/her talents and find time for themselves. Getting necessary equipment, using technology, and accessing all the services paying extra costs or admitting in a school is more easy among people belonging to high economic strata.

In our study, it has been found that people from lower socioeconomic group (16.46%) have reported that financial constraint was their main inhibitor in coping during the rehabilitation process. Most of the therapeutic interventions, aids, and transportation costs increase their financial burden. Sometimes, they have stopped the rehabilitation process due to the financial constraints and they cannot afford it. They could not access necessary well-equipped appliances like wheelchairs, and other necessary aids and equipment. Accommodating in school is also a major problem for them as they cannot afford special schools and paying extra for the additional services remains a constant pressure for them. Whereas people from higher socioeconomic strata (83.54%) were found to be comfortable in getting all the available services, they could afford in training their children with other skills, placing a home teacher, and using advanced technology to improve their skills. Getting proper access and gaining knowledge is also easy for the people belonging to higher socioeconomic strata. The inhibitors reported by them were found to be lack of acceptance from relatives and other family members.

In conclusion, it can be said that due to the vast gap in the economic status of India, minority population like individuals with disability often suffer. Creating opportunities, acceptance within family and society, support and guidance and an overall awareness can lead to major change and empowerment among persons with Multiple Disabilities and their families.

4.4 ETHNICITY

-Amanda Fernandez

“Diversity and inclusion are about giving value to every human being, no matter our differences”

Introduction

Ethnicity can be defined as a group of people sharing same language, culture, religion etc., The diverse country of India is a home to thousands of ethnic and tribal groups. This complexity can be attributed to many invasions by Arabs, Persians, Mongols and the last and most influential is the great invasion by Europe, which said to have a drastic impact on the Indian culture but relatively little effect on its ethnic composition.



India can be viewed as a rich tapestry of tribes, language groups, and social groups. India's communities can be summed up to be 4,636 inclusive of language and caste groups that speaks 325 languages and belong to four distinct ethnic groups 1) Indo-Aryans (72%), 2) Dravidians (25%), 3) Mongoloids (3%) and 4) Negrito (few thousands).

Ethnicity and Disability

Census 2011 depicts that,

Population of India 2011			Persons with Disability, India 2011		
Persons	Males	Females	Persons	Males	Females
121.08Cr	62.32 Cr	58.76 Cr	2.68 Cr	1.5 Cr	1.18 Cr

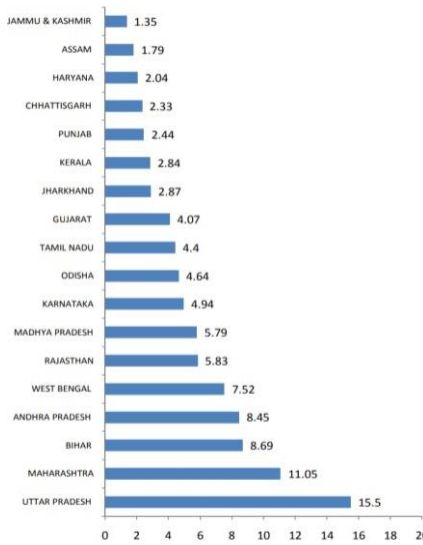
With regard to the social groups in India the amount of people with disabilities in the population is higher for males than females.

Population with Disability by social groups in India- Census 2011			
Groups	Persons	Males	Females
Total	2.21	2.41	2.01
SC	2.45	2.68	2.2
ST	2.05	2.18	1.92
Others	2.18	2.37	1.98

Source: Social Statistics Division, Ministry of Statistics and Programme Implementation, Government of India

The Census of 2011 also highlights the status of disability within different states of India. The Census states that among the states/Union territories, the proportion of persons with disability of the total population is highest in Sikkim (2.98%), Odisha (2.64%), Jammu & Kashmir (2.88%), Andhra Pradesh (2.68%) and Maharashtra (2.64%). The lowest population was found in Daman & Diu (0.9%), Dadar & Nagar Haveli (0.96%), Mizoram (1.38%), Delhi (1.4%) and Chandigarh (1.4%).

Proportion of persons with disability in Census 2011



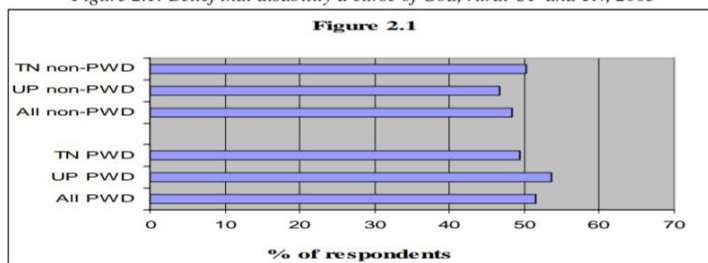
Ethnicity and Acceptance among families of Persons with Disability

The acceptance of disability would definitely vary among different groups depending upon their shared culture, attitude etc. The stigma and the recovery process vary depending upon their ethnicity.

Research in India has consistently pressed on the idea of marginalization of this category of individuals and highlights the segregation and stigmatization of families and Persons with Disability. Bacquer & Sharma (1997) points to the significance of karma in the acceptance of Persons with Disability. Disability is perceived as a punishment for sins and represented as divine injustice and wrongdoing. While the qualitative research has pointed towards exclusion of Persons with Disability, the background and ethnicity of the family plays a crucial role on the acceptance level of Persons with Disability within family and society.

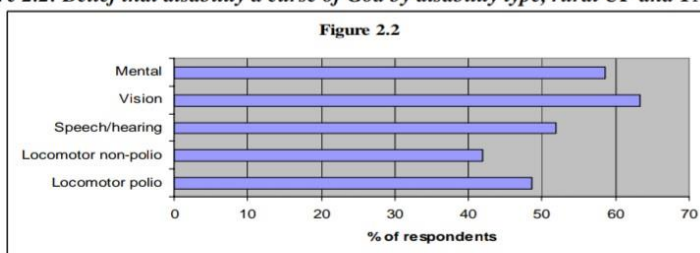
Following is a survey done UP and TN in 2005 suggests that disability is a curse of God.

Half rural respondents in rural UP and TN believe that disability is always a curse of God
Figure 2.1: Belief that disability a curse of God, rural UP and TN, 2005



Source: UP and TN survey, 2005. % of respondents replying that disability was always/almost always a curse of God

Figure 2.2: Belief that disability a curse of God by disability type, rural UP and TN, 2005



Source: UP and TN survey, 2005. % of respondents replying that disability was always/almost always a curse of God

Overall, it can be suggested that the acceptance of family of persons with disability is largely dictated by their ethnic background and upbringings.

Ethnicity and Coping among family of Persons with Multiple Disabilities

Family sum up to be the primary caregivers and providers for all the needs of Person with Multiple Disabilities, but such caregiving surrounds not only the needs of the Persons with Multiple Disabilities, but also requires physical, mental and financial resources of the caregiver (Murphy & Young, 2006). This physical, mental and financial resource of family members is often

mediated by the ethnic background of the family having a Person with Disability.

In India, the available research on ethnicity and coping is minimal; nonetheless the general understanding of this topic can be summed up to highlight the importance of acceptance, inclusion and awareness. It is documented that minority ethnic groups face ample of social and financial disadvantages in their access to legal support services and they are poorly served and excluded.

In India ethnic inequalities among the Dalits, Adivasis and other disadvantaged groups are worsened by having a person with disability. The lack of awareness and education about the disability may be high in some ethnic groups. The stigma, perception, and attitude towards disability and rehabilitation facilitate or hinder the rehabilitation process. For examples in some groups, believing the disability as a sin influence the acceptance and coping process of the families.



As part of coping, the reason for disability of a member is often directly related to the coping mechanism adopted by the family. For several ethnic groups who strongly associate with the power of God and relate disability to wrath of God more often believe doing rituals would help.

Praying is a potentially positive coping strategy and helps those who engage in it and it helps to relieve the stress that they enduring for a while. It gives them a way to avoid or escape their stressful life. Religiosity helps them to vent emotions and find

hope and strength to endure the difficult times.

On the contrary, perceiving disability as a curse from God can offset the families in dealing with this adversity in a positive way and not take necessary action to do appropriate rehabilitation process. The exclusion and seclusion of families from the society for bearing a Person with Disability may trigger emotions of anger, frustration and outrage. This leads to projection and displacement of the emotions in an unhealthy way. They keep them hidden as a way to deal with it by ways of denial. They fail to face the gravity of the situation that is acceptance, use adequate coping strategies, positively reappraising their situation and engaging in more altruistic acts of kindness.

Today, the Government and several non-governmental organisations are working towards helping families and Persons with Multiple Disabilities to live a more fulfilled life. They focus on building the capabilities of Persons with Multiple Disabilities, inclusion into the society with no bias on the base of ethnic background, religion or place. Families from diverse groups such as Adivasis and Dalits are educated and given a chance to use intellectualization and reasoning as a way to understand and deal with their situation. This is enhanced by providing monetary funds and adequate services for Persons with Multiple Disabilities. Awareness and education programs, increasing the strength of the professionals, and early identification programs in all primary health centres would facilitate the betterment of People with Multiple Disabilities belonging to all groups.

In the study conducted, sixteen samples were from minority group and six belonged to tribal population. About 56% have

reported that they have to move their homes because of lack of facilities in their area. Lack of acceptance from the community was also reported as other major inhibiting factor for the families belonging to minority group. Lack of information of Government services and financial constraints were also reported as major inhibiting factor for the rehabilitation process.

This clearly depicts the inadequate awareness process and knowledge among the minority groups. The education level also plays a major role in having adequate knowledge and to have proper access. The report from a Special School in Mizoram, the samples from the tribal population has reported that the main inhibitor is transportation, cannot access services, this is worse because of the climate and the geographical condition. No proper services and information is given to them through any of the professions and they do not have enough number of professionals to meet their services. The other major problem in some minority groups is lack of awareness and knowledge about the condition. This brings into light about the alarming scenario of the People with Multiple Disabilities conditions belonging to some groups. Hence, the various actions and programs should be implemented vigorously for the upliftment of the Persons with Multiple Disabilities and their families should be focused.

CHAPTER- 5
NEED FOR INTERVENTION FOR FAMILY MEMBERS
OF PERSON WITH DISABILITY

-Anitta Elias

“And however difficult life may seem, there is always something you can do and succeed at. It matters that you don't just give up”

-Stephen Hawking

The birth of a child is always delightful to the family. The situation may change when the child has a disability and the happiness can turn into shock and disenchantment among the family members. The presence of such a child is both restrictive and disruptive in nature, and this affects the family socially, economically, emotionally, psychologically and physically (Ali, 2012). However families play crucial role in a child's accomplishments as well as in reaching his or her maximum potential. A tremendous difference can be made solely by the efforts of the family to provide them with potential opportunities and get necessary services for the child to expand their competencies.

In the process of care taking a child with disability, the family need to bear a lot of expenses like medical bills, buying prosthetic and special equipments, charges involved with the admission to therapeutic settings, transportation costs, therapist consultation and service fees. This contributes to the financial complications in the family and when they cannot cope up with these demands, it may result in psychological distress.

Many families including the educated are unfamiliar with or ignorant about the cause, impact and prognosis of impairment on children (Ozozu, 2005). When the families lack information about their child's condition and how to address it with appropriate strategies, they start to suffer from emotional disturbances which results in poor mental health. It also prevents the families from accepting the child's disability condition which in turn becomes a block in exploring the rehabilitative opportunities for child and it makes the family condition even worse.

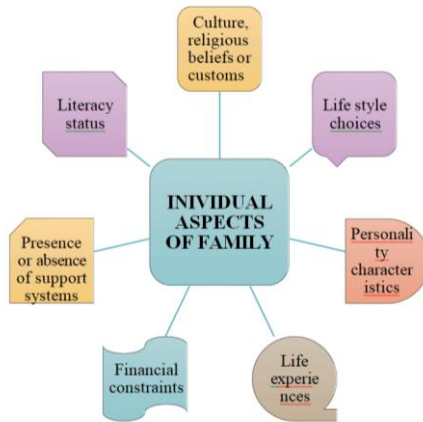
For most of the families, the basic and modest necessities that they wish for their children with disabilities are:

- The ability to communicate (minimum communication skills to convey their basic needs)
- Be independent as possible
- Stay safe and comfortable
- Be valued, appreciated, respected and loved by self and others; and
- To have unrestricted opportunities, this may allow them to become a full-fledged member of their community all the way through their lives

But a stigmatic and discriminative attitude of the society, financial burden, ignorance of the family towards the child's condition, the family discords which likely to happen, all eventually results in the psychological breakdown of either the primary caregiver or the whole family. Even though it is difficult to find solutions for every problems the family of persons with disability are facing, the issues has to addressed in such a way that each family member should be capable to effectively cope up with these difficulties with their available resources and environment, thereby enhancing their quality of life.

INTERVENTIONS FOR FAMILY

Despite of staying together and sharing every moments of life, every family member is unique having their own set of values, beliefs, attitudes, background and circumstances.



The interventions for family members should also consider the above mentioned individual aspects of each family. Even though the interventions appears to be similar in nature for everyone, its applicability and effectiveness is largely depends on the individual characteristics, belief systems, availability of resources etc.

Andazi and Amwe (1995) stressed the need for intervention programs for families of children with special educational needs through counselling, social services, family education, and skill training and promotion activities. They pointed out that a progressive society has a duty to provide parents a novel and persistent roles in the education and care of their child with disability. Nobody can better function effectively as decision makers and teachers as parents do.

- **Family Psycho-education**

Many of the parents will be stressed, anxious when they realize about the disability and will have difficulty to accept their child's condition. They will not be in a position to logically think and make decisions due to the emotional overload which in turn leads to poor psychological well-being and quality of life. There comes

the significance of psycho- education.

Psychoeducation could be defined as a patient's empowering training targeted at promoting awareness and proactivity, providing tools to manage, cope and live with a chronic condition (i.e. adherence enhancement, early warning sign identification, lifestyle, crisis management, communication), and changing behaviours and attitudes related to the condition, which helps to replace guilt by responsibility, helplessness by proactive care and denial by awareness (Colom, 2011). Giving proper psycho-education can empower the family members to understand the condition in a better way which leads to a sense of control and it also results in decreased level of stress associated with the condition.

Educational, informative and psychological counselling to the caregivers not only help them in adapting to their environment in the finest way, also aid them to understand their feelings and thoughts about themselves and their children, to accept their children with their abilities and disabilities and to re-determine their boundaries for the future in a more realistic way (Krishnan et al, 2018).

- **Parental Training Programs and Skill Training**

Since many parents in India are not highly educated, it's essential to provide them with the factual information subsequently about the causes of disability, development of necessary skills, usage of prevailing resources effectively, management of psychosocial stressors in better ways and similar concerns. Empowering the family members is as important as empowering the persons with disability since they are the primary key "therapists" for them.

Parents may need to be trained enough to assist their child to master basic functional as well as academic skills. Therefore the parental training can happen in different dimensions and it greatly depends on the requirements of each families as well as the environmental structure. Mostly, parents are in charge for the training and programming their child with disability and the professionals play the role to support and guide them to do this fruitfully.

Different kinds of training programs are needed for the parents in addressing the child's behavioural issues, skill deficits, challenges related to child's sexual developmental needs etc.. The family members should be mentally healthy to uphold the balance of their life also. Maintaining proper sleep hygiene, following healthy eating habits, effectively managing times to do their leisure activities have crucial role in reducing their stress and physical as well as emotional burnout. It can be ensured through the skills training programs.

Skill training emphasis on educating and training parents, siblings and other family members in physical and behavioural management of the child with disability and it is a significant area of participation by both parents and professionals. A professional should be able to evaluate the needs of parents and other family members, while considering the family as a complicated as well as a unique system. And by adding the knowledge of theories and concepts of family functioning, they should empower them and design individualized education programs to support them.

- **Individual and family counselling**

There is a misconception exists that the counselling is giving advice but in reality it is a talking therapy which can enhance life

and promoting positive change. Family or parental counselling aims at supporting the parents to attain a better understanding of themselves as well as their own personalities and sensitize them about the probable undesirable effect of their behaviour and its possible impact on their children. It deals with the aspect of parent-child communication, interaction and dependence-independence between them.



The need for interventions through counselling arises considering the facts that the most families of children with disability have many worries concerning the both present and future of their child with respect to their various functional aspects as well as in dealing with the developmental challenges of the child. In many instances, they may blame themselves as a reason of the disability condition and may doubt their own competence in bringing up the child as parents. Their emotions can become fluctuating from being irritated to grief-stricken when they fail to provide essential services required for their child. On the other hand, the feelings of being excluded or stigmatized by other parents or individuals within the society can put them in chaos.

When parent's concern about their child's well-being goes overboard, they tend to become overprotective which maybe not liked by the children and in some cases it can also create behavioural issues in children. In those instances, counselling can be supportive for the family of children with disability to assist the parents to deal with their distressing emotional states imbedded from the child's condition and enlightening them the importance of spending additional time and patience for the caring, nurturing, education and meeting the special needs of the child. Thus, parental counselling can be considered as one of the vital services that contribute to encourage a vigorous and balanced home atmosphere.

The counselling programs carry a major objective that to change the undesirable attitude of parents. Counselors need to deal with wide range of issues such as parents having problem in building a close and affectionate relationship with a child having disability. The counselor plays a fundamental role in eliminating the misconceptions and faulty beliefs about the disability and also he/she is ought to provide support to the parents at the preliminary and successive stages of counselling. A righteous foundation in basic problem solving skills is required for the parental adjustment having children with disability. Furthermore, the counselling has to be focused on concerning the possible difficulties that can happen in the future care and making the family capable of practicing healthy coping strategies.

- **Building support groups**

Caregivers invest majority of their time in take caring and monitoring the child, ignoring their own physical as well as mental health. Parental distress and family functioning impact children in numerous ways affecting their cognitive, behavioural

and social development (Wallander and Varni, 1998). Thus, lack of parent support and high levels of parental distress will affect the child's well-being (Middleton,1995).

According to Kaur (2010), there are eight categories of parents and family support models.

- ✓ *Network of NGOs with families:* NGOS play a central role in the development of society such as aiming on the empowerment and uplifting of depreciated units to the mainstream of the society. There are NGOs functioning exclusively for individuals with hearing impairment, visually challenged, intellectual disability, and physically impairments.
- ✓ They organize numerous programs and conduct camps for the Persons with Disability in order to support them financially helping them to fulfill their educational needs, to provide special equipments, creating opportunities for employment by providing necessary vocational training etc. Therefore, connecting families of persons with disability to corresponding NGOs can help them to create a friendly atmosphere and to establish a barriers free environment so that persons with disability can also lead a peaceful life in the society.
- ✓ *More Interactions with Families among themselves:* Families have to work together with each other to be responsible for giving suitable and rehabilitative care to the children with disability at home. The task of caregiving and nurturing of the child can become more relaxed if the family members help themselves through transfer of information, knowledge and skills and on discovering techniques to alter and adopt according to the needs of the child.

- ✓ *Counselling Services for Families with Special focus on Siblings:* The incompetence of any individual who is important to the family restricts the improvements in family's home and social environment. The disability condition of a sibling can have an adverse influence on the personality and socio- emotional functioning of the sibling without a disability condition.
- ✓ They experience isolation, anger, depression, fear, frustration and other behavioural issues resulted from various factors such as the societal attitude, being teased by peers, adjustment problem arising from difficulty in interacting with the child with disability. This will add on to the parental stress and tends to develop poor sense of competence in parents. Counselling services should be accessible to families with distinctive emphasis on siblings in order to get relieved from their anger, frustration and empower them to manage their worries and despair effectively.
- ✓ *Education about Balanced Nutrition and Personal Hygiene:* One's physical health is critical in determining one's mental health and vice versa. When compared to urban sectors, rural families may lack resources predominantly in well-being and education sectors. Families need to be cultured by professionals on elevating their information on balanced nutrition, malnutrition, infectious diseases and personal hygiene. In order to provide a healthy environment to the children, the families must be equipped with appropriate knowledge to take care of oneself.
- ✓ *Education about Disability:* The lack of knowledge about disability, its causes and management, can create misconceptions and unnecessary apprehensions in family

members. This can hinder the personal growth and well-being of both child and family members. Therefore, it's obligatory to make available the families with adequate knowledge about the disability and ways to approach as well as to cope up with the condition.

- ✓ *Frequent Medical Check-ups:* The lack of accessibility to medical facilities in the rural areas of the developing countries has become a foremost health care challenge, due to which children with disability are not done with proper medical check-up. Distinct care and attention concerning management of the children with disability should be provided to the families and families also should be cultured enough to monitor their health.
- ✓ *Stress Busting Exercises for the Families:* Stress is very common among families of persons with disability, they must be educated regarding the stress busting exercises which is one of the eminent means to weaken the undesirable effects of stress. Struggles ascend from negative thoughts, beliefs and actions can be resolved by directing the thoughts, actions and feelings on the positive facet.
- ✓ *Provision and Access of Literature and Audio-Video Information:* The families need to have a facility to access the literature and audio-video information by professionals about their respective fields and on various topics related to disability, so that the families can be well introduced about the disability, its causes, management, sanitation, hygiene etc.

- **Role of spirituality**

In India, spiritualism is not an obsession of the human mind; rather it is a heritage as well as a continuous tradition, and a

complete philosophy of human life, the correct way of living and right way of thinking (Dr. Asha Goswami, 2017).



Spirituality means existence of an individual's internal realm that includes certain principles, philosophies and inspiration. It signifies the meaning and direction of a person's life and helps him/her to deal with the vicissitude of existence

(Swinton & Pattison, 2001).

There are studies in fields of the mental health that emphasizes the role of spiritual belief and practices that contribute to resilience in parents of children with illness or disabilities (Canda, 2001). Spirituality can also lead to parents' positive acceptance for children with disability (Zea et al., 1994), and it helps to determine their process of coping as well (doRozario, 1997; Hill & Pargament, 2003; Miller & Thoresen, 2003; Poston & Turnbull, 2004). Spiritual beliefs are most important source of comfort and create a positive outlook toward life in the parents (Canda, 1999; Poston & Turnbull, 2004).

In Indian context, the utilization of spirituality as a component in counselling and therapeutic process can greatly contribute to the psychological well-being of the parents of persons with disability.

- **Psychotherapies**

Constant psychological stress, misunderstanding within the family, economic burdens, grief and strain were significant factors associated with the families of children with disabilities (Fareo, 2015). These factors may often end in mental health issues such as depression, anxiety and associated somatic disturbances. It can worsen the member's quality of life when these conditions result in poor sleep quality and severe psychological distress. In such instances they should receive appropriate therapeutic interventions from qualified professionals in order to restore their psychological balance.

In psychotherapies, the therapist focuses on the person's thought patterns which in turn affects their emotion and behaviour. The person's negative and maladaptive cognitions are identified and addressed through methods such as Cognitive Behaviour Therapy (CBT), Rational Emotive Behaviour Therapy (REBT), Logo Therapy or Acceptance and Commitment Therapy depends on the nature and severity of the problems.

- **Respite care**

Respite care is an emergency provisional care delivered to the caregivers of a child or adult in order to get a temporary relaxation from their routine care works. Respite programs are intended to offer a scheduled brief and time bounded pauses for families and other family members who take the role of care givers for children with several disability conditions. It aids in supporting and preserving the primary care giving relationship and also provides a constructive experience for the receiver.



Figure Source:
<https://www.fitness-studio1.com/wp-content/uploads/2018/03/CHILDREN-RESPIRE-CARE.jpg>

The physical, emotional and economic consequences resulting from the regular routine of care giving can be overwhelming for the family caregivers without some additional support. In that scenario, respite offers a halt for the family caregiver, which may contribute to sustain their vitality and well-being and also to decrease the chances of exploitation and negligence.

- **Community education**



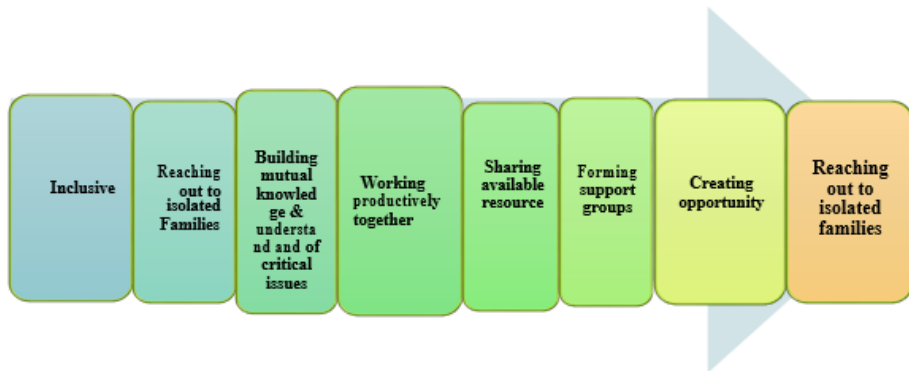
Figure Source:
<https://friends-with-two-disabled-clip-art.csp15622622.jpg>

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The need for intervention for families of persons with Multiple disabilities which arises from societal, financial, emotional and psychological components, the established interventions for the families is said to be effective and complete

only if the community where they live are accepting and understanding the disability condition. When the family receives the social support and perceives that they are being accepted in the community in spite of stigma, discriminations and negative attitudes, it can remove a huge amount stress from the whole family.

The community education should focus on bringing principles such as:



CHAPTER- 6

BEST PRACTICES FOR FAMILIES IN NIEPMD

-V.Vaijyanthi

National Institute for Empowerment of Persons with Multiple Disabilities has been providing services to Persons with Multiple Disabilities since its establishment. It has various departments for providing rehabilitation services to these individuals and is also committed for the upliftment of their families providing necessary guidance and support. Below are few such practices that were carried out at NIEPMD.

1. Psychoeducation

Psychoeducation is evidence based therapeutic intervention that can be given to family members of a person with disability with the aim of providing information and support to understand and cope better with the disability condition. The practice of family intervention is given on daily basis as a form of psychoeducation. It involves the following components.

- The diagnosis of the child is disclosed to the parents through effective communication by providing accurate information on the child's condition. Opportunities are given for the parents to ask questions and clarify their queries that make them feel comprehensible and clear about the condition of their child.
- Possible discussions would build confidence in the parents as they get equipped with the knowledge about their child's condition and how to handle them and help them to live a fulfilling life. They will also learn strategies to manage their child's behavior problems, if

any and learn therapies to teach at home for effective rehabilitation.

- Information shared would be truthful by admitting the limitations of prediction in terms of child's condition. Parents are also made to clearly understand their child's capabilities and limitations so that realistic expectations would be set for the child to achieve. This in itself increase the acceptance of the parents and would relieve them from unnecessary stress.
- To improve the process of rehabilitation, factors that would hinder the process of coping of parents like parent child relationship, parents with additional work load of taking care of a child with disability and other environmental stressors are focused through individual counselling and family/marital counselling along with follow-up appointments.
- Professional support and therapeutic guidelines are provided to manage parent's mental health and hygiene.

2. Hands on training for parents on home-based therapy

- Parents are equipped to impart therapies to their children at home which help the child to learn their skills within their environment and carry out day-to-day activities.
- This aids in practical development of the child and also he/she doesn't forget what he/she was taught by his/her therapist/educator during the last session. This aids in smooth transition of the child during rehabilitation.
- Parents who participate effectively can be considered as models in providing therapy to their child since there are no adequate therapists in rehabilitation sector.

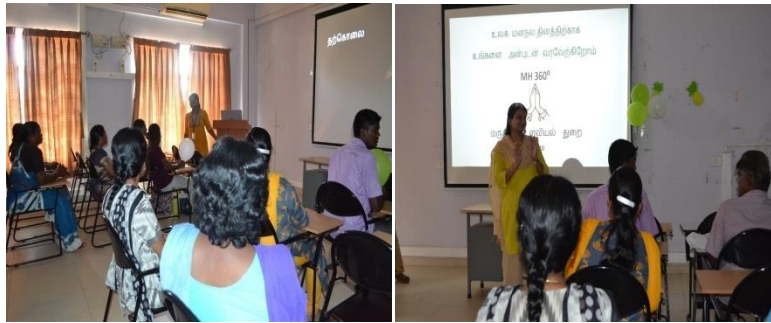
- Parents are also empowered as co-therapist who does their part of training and providing therapy to their child at their home and this would enhance their quality of life.

3. Parental training programs

- One of the major problems for parents of child with disability is that they face a great deal of challenge while carrying out day-to-day tasks for their child. Also the behavior problems that goes out of hand adds more stress to the parents when they lack the strategies to handle it.
- To deal with this, once in a month, the professionals and scholars from the field of disability conduct training programmes for the parents of children with disability in various topics highlighting behaviour problems, emotional issues, managing techniques, practical challenges etc. This creates better awareness about their child and remedies for that. It also aids in stress management of the parents by educating them about strategies and techniques to manage their child.
- Total session may go for 45 min to 1 hour and discussions will include space for clarifications, express their practical problems and emotional issues
- Parents are educated about the parenting styles, level of parental supervision needed for their child, behavior analysis and reinforcement techniques to manage and keep the behavior problems at bay and for maintaining progress chart that would help track the progress of the child during the rehabilitation process.

4. Group Therapy

- Group therapy which is one of the best practices in family intervention is a one form of psychotherapy provided by one or more therapists to a small number of parents of children with disability together as a group wherein group context and group process are used as a tool for change by building, exploring and examining the interpersonal relationships within the group.



- Group therapy discussions that concentrates on practical challenges in bringing up a child with disability with other parents make them feel that they are not alone and they learn how to deal with their anxiety of handling their kid in public, from similar other parents. Better knowledge provides better coping and this in turn improves the mental state of wellbeing among the parents of children with disability.
- Group counselling often forms the basis for formation of support groups wherein parents interact with each other promoting knowledge sharing and acceptance. Discussions in management of their practical problems encourages them to clarify their queries and serves as a mode of ventilation for their emotional issues.

- Parents are thus empowered by the support group formed and in long term, this would improve their quality of life.

5. Clinics Advisory Board

- One of the main sources of stress for parents of children with disability is lack or problem in services that they would be facing in the Rehabilitation Centre. Not knowing where to ask for it or talk about it makes the process of rehabilitation more stressful.
- To address this issue, Clinics Advisory Board is formed which consists of a chairperson, representatives from each department viz., social work, physiotherapy, special education, clinical psychology, early intervention, physiotherapy, occupational therapy and speech therapy along with representatives from parents.
- Meetings are conducted once in three months wherein parent representatives talk about the problems they face in NIEPMD that might be service oriented or infrastructure or facilities oriented.
- Solutions or actions are planned by Chairperson at the end of discussion with the board members. Implementation of the planned solution addressing parents' problems are also monitored and an Action Taken Report is prepared and produced to the Board during the next meeting.
- Representatives from the parental group is also changed every year so that various perspectives of parental grievances comes to light and are addressed
- This practice enhance the hope of parents in rehabilitation service and it facilitates the reach for service that would help in increased coping among parents during the process of rehabilitation.

6. Respite Care:

- Respite care is a caregiving unit established at NIEPMD comprises of two professional caregivers, one nurse and one special educator. Parents can avail the service from respite care by leaving their children with them to take care of.
- This gives a short-term break to parents from their round the clock routine of looking after their child with disability and let them to look after their own needs. This way, it serves a great way of relieving from the caregiving stress for a while and let the parents to replenish themselves with much needed energy to continue with their caregiving roles.
- Establishing such respite cares in rehabilitation centres and providing this service at a cheaper rate is one of the best ways to help parents to cope with their stress. In NIEPMD, this service is provided at the rate of Rs.50 per day.
- The professionals in respite care unit not just look after the child but will also take them to different services in NIEPMD and provide therapies to the child.

7. Gnanalayam (Parents' Library)

- Parents of children with disability can be provided with opportunity to read books on disability and keep them knowledgeable on handling their children. This could be one of the major facilitator of coping among parents of children with disability throughout the process of rehabilitation
- With this idea in mind, NIEPMD has established library for parents in the name of "Gnanalayam". This holds

books on disability, newspapers and magazines and articles and books on success stories of people with disability. Reading such stories will serve as a motivation for parents in bringing up their children

- Also most parents, after dropping their children in classes in NIEPMD special school or in Adult Independent Living Department (DAIL) might be spending their time doing nothing if their child doesn't need much assistance every now and then. In order to keep them occupied and also to make them knowledgeable, this library is of great use
- Videos like documentary on disability, teachings or already conducted training programme and lectures for parents of children with disability will also be played for the parents to watch and to gain insight on disability care.
- Parents are also facilitated to attend lectures from different department professionals and also experts in disability field
- This way parents get more informed about disability of their child, child's ability and limitations. This would help them to set realistic goal about their child and in a way increases coping among parents.
- Maintaining proper register to record entry and exit of parents along with stacking with enough resources and resource people in the library helps in increasing the efficiency of its operation.



8. Out campus Fun Activities

- Recreational Activities planned for children with disability that incorporates therapy goals are most enjoyed by the children with disability and this in turn makes their parents happy.
- NIEPMD plans for such out campus activities like a fieldtrip to sensory park once in three months. Sensory parks are specialized parks that have features to attract multiple senses of an individual to provide combined sensory opportunities to children with disabilities.
- Children with disability are taken to these parks along with their parents with the aim of improving their sensory integration. They also achieve good socialization skills in long run as a result of frequent visits to such playing spots.
- Parents also feel relaxed and they love seeing their kid playing in a park specially designed for them. Since the trip is arranged totally free of cost, parents who cannot afford such trip can also happily join the trip and make the occasion memorable
- Fun activities for the parents would be conducted which serves as a means to vent out their emotional burden and it also aids in building good relationship among them.



9. Caregiving course for parents

- Parents are also given opportunity to get a certification in caregiving by NIEPMD. This course provides knowledge in the field of caregiving in detail that the parent can use for their own child or can even work in caregiving settings.
- Parents who cannot afford for the course can even be provided with scholarships from CSR funds of the institute.
- Earning a certification in caregiving equips the parents with needed skills in the process of caregiving to their child with disability. Learning more about the disability types and disability care gives them clear idea of what to expect from their child and it brings about a positive attitude change and adjustment among parents. Ultimately, this increases the parent's level of acceptance of their child and promotes their coping.

10. Income Generation Programme

- Parents of children with disability usually have to spend most of their time around their kid and at least any one of the parents especially mothers in most cases are deprived of employment opportunities.

- This might add to their financial burden and eventually become an additional stressor. To tackle this problem, the institute provides income generation program for the parents who usually stay for the whole day to meet the needs of their kids at intervals.
- They are given opportunity to learn candle making, phenyl making and other such activities that could be a source of income to them.
- CSR funds from different organizations are used for buying related resources that could be useful in conducting these programmes. The products thus created by parents are also exhibited within the institute so that people could get to know about these products and may even buy them
- Parents who get skilled in these self employment venues are also helped to establish Small Scale Sector business at home and they are also referred by the institute to potential customers who might be willing to buy those products
- Parents who may spend their time otherwise, ruminating their problems being in institute for the whole day are thus given an opportunity to be productive and this in itself facilitate their coping to various stressors.

11. Annual Potluck Event

- Trips or picnic once in a while will surely serve as stress busters for these parents. Keeping this motive in mind, NIEPMD conduct Annual Outstation Picnic Event wherein all parents of child with disability admitted in special school are taken to nearby tourist spot at free of cost.



- This in itself lets the parents to come out of their circle as a full time caregiver, for a while, have their personal time and enjoy the picnic. Usually spots like beaches are chosen where people can sit and relax and children will also enjoy. The staffs also accompany to help the parents to handle the children.
- Potluck is also arranged wherein each parent bring a food item prepared at their home. A big lunch event is also organized with diverse food items and parents would feel special as they are given such opportunity and this increases the bonding among fellow parents, eventually leading to the formation of an informal support group
- Staffs from the institutes also conduct fun events for both parents and children that would serve as ice breakers and enhance interaction among one another. This is beneficial for both parents and children.
- Shy kids who generally wont interact even with their peers or staff members usually comes out of their shell and start interacting with others in such events. Parents also get delighted and satisfied to see their kids having fun.



- Rapport building is achieved among parents through these fun games and ample time was spent interacting with other parents and sharing their feelings. This would bring them out of their parenting distress and make such an activity a great stress buster event.
- Parents usually give a very positive feedback about such events expressing that they feel much relaxed. Children classroom interaction among themselves and also along with their special school teachers usually gets better after such events



12. Family Cottage Service

- Outstation people who come a long way for therapies for their children in NIEPMD usually face additional stress looking for accommodation near to the institute.
- To reduce this stress and burden, NIEPMD provides accommodation to the families at a cheaper rate to stay for a maximum of a week.
- Therapies and home programs are conducted to such families. This facilitates the parents to bring their children for rehabilitation centres.



13. Capacity Building Programmes:

- Lack of knowledge among parents about the services they could avail for their children with disability is the main inhibitor in the rehabilitation process. This is addressed by the institute by arranging programmes wherein parents are provided information about the NIEPMD protocols and disability schemes by State and Central Government. They are also made to know about the various Government Acts

and Rights of persons with disability and various benefits provided by the Government for People with Disability.

- Such programmes conducted once in a month are of great help to parents and promotes their understanding and knowledge in the field of disability and schemes provided.

GLOSSARY

ACT: A form of psychotherapy which encourages people to embrace their thoughts and feelings rather than fighting or feeling guilty for them.

Anxiety: A relatively permanent state of worry and nervousness occurring in a variety of mental disorders, usually accompanied by compulsive behaviour or attacks of panic.

CBT: A form of psychotherapy that focuses on modifying dysfunctional emotions, behaviours, and thoughts by interrogating and uprooting negative or irrational beliefs.

Compassion: A feeling of deep sympathy and sorrow for another who is stricken by misfortune, accompanied by a strong desire to alleviate the suffering.

Depression: A mental state characterized by a pessimistic sense of inadequacy and a despondent lack of activity.

Disability: The condition of being unable to perform as a consequence of physical or mental unfitness.

Multiple Disabilities: A person having more than one disability

Intervention: The action of becoming intentionally involved in a difficult situation, in order to improve it or prevent it from getting worse.

Logo-therapy: A highly directive existential psychotherapy that emphasizes the importance of meaning in the patient's life especially as gained through spiritual values.

Masturbation: Manual stimulation of the genital organs for sexual pleasure.

Prognosis: A medical term for predicting the likely or expected development of a disease including whether the signs and symptoms will improve or worsen or remain stable over time; expectations of quality of life; such as the ability to carry out daily activities; the potential for complications and associated health issues; and the likelihood of survival.

Psycho-education: Refers to the process of providing education and information to those seeking or receiving mental health services, such as people diagnosed with mental health conditions and their family members.

Psychotherapy: The use of psychological methods, particularly based on regular personal interaction with adults, to help a person change behaviour and overcome problems in desired ways.

Puberty: The process of physical changes through which a child's body matures into an adult body capable of sexual reproduction.

REBT: A form of psychotherapy that helps in identifying self-defeating thoughts and feelings, challenge the rationality of those feelings, and replace them with healthier, more productive beliefs.

Rehabilitation: The process of helping a person who has suffered an illness or injury to restore lost skills and so regain maximum self-sufficiency.

Resilience: The process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress.

Respite care: Temporary institutional care of a sick, elderly or disabled person, providing relief for their usual carer.

Stress: A state of mental or emotional strain or tension resulting from adverse or demanding circumstances.

Stigma: A strong feeling of disapproval that most people in a society have about something, especially when this is unfair

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ANNEXURE I

Checklist for coping facilitators and inhibitors

From the items given below, please choose the items which you think is inhibiting your coping in the rehabilitation process of your special child.

1. Health problems of other family members
2. Having alcoholic/hypersensitive/non-cooperative spouse
3. Lack of time for the child
4. Death of a close relative
5. Lack of acceptance from family/relatives
6. Lack of acceptance from the community
7. Unemployment of spouse/father
8. Difference in opinion with spouse concerning child's condition
9. Moving home/having transfers outside city
10. Misguidance by helping professionals
11. Lack of information about child's condition
12. Unfavourable attitude towards child as a person
13. Lost hope in treatment
14. Unable to maintain regular contact with the professionals due to distance
15. Lack of information/access regarding Government services
16. Lack of information regarding availability of equipments
17. Behaviour problems in child persistent throughout the day
18. Difficulties in admitting the child to school
19. Comparison of normal child with special child
20. Lack of understanding from the kid's siblings

21. Financial constraints
22. Experiencing threats regarding other family members' future
23. Misconceptions regarding child's condition (like black magic)

If you are facing any other factor that inhibits your coping, please mention:

From the items given below, please choose the items which you think is facilitating your coping in the rehabilitation process of your special child.

1. Believing that my child will get better
2. Investing myself in my children
3. Believing that things will always work out
4. Telling myself that I have many things I should be thankful for
5. Building a closer relationship with my spouse
6. Believing in God
7. Believing that my child is getting the best care as possible
8. Doing things together as a family (involving all members of the family).
9. Trusting my spouse that he will support me and my child.
10. Getting other members of the family to help with chores and tasks at home.
11. Making sure my child is getting regular treatment/therapy
12. Encouraging child to be more independent.
13. Concentrating on hobbies (art, music, jogging, etc.)
14. Becoming more self-reliant and independent.
15. Keeping myself in shape and well-groomed.

16. Talking to someone about how I feel.
17. Engaging in relationships and friendships which help me to feel important and appreciated.
18. Investing time and energy in my job.
19. Talking with other parents who are in similar situation and learning about their experiences.
20. Talking with the professional caregivers
21. Reading about how other persons in my situation handle things.
22. Gaining more knowledge about my child's disability and equipping myself with methods to handle my child
23. Being sure prescribed treatments for child(ren) are carried out at home on a daily basis.

If you would like to mention any other factor that facilitates coping, please mention:

Self-constructed tool to find the level of acceptance of disability among parents of Persons with Multiple Disabilities

Please tick the appropriate rating for each of the below given statements. There is no right or wrong answers and you are free to record any response.

1. I'm aware of my child's limitations

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

2. I'm not embarrassed when people question me about the disability of my child

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

3. I feel that I must protect my child from the remarks of others

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

4. I could manage my other family members along with taking care of my special child

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

5. I wish I could somehow revert my child's condition

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

6. I am very careful about asking my child to do things as it may be too hard for him/her

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

7. It makes me feel good to know that I can take care of my child

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

8. I have made enough search for finding proper treatment/service and I am happy with the treatment schedule and my child's improvement

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

9. I spend more time with my special child that I dont find enough time for my other children

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

10. I feel ok about having additional responsibility bringing up a child with disability

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

11. My special child's need come first and I may even ignore other family member's need

1. Strong ly Agree 2. Agree 3. Disagree 4. Strongly Disagree

12. I believe my child would lead a fulfilling life

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

13. I regret having a child with disability

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

14. I feel embarassed to take my child with me to attend functions

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

15. I regret as I'm responsible for giving birth to a child with disability

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

16. I dont mind when people keep looking at my child in public

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

17. My child would be in danger if she gets out of the home

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

18. One of the bad things about raising a child with disability is that you don't have enough time, to do things as you like

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

19. I feel sorry for myself as I'm having a child with disability

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

20. I know my child is capable of training with certain skills

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

21. I pay no attention to my child as long as he/she does nothing to bother me

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

22. I'm aware of my child's special needs and I'm fine providing it to my child

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

23. When others are around my child, I cant relax, I am always on guard

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

24. I keep changing the professional help for my child

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

25. My child feels that I'm the only one who understands him/her

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

26. I wish someday my child would become a completely normal kid

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

27. When my child misbehaves, I lose my temper

1. Strongly Agree 2. Agree 3. Disagree 4. Strongly Disagree

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Acceptance & Coping : Families of Persons with Multiple Disabilities

About this book

This book is intended to explore various types of families of persons with multiple disability and diversity of family systems to gain insight and how it could influence their level of acceptance of disability. The various factors that facilitate and inhibit the coping of the families during the process of rehabilitation of the person is also explained. This book would also help to understand the need for interventions for the families and specific strategies which would help to facilitate their coping and result in better outcome of the rehabilitation process of persons with multiple disabilities.

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