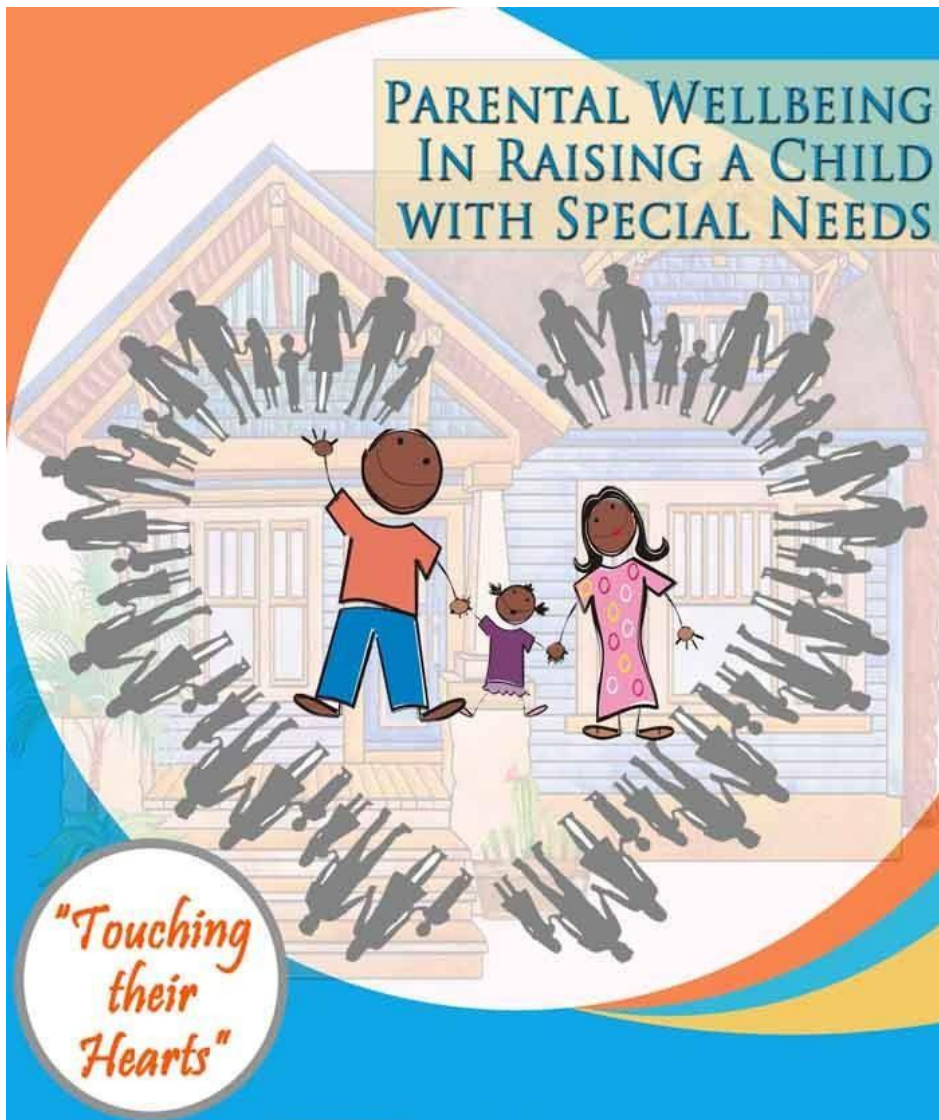


PARENTAL WELLBEING IN RAISING A CHILD WITH SPECIAL NEEDS



*"Touching
their
Hearts"*



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

Parenting is the most longed and cherished period of every parent. The realization of the child's disability makes the big difference to this experience. Parents suddenly feel different and experience distress. This follows with the sense of greater responsibility which leads to increased focus and weight age given to the welfare and wellbeing of the child with disability. In the entire scenario parental wellbeing will be the last or never added component in their life goals. It is natural for parents to sacrifice their needs in view of the empowerment of their children. But they do not realize that without taking care of themselves they may not be able to support their child at the optimum level.

*This book is the compilation of the various practical modalities thorough which every parent **should** take care of their mental, physical and overall wellbeing. NIEPMD practices and believes that empowerment of the child with disability begins from the empowerment of the parent. We believe that this book is the need of the hour as most of the parents of children with disability are busy focusing on the benefits of their children and lose their real self in that process. Either they hesitate to take support from others or they do not recognize the supportive resources available to them. Hence this book will help the therapists, support groups, organizations, community level workers, grass root workers and the parents themselves to provide support to the parents of child with disability.*

The real inspiration in bringing out this book are parents. Therefore we thank every parent, the real heroes in this endeavor.

-S.K. Anandhalakshmi

Foreword

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Chapter - 1

Parenting

-Hemangi Narayan Narvekar

Introduction

"The hands that rocks the cradle rules the world"

One of the most rewarding and difficult relationships in life, one ever undertakes or be in, is being a parent of a child. This part takes all waking and sleeping hours of the person. A parent-child relationship sets the basis for constructing a child's life. Parenting or child rearing is a way of raising a child. It is a series of interactions that happen between parent and child which includes bonding, nourishing, loving, caring, protecting, and guiding the child. It is like the nourishment that is crucial for a sapling to grow into a big and fruitful tree. Being a demanding role, parenting takes a lot of physical and emotional energy. The usual challenges of parenting get even worse when a parent has to take care of a child with special needs. In such circumstances there is focus on the care and treatment of special children, often the well-being of the parents gets neglected altogether. A significant part of being a parent is considering oneself too, not only the child. If the parent is stressed or exhausted, it is difficult to be the parent one is striving to be. But when parents are happy and at peace, they are better able to cope with day to day hassle, maintain connections with people around and enjoy parenthood. Wellbeing here means more than just ones' physical health. It involves emotional, social and spiritual health too. The wellbeing of the parents should be given foremost importance if the needs of the children are to be met. This chapter will discuss in details the challenges of parenting and how it affects the marital relationship and wellbeing of parents.

I: Parenting challenges - Unplanned Journey

'Parenting' as everyone knows includes purposeful activities intended at safeguarding the survival and development of children. Parenting is a positive, nurturing activity which normally involves the children, parents and other family members in lifelong interaction. These interactions include parental interest, expression of attitudes, values, and beliefs as well as their care and training behaviour. It is a continuous process. Each moment of a child's life that he spends in contact with his parents has some effect on both of his present behaviour and his potentialities for future action. This process of child-rearing is generally influenced by the characteristic ways of thinking, feeling and acting, prevalent in the cultural group to which the family belongs.



Figure 1: Types of Parenting Styles
(Image source: <https://whatparentsask.com/authoritative-parenting-tips/>)

In India, the knowledge of parenting comes from one's parents, grandparents and other significant people around. Hardly parents go around reading books and attending workshops focused on parenting. Few parents will verbalize doubt they have regarding child-rearing. The literature speaks about four major parenting styles that parents use while bringing up the child. The first one is Authoritarian Parenting in which parents are strict with rules and are

controlling which may facilitate discipline but children might end up being timid and lacking in self-esteem. The second one refers to Authoritative Parents who are authoritative and controlling but at the same time warm and communicative. They seek a balance between both. This style is considered best for children and research suggests that best-adjusted children are brought up by such parents.

The third parenting style is called Permissive Parenting. Permissive parents are warm, and lenient and lack control over the child. Such children might be growing up as a spoiled or misbehaved adult as a result of lack of discipline. The last parenting style is uninvolved parenting wherein parents demands nothing and gives nothing in return. In the worst scenario, it is seen as neglecting the child. No parent will be strictly adhering to one style discussed above. However, the best parenting would be the one where there is a balance of warmth and discipline as exhibited by authoritative parents. Parents would always learn parenting through trial and error and as such what would be beneficial for one child might not be good for another. It is all about tailoring one style according to the needs, likes and dislikes, temperament, and behaviour patterns of the child.

Amidst of all confusion on how to go about taking care of the child, sibling rivalry, maintaining work-life balance, exposure to media, unsafe environment, etc. the life gets more complicated with the challenges of parenting a child with special needs. Watching a child grow and learn is the most satisfying experience for parents. But what happens when a child is not able to meet those milestones or lags behind others in significant ways. It can be a mild delay to something like Attention Deficit Hyperactive Disorder (ADHD) and Intellectual Disability (ID) but it will come with problems a parent would never be prepared for. The unplanned journey of taking care of a special child would not be less frustrating than any other crisis in life.

The confirmation of the diagnosis will come as a big shock to the parents even if the diagnosis has been suspected for a long time. Some of the possible reactions of parents include anger, embarrassment, concern, anxiety, denial, confusion, rejection, bitterness, idleness, over-protection, shame, self-pity, shock, deep pain, sorrow, depression, hostility, mourning, wish to kill or suicide attempts (Barnett et al., 2003). Parental reactions altogether can be discussed in three ways of which the first is related to the crisis of change wherein parents witness the sudden unexpected change that has come in the form of disability of the child. The second type of reaction is connected with the transformation of feelings for the child. A child when born is expected to bring happiness and joy to the family. With the child comes expectations and dreams of the future. And when parents realize that now the child might not be able to grant them those feelings of achievement it tears them down. Thus it results in bivalent feelings towards the child. The harsh situations emerged takes them to the next type of reactions stemming from the crisis of reality. They try to think about how they are going to raise the disabled child with their present circumstances.

Although the joint family is on the verge of depleting we still live in a society where we belong to the bigger picture of the family. We still prefer spending time with relatives, celebrate festivals together, have get-together, spending summer vacations at the native place, etc. We are interdependent and coexist together. In the process of adapting to the child with disability parents in India seek out help and comfort from others. They will be trying to give information to their friends and family members. Most of the reactions they will be getting are one of shock resulting then to sympathy and suggesting solutions if any.

Apart from parents, the next group of people who will undergo similar feelings about the child and disability are the child's grandparents. They too undergo a loss of a healthy ideal child. The grandparents' grief and rejection might add to the emotional burden of the parent altogether. They can be a support

for the parents or at times the greatest hurdle in the process of adaptation. It's sometimes difficult to make them understand the disability of the child and the whole factors contributing it. They may lack access to the information they need for their healthy adjustment as compared to the parents who get some from health professionals. They may be blaming the parents for the child's condition or resort to accusing God, when in pain.

Parents' feelings may go from despair and confusion to a desperate need to do something. They will try to come to terms with the uncertainty of the future of both the child and the family. They will revise their views and expectations of the child as well as parenting adapting to all the circumstances that a child with a disability brings in. The process is certainly a painful one but as they get time to settle down the courage to adapt to the unplanned journey comes on its own. The journey of parenting a child with a disability is a difficult one and comes with a lot of challenges to deal with. Let us discuss some of it in detail in the next unit.

II: Parenting vs Self

In our culture, we invest too much into other's life and other's wellbeing. Only then we experience happiness. Our culture does not teach us to be self-centred. And as such being a parent is the whole extreme dimension of this perspective. Children are always at the centre of the family where they get so much importance that parents sometimes forget that they are also a separate individual and have other roles in life too. Parents' needs, wants, dreams, likes-dislikes everything revolves around their children (James, et al., 2013). Once a parent always a parent holds utmost true in our society unlike those from western nations where once children are independent parents don't interfere anymore with children's life devoting more time for themselves, enjoying and doing everything they couldn't do because of parental responsibilities.

When a couple gets married they have to work out their differences to live a life peacefully together. They have their challenges related to adjustments with each other's interests,

preferences, habits, etc. With a child coming up they have to again adjust to all these changes giving more priorities to the baby, keeping aside all the differences they have for the betterment of the child.

The first change that takes place when a couple finds out about pregnancy is the feeling of being mature. Small changes in a routine now become a big challenge and responsibility. For mothers especially the whole experience is life-changing. They have to undergo a lot of physical changes including an increase in body weight, loss of beauty, physical symptoms like nausea, loss of bladder control along with mood swings. After the birth of the baby, there are birth stretch marks or belly that hampers their body image. Turning into a mother from being a woman who used to take care of body and hygiene is a slow process which might eventually lead women to forget altogether who she was in the first place. The priority is always given to the child at the cost of her beauty and hygiene.

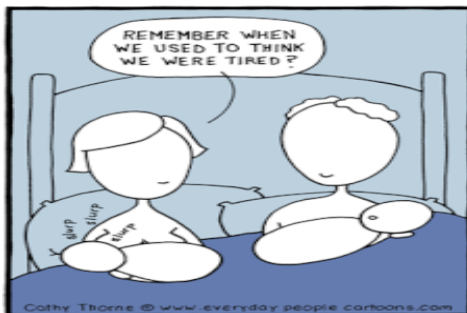
Another field that gets compromised is a women's career. After the birth women tend to become less career-oriented. They worry more and more about the future of the child than worrying about their dreams and career opportunities. It has been also seen that some also leave their job and promotions to devote all the time in bringing up the child. Those who work might make changes according to the child's needs at the workplace such as shifts or working hours.

A new mother would want love and emotional support from the husband and the fact that he understands the physical changes she underwent, changing sexuality and the confusion she has. For a man, it's the assurance which he demands that he is capable of handling the new member in the family taking care of his/her needs in a better way. Since the baby is the new priority, parents get preoccupied with the needs of the child usually ignoring feelings of each other and losing the previous touch and bond with a partner.

Couples might have differences of opinions when it comes to parenting the child. Since both of them had come from different families, have seen their upbringing in certain ways and the experiences in approach to parenting a child would be different in some way. Deciding a single pattern of parenting so that child would not get affected with the differences would be another new challenge. As such ideas from other people such as grandparents or relatives add on to the confusion on child-rearing. What may be the best for one would not be good to adopt by another parent. This tedious job would again lead to conflicts between parents.

Couple who are working and financially secured also might face some difficulty during the arrival of the newborn baby. Suddenly the couple may realize that money matters and they need to earn and save more than what they required until then. The loss of job of the mother in most cases can increase the burden. This financial strain can again take a toll on the relationship between spouses. The parents obviously cannot show this frustration and worry on to the newborn so in a subtle way it shows up on spouse in terms of anger, avoidance and criticism.

The parents might get involved so much with their children that they overlook their spouse. Many times it has been seen that the fathers are complaining about the wife not giving them enough time. They might find it difficult to get some quality time with each other. Couples may have hard times maintaining romantic relations. The additional responsibilities of being a parent can undermine all other roles of an individual.



*Figure 2: Parenting
(Image Source:
[https://everydaypeople
cartoons.com/products/
tired-parents-cartoons-
comics](https://everydaypeoplecartoons.com/products/tired-parents-cartoons-comics))*

The entry of a newborn in the family certainly changes the family dynamics. With the change in routine, there also comes a change in the way couples interact with each other. Parents conversation become more business-like which surrounds with details of child and parenting. From discussing each other's interests, sports matches and secrets the topics change to feeding baby, bathing, changing diapers to discussing grocery lists. Questions about one's day are replaced with how many times in a day diaper has changed.

Socially, there is the possibility of losing friends and social contacts because it may be difficult to spend time away from the child (Bodla et. al, 2012). The only left social contact of parents would be those of other parents who become acquaintance because children go to the same nursery or school. All they discuss then is about the child's health, interests and future.

Thus with the role of parents, they forget about their self and invest only in children at the cost of sacrificing their pleasures and interests. To be a good caring parent it is very important to prioritize themselves and their feelings as and when needed and keep on rejuvenating their energy levels. One can become a good parent only when one knows about his/her strengths and weaknesses as a person. Then only parents can work out the differences they have and develop a healthy personality of the child.

III: Parenting Struggles of children with multiple disabilities & high support needs

A child when born brings joy to parents and family. But when a child is born with some kind of disability or later at age, have a diagnosis of some delay or impairment it becomes difficult for the parents to adjust to the scenario. Parenting comes with a lot of changes in life and so as parenting the child with disability since

it takes more than what usually it takes to bring up neurotypical children such as problems relating to additional care to be provided, medication costs, struggles with the stigma associated with the disability, etc. The details of such struggles are discussed below which will provide a better understanding of the additional roles and responsibilities a parent of child with special needs has to take care of.

The first challenge of raising a special child is gaining the right knowledge about the disability. In India, there's scanty knowledge about disability with the general population. Although there has been an improvement in the last few years we still are not aware of the conditions prevalent. With parents, the knowledge about the disability comes from the professionals when the child is diagnosed. Usually, it's the Pediatrician followed by a rehabilitation team. Few professionals will be giving them the details of the whole situation including the disability, causes and treatment opportunities at one shot or during the first interaction. Educated parents adhere to search on the internet or books available. Information obtained, thus, from the websites should be interpreted and relied on cautiously as it can mislead the parents at times for not understanding in a proper way. It takes years for them to gather complete and proper knowledge about the condition.



*Figure3:Parenting
(Image Source:*

<https://www.marriage.com/advice/parenting/parental-advice-new-to-parenting/>)

During search for the information, parents will come across many myths surrounding the child with a disability. It might be from some relatives or colleagues or friends or people around who come in touch. They might see people rejecting them or are overenthusiastic in suggesting solutions. A country like India which has religious and spiritual inclinations will certainly take help from spiritual people or gurus or religious medium when in crisis. Taking the child to temple, performing religious rituals, using herbs are some of the ways parents might think will make a difference. Doing only these might delay the process of treatment and also failures with all these attempts may add to the hopelessness.

The myths about disability in society might lead to stigma. People who think it's the curse of God or sins related to past life may make the situation worse for the parents. Parents will feel guilty and frustrated when they tend to hear such perceptions from people they come in contact with. The rejection either verbally or non-verbally from crowd, avoidance, and sympathy makes it all the more painful.

Taking care of the child until they are independent is the greatest responsibility of parents. Few parents have a clear idea about this growth of the child. Once they taught them doing chores on their own they can gradually leave children alone. However, this becomes a huge problem for those children who have a disability. They either learn at a slower rate or might not learn as expected. So parents have to give them continuous care and support throughout. Even the activities of daily living might be trouble for such children.

Taking care of the child for years might disrupt the whole routine of the family. It becomes difficult for the parents and especially mothers to focus on their job leaving the child. Most mothers will resort back to become a homemaker in such a scenario, because of constant supervision. Planning career or events becomes difficult in such a situation. Thus the routine of the family has to be modified and adjusted according to the child.

Extended family will always have the grandparents at the rescue. Grandparents at home are the great support to parents having such a child. They are more lovable and caring towards the child. Although they might be in shock and have their own emotions to adjust with, they would be mostly willing to help their children and grandson/granddaughter. However, the old age and generation gap would be a problem while child-rearing. Most of the times they would not understand the disability, the reasons for child's behaviour and also it would be difficult for them to avail public and medical assistance during emergencies, emergency cash or travel and handling unexpected situations which are outside their parenting experiences. So parents cannot depend on them for helping out with child-rearing, feeling helpless again.

Indian parents give a lot of importance to the academic performance of the child, unlike parents in the west. The whole future and success are based on the child's scores (Das, 2017). When a child gets top rank it's a huge achievement for the parents too. Imagine a parent now who is deprived of this achievement. A big disappointment comes to parents as far as academics is concerned when a child is a slow learner or has a learning disability.

They have to struggle for accommodating a special child in a normal regular school where he might not get adjusted or teachers may not understand the situations and behaviour. Finding a special school near the home is also quite difficult. Some try to appoint special educators visiting them at home due to unavailability of the same in near surroundings. Overall it becomes really difficult to find proper resources which can help the child learn better at-least the basics needed to survive.

Now there are various provisions made by the government to help the special children with their academics. They are given extra time for writing paper or use of calculator or scribe or exemption from language, etc. however there is limited knowledge about the same as well as the procedure of availing the benefits. Parents are made to run from pillar to post for various purposes like

certification, assessments, availing the benefits dispersed by the state or central government adding burden to the parents.

Also, there is a lot of confusion and sadness among parents about the child's future and career. They try to find out if the child has any ability he can excel into and can at least earn some amount for living and independent life. They might put them for some courses or vocational training to support them. Searching for the best possible way for the child to lead his life is the biggest worry.

Being in a collectivist culture, parents in India assume a greater involvement in the development of the child, unlike western parents. Thus, in face of disability, the involvement with children is even more. The values which an Indian parent wants to see in their children and are considered of utmost importance such as obedience and compliance cannot be achieved and expected. Besides, in India, a parent usually perceives the child as the support system in old age. While in the western world, the parenthood is usually seen as a process of enjoyment which concludes at a stage where the child becomes independent. Therefore, the reliance on children for the future is more prominent in Indian parents and it leads to disappointment and crisis when they are not able to foresee a secure prospect.

However, even when we talk of differences in parenting across the world, one important thing to note here is the way parenting has been changing due to globalization. Societies are integrating values of others which they deem useful for children of the present generation. For example, like western cultures, more and more parents today are emphasizing personal and financial independence of the child, unlike the previous era where parents used to be overprotective and give importance only to familial devotion (Chen et al., 2015). Influences from other cultures do affect how parents see their parenting styles and this can also play a potential role in how disability is perceived by a particular parent.

Many times along with the apprehension of the future, the child may also have some medical issues which will increase the complications related to health and finance too. Frequent appointments with doctors, diagnostics, failures of medical insurances to cover the cost of medicines and treatment may be a burden. Along with the medical cost of assessment and therapy sessions for the overall development of the child, finding a suitable mode of transport, equipment and adaptations to the home, compounded by absenteeism from work when accompanying the child can add to the financial crisis. Taking care of finance would be difficult with a single parent earning with unimaginable for the ones who are below the poverty line.

Another biggest challenge in raising a special child is lack of help and support from the spouse. Mostly in India, it has been seen that fathers are the one who is being cold with the whole process of parenting especially more, when a child has a disability. There might be many reasons behind this. First being not knowing what exactly the child is going through, blaming the mother for the child's disability, feeling it to be a burden because of financial cost and many more. Thus when there is strain on any one parent it is detrimental to the child's development.

Also with a child having a disability in the house takes all other's attention and care. Most of the times it has been seen that siblings, either elder or younger, feels unloved or ignored by all this attention that goes to the special child. Being a child they are not in a position to understand why everything revolves around the special child and why their demands are not met compared to the one who has a disability. That frustration and sibling rivalry might show up their way through attention-seeking behaviours like hitting special child, being cranky, failing in school, etc. Making the sibling aware of the difficult scenario and giving them an equal amount of time is another significant challenge that all parents undergo.

Because of the stigma attached to the disability and workload of the parents the child frequently lags in social interactions. Friendships are important at every stage of life. Communication and play with normal developing children is thus necessary for the well-being and learning of the child. Though schools provide the opportunity for socialization still it's a difficult task for the children with disability to adjust to the normal peers. Parents have to make extra efforts to make connections between them giving them time together, organizing play area, and providing reinforcement and also not to get disheartened with peer rejections at times.

All these challenges along the lines of disability make the situation difficult for the parents. Added workload and nothing to see at the brighter side can seriously impact the health of the parent. How much it impacts the parent depends on several factors which are been discussed in the next units.

IV: Marital relationship

When there is a child with special needs in the family parents have to deal with so many additional things around. Together the couple dreams of a healthy child but then with the diagnosis, they have to face a life very different from what they had imagined. Their overwhelming feelings, both individually and combined, are normal and natural in the situation but are very difficult to cope with. When powerful emotions surface, because of the disability, it may put relationships on trial and the problems in a marital relationship might occur. There appears to be more reported marital distress among families of children with special needs than those with normal developing children (Seligman and Darling, 1997).

It has been seen that many times spouse disagrees about the child' diagnosis or the kind of treatment a child needs. The less emotional parent often becomes indifferent and on the other end - usually the women - grieves more openly. Very often the mother

spends every waking moment to learn more about the disability, find needed services, and connect to more mothers in similar situations. This becomes so time-consuming and when one parent is over concerned with helping the child the other feels left out.

Feeling abandoned, a husband may turn to others for solace or push themselves in work as an escape from pain. Another possibility is that he may distance himself from the child and family as a means of self-defence. There is a high rate of fathers who simply pay attention to work while leaving a mother to raise the child at home and school, creating a distance. This is not true with all fathers. However, far too often this is the common scenario.

Many parents report that neither of them gets enough time and attention for themselves as individuals. There is a great deal of resentment. She resents that he doesn't spend as much time with the special child as she does, and he resents that she doesn't recognize the colossal effort he puts into coordinating schedules, visiting the school and fighting continuous battles to get what their child needs. For a relationship that is already fragile or unstable, the disability of the child can be "the last straw." Sometimes a child's disability and behaviour are too much to handle for one of the spouses and they just move out of the marriage.

At this point, couples often get divided resulting in marital discord which all too often leads to divorce. The divide can get wider with the demands of care. The divorce rate for couples with special-needs children hovers around 80 per cent. Research studies have shown that parents with intellectual disability exhibited more negative spousal communication behaviours like put-downs, blaming, denying responsibility and engaged in higher rates of negative reciprocity (Floyd & Zmich, 1991). Problems with sexual intimacy, communication or ability to settle disagreements, finances, spirituality, social life, future planning and recreation are some of the more associated reasons behind marital distress.

The intense stress of caring for a special child can force parents to take the support of substances like alcohol, tobacco, etc, which consequently leads to dependence or substance abuse. Physical and emotional exhaustion can be so disturbing that it becomes difficult for them to continue living without drinking or smoking. It is seen as one of the ways of coping with the child's diagnosis or problematic behaviour. They may think that it help them alter the way problems are perceived. Parental substance abuse is often more alarming because it not only affects the parenting of the child but also affects the spouse and family as well. The addicted spouse would thus less likely to fulfill responsibilities which increase the burden on the other spouse all again.

Checking for following signs of how you and your spouse are behaving will help to become aware of the arising problematic situation. For example, do you or your spouse:

- Devote most of your time, energy, and attention to your child and have "nothing" left for yourself or your partner?
- Avoid being at home and find excuses to stay away?
- Appear to be addicted to drugs, alcohol, food, work, or exercise?
- Seems to have trouble communicating with your partner without blame, anger, defensiveness, or frustration?

What would help sustain the marriage in such a complex environment and endless problems are making time for the spouse, accepting that it's okay to have different ways of doing things, remembering that you are a team and most importantly sharing the responsibilities. Stop blaming each other, be patient and practice forgiveness. Don't forget to be romantic and intimate. Celebrate each milestone. Talk openly about problems and issues when they occur. And last but not the least seek professional help before your marriage is in jeopardy.

However not every marriage will result in distress or divorce because of the disability of the child. Research also suggests that many parents of the child with special needs can also have average and above-average levels of marital satisfaction (Flaherty & Glidden, 2000) and long- standing marriages (Hartley et al., 2010). Many have reported positive spousal interactions and attributed their strong marriage to the presence of a child with special needs. Working together to care for the child helps them become best friends and develop a more profound connection.

V: Parental well-being vs children with multiple disabilities

Happy parents are more likely to raise their children in a better way. Being happy is even more critical in bringing up a child with disabilities. Unless you are content and happy with whatever you are doing adjusting to life becomes difficult. When we talk about the happiness and well-being of the parents, it is not only about being physically fit but also means being psychologically and socially sound. Being physically fit means able to function properly and carry out physical activities without having any physical limitations. Whereas positive mental health refers to psychological wellbeing. The ability to communicate and maintain meaningful relationships in the world contributes to our social well- being. To build our overall well-being all these areas should be functioning properly.



Figure4:Dimensions of Well-being (ImageSource: <https://apneaseal.com.au/how-a-bad-nights-sleep-negatively-impacts-your-physical-and-mental-wellbeing/>)

Disability-Related Factors

Being a parent takes up a lot of energy and a lot of factors related to parenting a child can affect the well-being of the parents. When we talk about raising a child with a disability there are factors like the type of disability the child has, duration of the disability, functional level of the child whether the child can speak and manage certain things and dependency levels like mobility or ability to do things plays a big role in parental well-being (Kandel & Merrick, 2007). If the parents have to struggle with taking care of everything of the child because the child is not at all independent in many things the burden of caregiving would be too exhausting.

The child's behaviour problems such as anger outbursts, self-injurious behaviour, stereotypic behaviour are also indicators of the well-being of parents. If the child shows such behaviours, controlling and managing those throughout will take lot of energy of the parents. This frustration, emotional exhaustion might lead to anxiety and fatigue. It also affects the physical well-being of the parents which shows up in reduced immunity, headache, body pains and eventually physical illness like high blood pressure, diabetes, Cardio Vascular Disease (CVD), etc.



Figure5: Disability-related factors affecting Parental Well-being

Children with disabilities are usually emotionally immature, unpredictable and fragile. They don't understand the societal rules.

Also with the years, they would have developed the tendency to personalize things that might have nothing to do with them. Like when another child or family is laughing at something they might think that it was them at whom these people laughed or made fun of. Furthermore, they also have mood swings and are impulsive at times. This emotionality is hard to live with. Children's helplessness and feeling of failure could be contagious and also affects parents confidence and competence to handle such difficult life situations.

Parents' or Caregivers' Characteristics

Parent's or caregiver's certain characteristics like the educational level, amount of financial resources they have, the security of employment, marital status also have an important role in psychological well-being. Those parents who are highly educated and have better job opportunities would have better psychological outcomes than those who are less educated (Iris Van der Heide et al., 2013). Lack of education and lower socioeconomic status affects awareness about disability and the sources for dealing with the disability (Mackenbach., 2008). Single parenthood either because of the death of a spouse or divorce will lead to poorer mental health (Behere et al., 2017; &Weitof, 2002)..

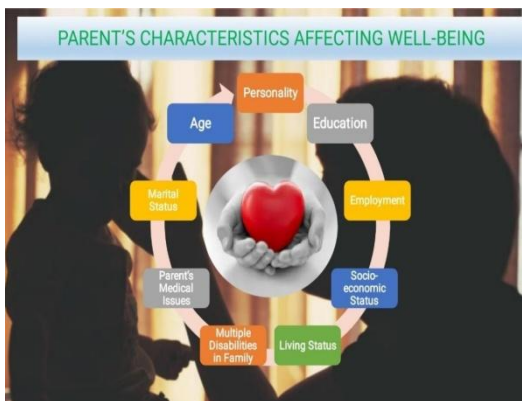


Figure 6: Parents' Characteristics affecting Parental Well-being

Besides, the parental age at the onset of the child's disability, whether the child lives with the parent and the presence of multiple children with disabilities in the family are also predictors of well-being. Parents who are older at the time of the birth of a child with

a disability are more matured and ready for handling the child and probably also with parenting experiences than the younger parents. If the child stays with the parents, they have to spend more time and energy providing care which may, in turn, affect their physical and mental health. The presence of more than one child with disability or behaviour problems can also increase the stress levels of the parents. Sometimes parents with old age and stress might also develop some psychological problems like depression, psychosis, substance abuse which make life worse (Ha et al., 2008).

How parents see and judge the situation also explains their psychological well-being. Often with the increased caregiving demands, medical expenses and uncertainty of diagnosis and treatment can impact their beliefs of the life situation negatively seeing things. The personality also has an important role to play with dealing with life situations. The coping resources of the parents will either help them deal with the demands or get drained with it. It all depends on the outlook of parents.

Family Factors

Although it is obvious that traditionally because the mother is more into caregiving of the child the stress and anxiety will be more in mothers while raising a child with a disability, the research suggests that fathers are also affected more or less similar with a child of special needs (Yogman et.al, 2016). Father's worry would be more related to the finance and other resources needed to look after the child. Thus irrespective of gender both the parents are bound to suffer from crisis and ruin the mental health.

Often when the firstborn child of the parents is diagnosed with any kind of disability, the parents become anxious about trying for another baby. They suffer from a lot of stress related to the birth of the child with questions like what if the next one also gets similar problems. They are in confusion whether their longing for a neurotypical child will turn again into disappointment, whether they can take care of everything with a child with a disability, whether the newborn will understand her/his sibling

with the condition. Especially the mothers might be always in some panic state while undergoing decisions about conceiving child affecting her mental health to a larger extent.

Another most important problem that affects the well-being of parents is sibling rivalry. It has been noted many times in family where there is a child with a disability, his/her brother or sister will resent the amount of attention and care given to the child with special needs. They always feel unimportant and many misunderstandings occur. Siblings might feel the child with a disability is a spoiled child who is capable of doing everything but not doing it to get parents attention. Parents struggle with making the sibling understand that they love them also equally and nothing is being done purposefully. Resentment or anger from their children makes them feel bad and worthless.

Grandparents may tend to blame parents for giving birth to a child with a disability, for not doing things right or enough to make things better because of lack of awareness about disability. Instead of providing support to parents they make things worse for them by making them feel guilty about everything.

Societal Factors

If the child is hyperactive or destructive neighbours or other people who come across can be also intolerant and express anger and disgust which makes parents feel shameful and embarrassed. Society's questions and so called norms makes it difficult for the parents to live a normal life with a child with disability. This might lead to secluded life cutting on contacts. Parents become isolated and then feeling of loneliness beeps in.

The place where the child is living decides the socialization aspect. Raising a child in rural areas with lack of awareness, lack of treatment facilities and stigma surrounding the disability may make things worse for parents. Many times the parents come across some negative reactions or comments from people around such as,

'She'll probably grow out of it. Some children are slow only', 'What's wrong with him?' 'Is she like that because you went for work right up until she was born?' Dealing with such people and letting go of those feelings is kind of tough always.

Having a child with a disability gives significant stress to parents who have the responsibility of taking care of their daily needs. This continues often even after their children grow up becoming an adult. An unpredictable future and constant worry about making the child independent makes them vulnerable to many physical problems which might even be worse with parent's growing age. They have to be there for their child's needs even after they become old. Worrying about their death and life of children after death haunts them. Not all the things can be mentioned but these are just a few that would affect parents. No one can imagine the struggle they would be undergoing raising a child with a disability.



Figure7:Self-care
(Image Source:
<https://familypaths.org/parenting/self-care/>)

Though we discussed a lot of difficulties related to parenting a child with a disability it's positive side cannot be forgotten. One of the greatest thing about raising a child is that parents develop greater cooperation and teamwork and commitment which deepens their relationship with each other and makes family stronger. The bad times are a filter of finding the people who truly love you and having to raise a child with a disability helps you understand who support and care for you and your family. Bringing up a child with a disability would gradually develop compassion and empathy for such people and also will teach how to give unconditionally without wanting in

return anything which is the greatest human virtue. It helps promote growth, improved relations with others and positively changes spiritual values and philosophy of life.

There is no handbook of how to go about doing perfect parenting for children with disabilities and achieving better mental health. Mistakes will occur every now and then at every stage of life, loss of hopes and confusion will take over but what is more important is the love we have for our children. Acceptance is the first key to happiness. Accepting the child the way he/she is, not thinking about society, slowing down in life to take care of yourself a bit will always benefit in the longer run.

Summary:

- One of the most rewarding and difficult relationships in life, one ever undertakes or be in, is being a parent of a child.
- Parenting is a positive, nurturing activity which normally involves the children, parents and other family members in lifelong interaction.
- The best parenting would be the one where there is a balance of warmth and discipline as exhibited by authoritative parents.
- Amidst of all confusion on how to go about taking care of the child, sibling rivalry, maintaining work-life balance, exposure to media, unsafe environment the life gets more complicated with the challenges of parenting a child with special needs.
- The multiple challenges of taking care of a child with disabilities such as treatment cost, financial strain, the stigma of the society, loss of relationships, etc. lead to frustration of parents.
- In India, where parents are equal to God, the whole responsibility of growing up a child without giving a priority to ones' own life and health makes things difficult

for the parents.

- The parents need to know that they are important and needed to be paid attention to if they want to do everything possible for the betterment of their child.
- Loving yourself is not selfishness but it's a way through which you are better able to love others.

Suggested Readings:

Marc H. Bornstein (Ed.). (2002). *Handbook of Parenting: Children and Parenting* (2nd ed.). New Jersey: Lawrence Erlbaum Associates.

Chapter - 2

Supporting for mutual wellbeing in the family

- Anusree P.R

Introduction

Are you happy? Are you satisfied with your life? We had come across such questions in the past and in present days and to be precise every day in fact. Quite usually we tend to balance our happiness and people say "I am fine". Here, we are talking about our well-being. The term 'wellbeing' itself has a positive sound. Wellbeing is our ability to maintain a level of life satisfaction in all the dimensions. A wellbeing person can be resourceful enough to overcome all the physical, psycho- social demands. Maintaining wellbeing every day is quite difficult if we don't have enough resources to survive.

Another question that we come across frequently is "is this really a problem for you? Different answers. Exactly, each of us looks at the situation differently. That perception difference also matters in how much we are enjoying our life and to what extent we are satisfied.

We know that disability in a family demands continues mutual supports between members to meet family wellbeing as a whole. Support means, we bear the weight of something or keeps it upright. In the chapter 'supporting for mutual wellbeing in the family' we are talking about how the parents can facilitate themselves to sustain wellbeing. The wellbeing of the whole family means, the wellbeing of each individual within the family system. Mutual parental involvement and shared responsibility are important to ensure the overall wellbeing of the family. Rather than cumulating all the responsibility on a single shoulder, each one should take their responsibility and brighten their roles in the family. In any family system, siblings are lifelong resources for their brother or sister with a disability. Extending help to their special needs sibling will create magic throughout their life. Apart

from all, beyond the family involvement, getting a community-based support system is a crucial element to achieve the optimal benefit of rehabilitation.

The whole family should support each other (financial support for independent living, gather knowledge for self upliftment), care for one another (providing medication at proper time, ensure that each of the family member is eating well and provide them quality food), face challenges together (Listening to each other and and help to handle conflict situation, Find a time to sit together and discuss about the problems that family faces which help to come out with possible solutions from each family members), spread love and feel fulfilled with happiness(share happiness within the family, celebrate special moments such as birthday, anniversary etc.)!!!

1 - Helping Yourself

Parental wellbeing has countless influence on the overall wealth of their children. According to Resch et al (2012), each parent has a great influence on the wellbeing of their children with any disability. Therefore, understanding the factors which influence and improve parental wellbeing is crucial. Parental wellbeing can be influenced by various factors such as individual characteristics of the parent (both psychological and physiological factors) coping styles, way of perception on the disability, level of physical health, and so on. Apart from those factors, socio-economic status of the family also plays a vital role in family wellbeing like employment status of family members, economic status, and social support and so on. Understanding the level of parent's wellbeing and its associated influencing factors is important. And this understanding will help plan the rehabilitation which intern help improve the overall wellbeing of the family.

At the moment, when a child was diagnosed with any disability, parents may feel stressful. They may find it hard to understand and adapt with their child's diagnoses of disability. Many parents exhibit the feeling of hopelessness, maladaptive coping, and secondary traumatic stress following the diagnosis of disability in their child. As professionals, it's crucial to identify parent's resources to cope with such situations. We know that disability demands more resources and personal attention within the family and it requires the systematic continuous healthy involvement of the whole family. Studies say that parents of a person with disability are less concerned about their own health and wellbeing. While dealing with a therapy session, parents used to comment that, they are not at all concerned about their health, but they are living for their child. Gradually the parents start to face burnout. It's a fact that raising a child/person with disability demands long term systematic caregiving support and responsibility. Therefore, systematic caregiving requires both physical and psychological involvement of parents in a long term condition. Additional demands of a great deal of time and energy (psychological and physical energy), increases the worry, negative thought, and caregiver burden. Continuous expenditure of physical and mental energy results in a significant reduction in both physical and psychological wellbeing among parents. Consequently, disability within the family creates again invisible disability among parents. Most of the time, the healthcare sector also fails to identify hidden psychological distress of the parents. Hans Selye, is known as the father of stress model. According to his model, during stressful situation, people undergo three levels of responses. In the first phase of reaction (alarm state), people experience fight or flight response. People try to protect themselves from stressful situation. During this state, various physiological reactions like increased heart rate takes places. In the second phase (resistance state) people mobilizes all the physiological resources to fight against the stressful situation and counteract to initial stroke. Gradually the physical resources start getting exhausted which is the third phase. Struggling with stress

for long periods can drain physical, emotional, and mental resources to the point where your body no longer has strength to fight against stress. It results in both mental and physical disturbances such as burnout and depression. Hence, helping people who need support during crisis period is crucial. Taking care of a person with disability requires continuous resistance and mobilization of resources. Therefore providing professional support to parents is a significant part of rehabilitation in any disability.

Many studies revealed that parents with a high level of caregiving stress are negatively associated with involvement in disability management programs. There is a strong association between the level of parental wellbeing and successive parental mediated intervention for their child with disability.

The greater attention to psychological wellbeing among parent/s is important. As an author, I suggest, it is better to use the term 'helping yourself' to highlight the importance of personal care. As we already know that disability demands continuous systematic demands, **facilitating enough resources among parents is fundamental**. The resources could be in many ways such as physical wealth, improving knowledge about the disability and available services, seeking social supports, stress management, time management, and utilization of various services appropriately, and so on.

Helping yourself means strengthen various resources within yourself, and use all to improve the wellbeing of yourself. Ultimately, it can improve overall family wellbeing.

Helping yourself by;

- Gather knowledge: Sometimes, unawareness creates uncertainty. Lack of proper knowledge about the disability itself creates major stress among parents. Ignorance/lack of proper understanding itself acts as a barrier for wellbeing. Hence,

health professionals should assess the level of knowledge the parents already have about the disability. Parents have to increase their knowledge and understanding of disability through various sources. The educational programs should extend its works beyond the usual project such as the name of disability, its major symptoms, treatment/services, disability benefits, etc. The various study emphasized the importance of supportive training and educational programs for parents of persons with disabilities. Parents especially, mothers of children with an autism spectrum disorder, shown a significant reduction in stress and improved coping skills after the educational program about the disability and child's behaviour. Parents will be able to handle better with high level of knowledge about the disability. Thereby increases the treatment adherence (go for health checkups) and improves subjective wellbeing (e.g. outings to enjoy and have positive outlook).

Fill your knowledge bucket through various ways such as through professionals and social media etc. Better knowledge, enhances subjective wellbeing.

- Look at your physical health: As a mental health professional, during the service most of the time I had come across, parents comments like 'we couldn't get enough time to take care of myself', 'I am living for our children', 'worrying about child's future after my death, so we are spending our maximum energy taking care of them'. Being a caregiver of a child/person with a disability requires continuous systematic time and energy expenditure. Most of the time most parents ignore their health. An unhealthy routine like unable to eat properly, excessive physical energy expenditure, lack of proper exercise, etc. are the most common problems among parents. This could be leading to various lifestyle diseases among parents (e.g.: Diabetic Mellitus, hypertension). Reporting a lack of proper

sleep is very common among parents of children with disabilities. It further creates stress among family members and lack of physical health among parents will lead to less involvement in the child's rehabilitation process. By considering this helping themselves by strengthening physical health is a crucial part of the optimal rehabilitation process in any case. Improving immunity will help the parents to overcome any kind of disease. Having proper healthy food, consumption of water, engaging in regular exercise is highly recommendable to parents. Parents have to follow their consultation properly. Time management is very crucial to handle their life activities. Priorities work based on demands and emergencies. Parents have to set a time to empower themselves by engaging in facilitating themselves and care for themselves.

- Enhance Psychological wellbeing: The psychological wellbeing of parents of a person with a disability is determined by various factors. The level of parents' physical health also acts as a mediating factor of the psychological wellbeing of parents. The type of disability of the child, child's behaviour, personal characteristics (e.g.: resilience, coping with stress, perception of disability, hope, etc.), effects of rehabilitation, socio-economic factors, community support, etc. can be considered as a determining factor of psychological wellbeing of parents of a person with a disability.

Parental training and educational program have a modest effect on improving subjective well-being among parents. Teaching stress management techniques such as the adaptation of available coping resources to parents will help them to cope with the situation easily. Adaptation of emotional coping like emotional catharsis (e.g.: crying), providing life skill training especially, time management, decision making and problem-solving will facilitate

parents in finding out possible alternative solutions to any demanding situations.

Being resourceful is enough to bounce back from a stressful event, which predicts the psychological wellbeing of parents of a person with disability. Parents with an optimal level of resilience will be able to come back to the usual routine after experiencing stressful situations. A resilient parent will always be able to adapt coping skills appropriately, such as seeking social support, hold problem-solving skills, and an optimal level of hope in the future. Hope for the future acts as a key that drives the mental spirit of the person to overcome the situation effectively. Modification of negative perception of the disability into a positive dimension is fundamental to achieve the subjective wellbeing of parents. Various psychotherapies provided by clinical psychologists like acceptance and commitment therapy, cognitive behaviour therapy and mindfulness-based stress reduction facilitate the parental wellbeing.

Positive psychologists says that practicing hobbies is a way for happiness and wellbeing. Spending quality time with oneself like engaging in hobbies (such as: listening to music, singing, drawing, craft making, cooking, reading and so on) will improve wellbeing and quality of life. Psychological wellbeing can improve through engaging in various activities like learning new things, travelling, dressing up well, and eating favorite food and so on. Studies shows that (Zawadzki, 2015) leisure activity can provide immediate stress relief, improve mood, balance heart rate and happiness and wish for a longer life.

- Being in touch with the community: Humans always need to be affiliated. Social networks have the greatest effect on individual wellbeing. There are plenty of scientific studies that highlight the positive effects of social support on the wellbeing of people. Social support includes emotional support and instrumental support (material support like getting financial support) etc.

which improves parent's self- confidence and resilience throughout life. During stressful situation social support provides physical and psychological advantages to face and overcome the situation (Brummett.,B.H., 2005).Community support will ensure the rehabilitation services for their child such as transportation, schooling, vocational facilities, etc. The rehabilitation of the child will have a positive effect on subjective wellbeing among parents. Recent study found an effect of social support on mental health of health care workers and resilience plays a mediating role among healthcare workers during the epidemic of covid-19 (Hou, T., Zhang, T., Cai, W., Song, X., Chen, A., Deng, G., &Ni, C.,2020).

2. Helping your spouse-mutual parental involvement

A family is a basic unit of socialization of a child within which parents play the primary and foremost role. The role of a parent is infinite. They provide adequate food, fresh air, security, recreation supportive environment for socialization, guidance, direction, assistance, education, observance, emotional development, and overall health.

Families are a vital supply for the welfare of an individual with a disability. Living with a child with a disability will have crucial effects on the whole family structure and function. The shared responsibility of the whole family ensures wellness among each member. Being single parent of an individual with a disability is troublesome to sustain.

The optimal rehabilitation of disability needs mutual responsibility and support from both parents within the family instead of a single parent shouldering the entire responsibility. On the other hand, understanding the disability and shared support between parents of a person with disability is the core pillar of the wellbeing within the family. Wider the shared support, earlier the child gets rehabilitated for inclusion and

mainstreaming. The systematic rehabilitation of disability requires multiple disciplinary supports to learn varied skills that are required across the age span – such as time management, medication, professional support seeking, home management, basic support such as wheelchair facilities, and so on... In cases of profound or severe disability, involvement of both parents is even more important.

As mentioned in the introduction, a family is a basic unit of socialization, which consists of multiple duties and responsibilities. Therefore, the division of duties and responsibility within the family is crucial. It enables smooth family functioning and predicts the overall wellbeing of each member of the family. Spouse's support (husband /wife) is important to ensure the success of rehabilitation. The role of parents in the case of disability is wider than a non-disabled case.

The literature reported that the majority of single-parent experiences physiological and psychological burnout. They also experience lack of confidence, feeling of loneliness and secondary traumatic stress. The parent find it hard to follow the routine properly due to lack of support from others. Mostly, the mothers reported loneliness, traumatic feeling, and depression and find it hard to handle several responsibilities at the same time (Kotwal, 2017).

We know that parents' plays multiple roles simultaneously, if all those duties are taken care by only one parent, gradually they become exhausted. Being a parent is hard and being a parent of a person with a disability is extra hard to overcome. Unfortunately in many cases, the parent faces stigma and social negligence after the diagnosis of disability in their child which makes it even more difficult for the single parent. Therefore, mutual parental successful mindful involvement is a part of the management of disability. The mutually shared responsibility among both parents to take care of disability will ensure the overall quality of their family. As I mentioned earlier, overcoming the trouble together will ensure the long term welfare of parents.

Parents of children with disabilities are facing various psychological issues such as depression, distress, adjustment issues, and so on than other parents, and the psychological issues are high among single parents. Studies show that the parents face stress after the diagnosis of disability for their child, the spouse's mutual support strengthens the resilience among both parents. Family-oriented support for both parents is required to enhance the mutual responsibility among parents on disability. The first and foremost important aspect is that, providing knowledge among both parents about the disability. In many cases, one parent takes all the responsibility of the rehabilitation, spouse sometimes never has any knowledge even about the disability. Eventually, the caregiver burden is found to be very high among such parents. Hence, health professionals should acknowledge the attitude of both parents on disability management. Another important aspect is acknowledging the factors affecting the emotional wellbeing of parents. The level of the emotional wellbeing of each parent will be different. Here, a mutual understanding among spouses (husband/wife) is fundamental. Enhancing the marital wellbeing of parents is important. Open communication between husband and wife about their expectations will help them understand each other. Enhance husband- wife relationship by spending quality time with spouse, going out, complement each other, celebrate spouse's special day, and give emotional support to one another, care each other and survive together. Emotional understanding among husband and wife will enhance the marital wellbeing too.

3. Involving siblings - a gift to parents

In the overall family, there is one/more member/s, who has been neglected due to parent's effort to provide extra attention to children with disabilities, called 'siblings of a person with a disability'. Siblings' relationship is the long-lasting supportive relationship that a child forms. Siblings can be a friend, a parent, a

teacher, and the best guide throughout life. In any society, it is a quite usual thing that, children help their brothers and sisters. Likewise, siblings can be lifelong sources of support for a person with any disability. Even siblings of disability are at a greater risk for developing emotional issues, stress, and anxiety. Mostly this occurs as parents are busy in disability care and neglect the emotional wellbeing of the typically developing child. As a result they may internalize their emotions. In some cases, they experience multiple difficulties like facing peer pressure, lack of participation in extra-curricular activities, and failure in academic participation leading to emotional disturbances. Most of the time siblings face neglect from therapists too. Let me explain one context, during the visit to the treatment center parents tend to make siblings wait outside. Even siblings have various questions and doubts regarding their brother/sister's disability. They may develop misunderstanding about the disability and it became worse than actual. A feeling of guilt, embarrassment, anger, and jealousy are the most common mixed emotions faced by siblings of children with disabilities. That means, siblings, of children with disabilities also have their own needs and wants. The whole family system has to give attention to them also. As mentioned earlier, siblings are a lifelong source of support like a second parent for their brothers and sisters. Parents can make an emotional bond between children by providing, an adequate level of attention to typically developing children in the family.

Living as a sibling who has a disability is a different learning experience. These siblings often develop various life skills throughout their life with their special sibling. They develop the skills of empathy, responsibility, helping others, cooperation, and self-control. Siblings act like a leader and guide for their siblings throughout their life. Parents and health professionals have to give much more attention to siblings to enhance their involvement in disability care. It's important to establish an emotional bond between siblings with disabilities within the family. Very importantly, parents have to keep in mind that, their typically developing child may need a constant explanation, why

their brother or sister needs special attention always. That will help the child to be more responsible rather than neglectful. Facilitate the typically developing child by providing a proper understanding of their sibling's disability and enhance their responsibility too. For example, set the stage early for open and honest communication so that your children feel comfortable asking questions or expressing concerns or frustrations.

Parents have a vital role in monitoring the responsibilities and duties given to typically developing siblings. Child's attitudes towards their sibling's disability will predict the long-lasting effects on emotional development and support systems. If parents are able to provide a supportive encouraging environment for healthy siblings, they can be a helpful and trusted support for their siblings living with disabilities.

In a family system division of responsibility among each member will help the smooth functioning rather than a spiral effect of duties on one or two persons. Most of the cases, managing disability require physical energy such as helping them to go to the toilet, bathing, or managing anger outbursts and temper tantrums. Parents can do such things easily. Younger siblings can take other responsibilities like developing soft skills (drawing, pushing wheelchairs, helping them to learn social skills, managing time, reading books, and so on).

Parents can enhance the unique skills and strengths of the siblings. During the therapy sessions for social skill building among autism, siblings have a crucial role in enhancing social skills. Parents used to report that, their children special needs, especially children with autism tend to imitate their siblings during social interaction. Typically developing siblings can be creative to adapt the various plays to improve communication skills with their special needs sibling.

As a mental health professional, I have come across good experiences during therapy sessions. Especially children with childhood autism would able to maintain eye contact easily,

respond to name-calling, social smile, sharing things while playing. Those social skills were achieved quickly when the session was accompanied by a child's typically developing brother or sisters. Professionals and parents can facilitate the therapy by including typically developing siblings. Those approaches result in better and faster outcomes. Siblings modeling can be very useful in the home management plan also. Echolalia (repetition of speech or vocal sounds made by another person) is one of the common symptoms among children with autism. Such clinical symptoms can be managed through active involvement of typically developing siblings. Typically developing siblings can be a therapeutic element here, by which they can guide the child through exhibition of socially acceptable vocabulary. For example, be a model of how to say hi, hello, bye, good morning, etc. Likewise, siblings can deal with the tendency of echopraxia (imitating other's actions), by showing socially acceptable actions and posture (e.g. shake a hand, welcome hand, etc.). Various studies have also confirmed that children with Autism more easily adapt to social skills by imitating their typically developing sibling's actions than those they don't have any siblings. Sibling-implemented reciprocal imitation training is found to be one of the effective methods for social skill training for children with autism (Walton, K. M., & Ingersoll, B. R, 2012). Siblings' natural play patterns provide opportunities for social interactions and play initiations among children with autism than those of parents. Another important aspect is that, typical siblings also make few attempts to interact with their siblings with autism during free play sessions (El-Ghoroury & Romanczyk, 1999), which facilitate social interaction with their brother or sister with autism.

Setting up Activities for Daily Living (ADL) for the child with disability make every day functional and simple. ADL are the skills and practices necessary for independent and development of a child. Parents can set up daily activities for both children with and without disability. Children without disability may learn the ADL through imitating others (e.g. washing hands,

smiling on others) and coaching by parents. A child with disability requires additional support and systematic training. Their sibling act as the additional support. Children learn ADL through communication also (e.g. parents give frequent reminders and verbal instructions to children for doing daily activities). Parents can take simple measures to teach various skills for daily functioning like teaching them to eating by hand, pick up the tooth brush, buttoning the shirt, washing hands and etc.). Giving reinforcement/appreciation such as “saying good’, saying good girl/boy, giving likeable things, giving stars and etc.) followed by successful activities will enhance their skills. Simultaneously, providing ADL training and reinforcement for typically developing child is important. Gradually, parents can reinforce their typically developing siblings to be a part of ADL training for the child with disability. Interestingly, the children with disability start to imitate their typically developing siblings. Together, both children learn adaptive skills and able to complement each other. Emphasising the benefits of each activity they teach the children are important in order to enhance the value of it. It further benefits the parents to reduce the life time cost of care.



Helping by pushing the
wheelchair



Shared Playing



Celebrating Disability



Learn together

Hence, facilitating the typically developing child with a better understanding and knowledge about the disability is the foremost thing. Open communication between the parents and typically developing siblings can facilitate various better outcomes: such as,

- Ensure that, siblings can be a part of the family decision-making process about disability management.

- Shared responsibility within the families can be strengthened.
- Parents can facilitate an atmosphere inside and outside the home to enhance the shared activities together among siblings. Shared activities can enhance time spent together, playing together, learning together, rewarding each other, support each other, etc.
- Teach typically developing siblings regarding how they can be a part of disability management of their special need brother/sister.

Ultimately, growing up with siblings with disability will facilitate lot of skills which further facilitates overall wellbeing of the family. Most of the time it's quite a beautiful thing that the siblings take the initiation of celebrating disability, celebrating birthdays of their brother/sister with a disability, celebrating each moment. Such an atmosphere can strengthen family involvement in disability management together. Likewise all hands together will create an umbrella of wellbeing within the family by understanding the disability.

4: Seeking community support

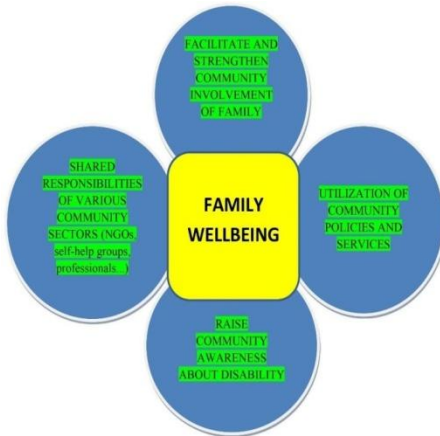
Community-based rehabilitation is part of disability management. It has a crucial role in the optimal rehabilitation of parents with disabilities and their families. Establishing a support system beyond the family such as to friends, neighbors, self-help groups, NGOs, and so on have a significant role in a family coping. Studies found that earlier the intervention and the more support provided to the family, find it easier to function throughout their life span (Levy Schiff, R. and Shulman, S. 1998). Seeking social support is a way of coping with life stress and it satisfies parent's need for appreciation, affection, security, and belonging. As we all know, human beings are social beings; the network of community support always acts as a smooth fighter of

stressful situations.

Getting a committed social support is a major concern of parents. Community-based rehabilitation enhances the community mobilization in which the people from different sectors hold their hands together for the wellbeing of disability. Wider community network will predict the maximum wellbeing in the family of disability. Through the systematic community rehabilitation, it can mobilize the community e.g. people with disabilities, relations, self-help groups, disabled people's organizations, community members, local authorities, local leaders, decision- and policy-makers, to break barriers within the community and ensure the successful inclusion of people with disabilities in their communities with equal rights and opportunities. The aim is nothing but enhancing the societal concerns over the disability thereby improving the inclusion of people with disability in the society. Disability management and wellbeing of the family is a societal responsibility too. The collaboration of support from each community sector such as professionals, neighbors, NGOs, policies makers, transport systems, self-help groups, and so on have the power to create a big umbrella shelter for people with disability. Little progress in each sector will create drastic progress in society. Any support from the community can help parents to bounce back from life stressors. Community networks will help parents to get more knowledge about the available resources and utilization of those resources for the overall wellbeing of the family.

Another important pillar of rehabilitation is 'acceptance of disability'. Some parents hold positive attitudes about their child and provide maximum possible opportunities to them. Once the parents accept the condition of disability, they can gain knowledge about the condition. If a parent is well knowledgeable about their child's condition, it will ease the process of empowerment of the child through various opportunities.

Once the parents identify the brightness in their child rather than looking at the disability, the mutual wellbeing will take place within the family. Parents will learn to utilize existing possible community.



The above picture explains the process of community rehabilitation for the wellbeing of the family having child with disability. The professionals must acknowledge the importance of the family and a positive attitude towards disability which controls decisions concerning the disability and the family.

Seeking social support is one of the major source of wellbeing. Understanding the available source of social support is important. Parents can seek various kinds of social support like seeking professional help, therapist opinion, advice, economic support from others and so on. Seeking emotional support and having a strong social network of family, friends, and neighbors can improve parent's coping skills and psychological wellbeing. Maintaining balanced emotional wellbeing of the parents is the pillar of the overall wellbeing of their child with disability.

Community workers play a major role in removing societal barriers for people with disabilities and their families. Such community-level rehabilitation removes the negative attitudes and behaviours towards people with disabilities and their families. Thereby parents can feel free to approach the community for support. Ultimately, the family wellbeing can be achieved through the maximum inclusion of disability in the mainstream community.

On another side, there is a large gap between the services providing and received by the disabled population in the country. Rural community receives less community services compared to urban community. People with disability who live in rural community encounter scarcity of the health care services. The socioeconomic status plays a major role on effectiveness of community rehabilitation. Lack of awareness of disability and poverty are encountered the major barrier for community based rehabilitation. Limited accessibility of adequate housing facilities, lack of educational programs and other specialized healthcare are major barriers in rural community compared to urban.

Summary

In the chapter 'supporting for mutual wellbeing in the family' we talk about various supporting systems to enhance the wellbeing within the family of person/children with disability. Following are the key points of the chapter:

- ✚ Disability in a family requires multiple familial, functional and structural changes.
- ✚ As a parent or bystander, subjective wellbeing is fundamental to provide optimal care and support.
- ✚ Support by self through seeking social support, care for physical health, and adaptation of better coping skills.
- ✚ Hope and expectations are tools that enhance parental subjective wellbeing.
- ✚ Resilience predicts parental wellbeing among children with disabilities.
- ✚ Shared responsibility between spouses will enhance parental wellbeing.
- ✚ Siblings are lifelong resources who act as a friend, teacher, guide, and companion, for their brother or sister with a disability.
- ✚ Seeking appropriate community support ensures the optimal level of rehabilitation.

- ✚ Community- based rehabilitation is important.
- ✚ Systematic community support will enhance the wellbeing of the family which ensures inclusiveness of child with disability.

CHAPTER - 3

CAPACITY BUILDING OF PARENTS

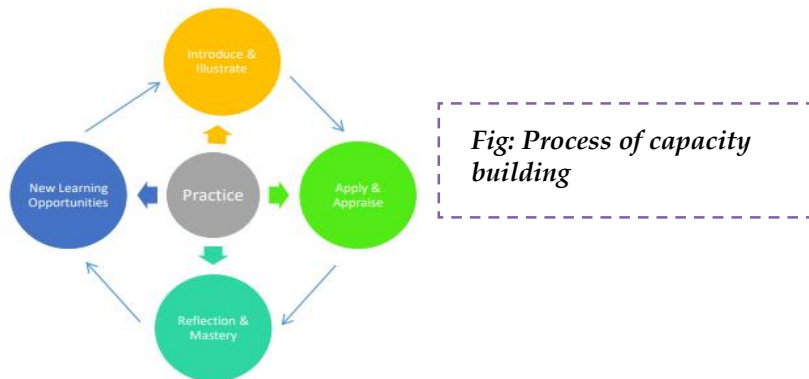
- *Rebecca Lalnundiki*

INTRODUCTION

“Capacity building is the process by which individuals, groups, organizations, institutions, societies and countries develop their abilities, individually and collectively to perform functions, solve problems, set and achieve objectives, understand and deal with their mission in a broader context and in a sustainable manner” (WHO, 1997). Capacity building is significant not only with persons with special needs but also among their families, professionals and volunteers. Furthermore, emphasizing the importance of capacity building among parents is crucial as they are the primary caregivers. Parents of children with special needs have a different experience and expectations referring to their child state of disability. Often they have depression, anxiety, emotional dysregulation, etc. due to the difficulty they face in taking care of their child; the knowledge of having a differently abled child itself can cause a shock and sometimes not accepting the situation which further results to the poor wellbeing of both the child and parents (Kuyini et.al., 2015). Parental wellbeing including mental and physical health, marital relationships and participation in social and economic life can affect the child’s disorder leading to many behavioral, emotional and physical problems.

Capacity building helps parents in understanding their current situation, increase their abilities and giving them confidence in supporting their child. In practicing capacity building, one has to follow a method / process (J.Dunst, 2013):

- Introducing the technique to the parents by professionals
- Practice and then evaluate the experience/practice
- Assessing and reflecting of their understanding and ability to use the practice
- Identify in other learning opportunities to build and strengthen their understanding and use of the practice based on their experience.



FINDING RELIABLE RESOURCES/INFORMATION

A reliable resource means, well- reasoned and evidence based theory to support the information provided. Educating yourself about your health issues is an important part of managing your health. You should ask questions and doubt about your health to professionals so that you can view your issues from different perspective and have knowledge about the options available. Today media becomes an effective and easy way of giving information reaching a wide population. A reliable health information is found in different sources and while checking for the reliability of information one should check-“about us” page on the website, whether the article or study is proved by qualified professionals, whether the study was done by

recognized institution or under professional guidance, as health information is constantly changing from time to time due to the new discovery and inventions checking whether the information updated is recent is important, also look up for medical research to back up the information shared (BHC, 2015), some of the resources of information which are reliable are:

- Health professionals like doctors, nurses and allied health professionals like pharmacist, clinical psychologist, therapist, etc.
- Health brochures from hospital, doctor's office or community health centres
- Telephone helpline in centres, clinics and hospitals
- Website which is well known like government sites, certified organization sites and journals related to medicals and allied health and research paper or case study done by professionals.

In a developing country like India, there are still many stigmas due to the association of rituals practiced by the people and many hold the belief that having a disabled child is a curse related to evil spirit and some believed disability can be cured by performing rituals. Also, in many clinical cases, we see families blaming the child's mother as a result of the child's condition. Unfortunately, all these beliefs were widely spread, giving false hope which leads to many psychological problems to the families. These beliefs were not useful in making the child's progress and development.

It is of crucial importance that these false beliefs and superstitious assumptions are not to be given any importance by the family. Parents and caregivers must be well-informed regarding the interventions required in looking after them. The first and foremost step in capacity building is conducting a detailed assessment for these children with special needs, including their health and behavioral concerns pertaining to both skilled behavior and behavioral problems. Skilled behavior include brushing, bathing, eating, language, motor skills etc.

while problem behavior are behaviors which cause harm to others and to himself like crying excessively, breaking objects, spitting on others, smiling and talking to himself without any reason, stealing, not obeying commands, etc. These assessments and medical examination can be carried out by trained and certified professionals from both the medical and allied health sectors. In many cases, the problem of the child can be due to physical ailments leading to psychological problems or vice versa; finding out the root cause of the problem is the major concern of these professionals. Also, any new information regarding treatment, therapy or ways of monitoring and guidance for the child's daily activity etc. should be applied or practiced only after consultation of the aforementioned professionals before changing the pattern of treatment or therapy. One should always cross check the reliability and validity of new methods and treatments before blindly following them.

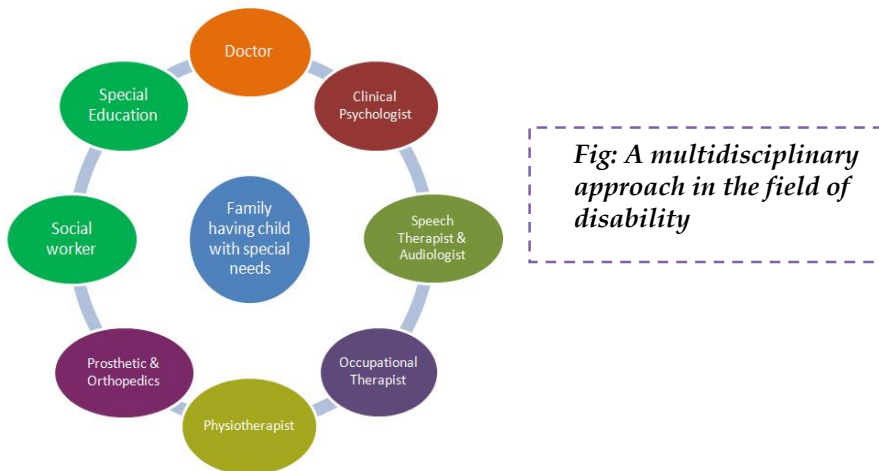
Having a child with special needs can leave the parents in a stressful and anxious state, especially in cases where the parents refused to accept the child's condition and often think that it can be cured easily. Parents should not believe promises of miraculous cures, wonder drugs and other extreme statements unless there is a reliable proof ; they should keep in mind that only a medical professional can give suggestions and advice regarding the condition of the child after knowing the child's history.

GETTING SUPPORT; WHY, WHEN AND WHERE SHOULD I GET SUPPORT?

Why should I get support?

Parents with special needs have a crucial role in collaborating with other professionals and volunteers in society for achieving the child's progress. A multidisciplinary intervention is necessary where doctors and other allied health professionals like speech

pathologist (person who evaluate, diagnose and treat communication disorders like speech disorder, communication disorder, voice disorders etc.), physiotherapist (person who treat people having disease, injury or deformity by using physical method such as massage, heat treatment and exercise), occupational therapist (person who treat injured, ill or disabled patients through the therapeutics use of everyday), clinical psychologist (person who diagnose and treat patients with mental and emotional illness including disabled using psychological technique) social worker (person who help others with their social and interpersonal difficulties, promoting human rights and wellbeing) and family work together as a team using the most effective techniques and plans in achieving the goals of the child with special needs. The prosthetics and orthopedics department are working on the artificial limbs and other assistive devices so that children with special needs who are in need could adapt in their day to day lives, making their daily activities easier.



The professionals conduct a detail assessment of the child which includes assessing and monitoring the child's health, skilled behavior and behavioral problems. All these behavior can be addressed to the professionals and seek their guidance where

different management strategies will be carried in treating the child with special needs both in clinical settings as well as at home. Also, parents seeking guidance and information from professionals in handling their child are equipped with a better understanding and broader perspective which assist them in looking after the child. Moreover, the environment of the child is important, and the child's development is strongly related to the psychological wellbeing of the family. The marriage life, interpersonal relationships within the family and how they work as a team in raising the child should be addressed effectively. A good support promotes both parents and child's mental and physical wellbeing.

When should I get support?

Early intervention is of great importance marked by the Government in many health schemes. It must be noted that the earlier the treatment the better the prognosis in dealing a child with special needs. As soon as parents notice that the child is having a problem in developmental milestone or having doubt in the child's condition they should consult health professionals at the earliest. Also, parents with special needs often have problems in creating inclusive environment in schools, public spaces etc. they should contact the higher authority, professionals, neighbours, friends without hesitation as it gives large impact on the child's lives. They need support throughout their lives from friends, family and professionals (Smith, 2019). In support of early intervention, between the ages of 3-15 months the child goes through tremendous growth especially the brain development which is greatly influenced by the child's early experience. A study conducted at Harvard University concluded that there are several findings highlighting the importance of early development (Sue Goode, 2011)

- The neural circuits which are essential for learning and behavior and health are most flexible during the first three years of life and over time they become difficult to change.

- The brain is strengthened by positive early experiences, especially stable relationship with caring and responsive adults, safe and supportive environments and appropriate nutrients.
- Early social and emotional development and physical health provide the foundation upon which cognitive and language skills develop.
- High quality early intervention services can change a child's developmental pathway.
- Intervention is likely to be more effective and less costly when it is provided earlier in life rather than later.

Where should I get support?

Being a parent of special needs can be a challenging task. Focusing on the child's needs, one has to focus on family needs and pay attention to other siblings, their partner as well as to themselves. Hence, parents need strong support physically, psychologically and financially. One way of getting support is by consulting health professionals, special educators, social workers who can help in monitoring the child's daily activities. Besides the Government hospitals, there are some centers under Government where one can avail the provisions; some of them are District Disability Rehabilitation Centre (DDRC), Composite Regional Centre (CRC), District Early Intervention Centre (DEIC) and many other National Institutes of Different Disabilities in the country. These centres comprise doctors, nurses, clinical psychologist, physiotherapist, occupational therapist, speech therapist, special educator and social worker, who work together as a team for the development of the child with special needs. Government under the Ministry of Social Justice have set up many schemes for person with special needs like Inclusive Education for the Disabled Students in the State (EIDSS), Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP), Deedayal Disabled Rehabilitation Scheme (DDRS), PRERNA are some of the schemes which provide

assistive device, monthly stipend to students, free cost education, vocational training and job placement, free health services, concession in Government transport. These schemes can be enquired in the centres mentioned above, as well as in the office of Social Justice in every state.

When we talk about support, a focus on daily activities may include simple activity like:

- Building friendship outside the group of special needs. Being a parent of special kids the only thing we talk is about the child's stories everywhere. Even our social gathering include parent with special needs. Just like every other parents we need a stress free time, where we can talk and engage in activity on the things we are interested (Rudy, 2019)
- Keep the child in others care for a while - respite care. Many of the parents are too attached with the child and forgot to take care of themselves. Hiring a babysitter or someone in the family for some time will help you to gain self-awareness and reduce stress, providing a time to engage in other activity as well (Rudy, 2019)
- Venting out is important tools for mental health. Joining support groups to share your stories or things which disturb you. Also making appointment with clinical psychologist for counseling and therapy are of a great help for psychological wellbeing (Rudy, 2019)
- Taking exercise and maintaining nutrition could sound a minor issue but it can be of great self-support activity as many parents need energy and good health in order to look after their child. These could be a great help in maintaining physical and mental health (Rudy, 2019)

COMMUNICATING WITH OTHER PARENTS FOR SELF-BETTERMENT

Communication with other parents can be of great support mentally and physically. Getting information from other parents who face the same problems, receiving and providing emotional support increase the chance of confidence and reduce stress among the parents with special needs. Staying in touch on a regular basis not just when crisis occurs can build up the relationship and support among parents, especially reinforcing parent build psychological wellbeing (Webster, 2019). Communication can be individual and group using phone call, meetings, text, letters, mails, etc. For most parents, it may be difficult to meet up in person but many have phones and can utilize social media like whatsapp, facebook, skype etc. Parents can create groups in whatsapp, facebook or instagram and keep a current membership list or make fees (this will help your group look different and make it exclusive). By using social media as a common platform, parents can share mutual concerns and doubts regarding the child's condition and inquire any kind of information they wish to know. Also, stories of success and challenges can be shared with other parents for moral support and encouragement. Creating a group can be of great help in sharing information and reminders for meetings and discussing any topic. (Graham, 2019)

Technique in building relationship-

- Listening to other views- It is easy to dominate conversation with others. Many of us did not realize that we repeat our dialogue several times which can be irritable, also avoid exaggerating stories in a dramatic way and control the pitch of our tone. This creates loss of interest to the conversation, creates impatience to listen and further ruins relationship. Listening to others can also be a good tool for insight or self-reflection as other parents

who were in similar condition will understand the hardship and give honest feedback on how they are taking care of their children, giving insight on whether they are doing it right or wrong.

- Discussing concerns about the child- Providing information about the child's needs and progress can be of great help. This can be helpful in receiving and providing reliable and effective resources. Not only our needs but sharing the hardship and struggle in achieving their goals can be great a challenge and motivation for others and also enhance self-esteem for them. Being a part of the group or in one to one conversation we should not force the other person to take part in the conversation. Also it helps in creating an understanding of what to expect with the situation you are facing.
- Confidentiality - Sharing information and stories of others should remain within the group. Every person within the group should maintain respect privacy of other group members and not misuse and take advantage of the trust that group members have towards them.
- Consistency in strengthening relationship- Maintaining a consistent relationship helps in knowing a person better resulting in mutual understanding and sturdy support. Even if we cannot give support through our presence a simple words of concern and addressing how much we care for them could be of a great support for others.

People might not know what you are going through and what your child needs. In this case directly telling on how you feel, your worries and where and how you need support is effective. Examples for informing/addressing of your difficulties to others like:

“We cannot come for the event as the place is not accessible for our child who is having a condition of cerebral palsy and we cannot leave him at home as we have to arrange caregiver which is very expensive and we cannot afford right now”.

“I am exhausted as I have to stay awake whole night to monitor my child as he keeps on getting fits these days, it is very stressful and tiring as there is no one who can help me out”.

When people claim to understand you, remember that giving you their support is an easy act. Also keep in mind that there will be some people who will not understand your situation and the hardship you are facing. So be prepared to face any kind of people to whom you share your stories. Communication skills are important tools for maintaining a good relationship. Parents having good skills in communication not only have a good influence on the child but as well as to inter personal relationship outside family.

Welcoming/inviting: Be open to conversation, ask open ended questions like, “I heard Nitin is not doing well these days how is he today?” An open ended questions show that you are interested in the topic. There are some parents who share without asking while some needed an invitation from others for conversation. Our expression and body language should also be inviting for others showing them that our attention is on them.

Skills required for effective communication:

1. Observation: Observe the other person’s mood, whether they are interested to talk or avoiding the topic. This is necessary as there can be many times when one might be in a bad mood due to many personal issues. In this case avoid the issue but telling them that you are there for them anytime when they need you are comforting words for them.
2. Good listener: Being a good listener can be challenging, a good listener is paying attention to the topic and to the person with whom he is interacting. A good listener should have good eye contact, respond appropriately and wait for other’s response as well.
3. Respectful: Respect the decisions or views others have

even if it is against your beliefs. Knowing about their problem and hardships of the other person and the knowledge about their disability creates empathy towards them. In developing empathy one should imagine themselves as the one having problem, question the person why is she feeling this way so that she can express her emotions freely, aware and attuned of what the other person is saying so that you can understand the true feelings and intentions and lastly offer support. This builds a strong bond in relationship.

4. Be positive: For many parents of children with disability a word of encouragement, positive statements and motivational words can be a tool for stress relief and helping them in viewing their conditions in an optimistic way. This results in obtaining a healthy lifestyle for both parents and child. As seen in many studies parents who have an optimistic view have a great impact in their child development.

Group activities for parents with special needs

1. Lifeline- In this activity every individual should draw a timeline representing your mood since the birth of your child highlighting the high and lows mood. Depending on the number of the group members the highlight can be of more or less Example: 2 high and 2 lows. This could be in written form first and then later sharing in group meeting.
2. Image connection- Select a word (kind, resilience, honest, fear, guilt, compassion etc.) as a theme during every meeting. After selecting a word all the members have to draw a picture related to that and invite the members to talk about a time related to the word describing their parenting with their child. Also, this activity helps parents in venting out their stress, giving them the opportunity to address their own concerns

whether about a child or their personal problems.

3. Meditation and Yoga- Practicing meditation and yoga as a group can be helpful for parents stress relief and boredom. For practicing, the settings have to be a quiet place, dim lights, soft music etc. After practicing each one should talk about their experience, how relaxed they are, whether it is helpful or not.
4. Values clarification-This activity provides insight to many parents. Each group need to have 83 print cards which contains one value in each. Each group have to classify the cards into three groups: values no important to them, values important to them, values which are very important to them. After categorizing each group have to minimize their most important set of values to top 10 and then put them in rank orders.

After every group sorted their cards following questions are raised:

- How are you living in accordance with these values? In what areas have you acted inconsistently?
- What problems are you facing in following your values?
- What are the things you have to change, how will you attain or keep you values? What you should do more? What should you do less?
- How have your values changed when you have a child with special needs?

What I can and cannot control- This activity is also giving an insight on how we perceive things in many areas. Each individual have to make a chart on which draw a circle and inside the circle mention 5 things which you can control and outside the circle 5 things which you cannot control. After writing, the participants are divided into groups or pair which is convenient for more detail discussion.

PARENTING STYLE AS A KEY DEVELOPMENT

Many of the skills children acquired during the early years are fundamentally dependent on the quality of parenting. High quality caregiving, characterized by a sensitive, cognitively stimulating and moderate controlling approach is crucial for children's development and safety.

The **quality of consistency** in parenting is the key determinant of the child's cognitive potential, skills and behavioral functioning. Hence, a continuous effort in improving the quality of parenting is important due to their child's condition. Parents with differently abled children become overprotective due to their anxiety related to the child's condition. Not just emotional and behavioral content the physical health which includes sleeping problem in children - How parent settles their child to sleep and responds to night wakening. Teaching parents to allow the child to self - settle at the start of the night can greatly improve problems getting to sleep and re-settling overnight. Also, studies have found that randomized controlled trials have demonstrated that teaching parents to use graduated extinction (parent checks on and comforts their infants at increasing time intervals but leaves the room before the infants fall asleep) reduces infant sleeping problem and maternal depression symptoms. Furthermore, study has found that children with authoritarian parents tend to experience more negative emotions like fear, anger, guilt and nervousness comparing to other children raised in permissive and authoritative parenting style. (Giselle, 2015)

There are different things to follow or requirements when practicing positive parenting. In order to change like Jung said "If there is anything that we wish to change in our child, we should first examine it and see whether it is not something that could better be changed in ourselves. In agreement to what Jung said Maureen Healy has come up with some basic requirements for parents to follow (Haely, 2009).

1. Getting our stuff together- Here first thing is preparing us for transparency in dealing with children. In early days many of our parents practice authoritarian style of parenting which is strict, stern, obeying command and rules without questioning and enforces good behavior by punishments. Instead of adopting the same, let this experience help us in having more insight and awareness in bringing up our child.
2. Being positive and firm-For many parents having special child being positive and firm is hard. This second requirement could be the influence of the first point. Often parents get blind by their disability, we pity them even when they need strict guidance. This results in children not acquiring their skills or their abilities to the fullest. Also along with consistency in discipline being positive and firm includes making a child feeling loved and safe. Positive parenting is focusing on the child's strength.
3. Focus on positives- Even if a child is screaming and engaging in undesirable act instead of screaming back and yelling at him finding out the reasons why he did that, often children shows behavior which is undesirable as their needs are not met. After finding the cause you can redirect (i.e. outdoors, running around, singing, punching bag etc.) them to vent their emotions and then provide needs. Having a mindset that being a parent you can solve any problem and learn how to remain calm in finding solution is required.

Study has found that positive parenting can be effective in helping young children with special needs to become more independent and cooperative. Also, by using positive parenting style the symptoms and severity of the child's disability are likely to decrease (Lee, 2016)

Positive Parenting include-

- Making frequent eye contact especially while interacting with the child
- Use positive and negative reinforcement effectively (positive reinforcement-something is added to increase the likelihood of the behaviour. Eg: A child gets some snacks for finishing homework; negative reinforcement- something is removed to increase the likelihood of the behaviour. Eg: A child does not like his mother scolding for not making his bed, in order to avoid his mother scolding the child make his bed).

Also reinforcement can be primary and secondary reinforcement. Primary reinforcement is reward that fulfills our biological needs Eg: food, sleep, water etc. While secondary reinforcement is reinforcement refers to a situation in which a stimulus reinforces a behavior after it has been associated with a primary reinforcer. Eg: Money, grades.

- Using positive statement rather than criticism or blaming them. Eg: Instead of using "Do not hit your friend" use a positive statement like "Be good to your friend".
- Demonstrating things with patience. Making the children understand in simple terms and repeat it until they are satisfied with your reply.
- Responding immediately when they are in need. Even when caregiver is busy, the caregiver must make the child understand giving a reply that he/she will come to her soon after work. This gives security to the child.

Parents of children with special needs perceive their children to be more vulnerable to accidents and injuries due to their disabilities (Quinn, 1998). Parents are afraid that their child might injure himself/herself easily as some of these children have problem in speech, motor functioning and poor cognitive skills. They are also afraid that others might hurt and bully them.

Although these perceptions can seem realistic for parents, over thinking can lead to overprotection of the child which hinders the development of the child. Parents must learn how to set boundaries depending on the ability of the child and the nature of the environment while keeping in mind that children with special needs require practical teaching and guidance instead of verbal teaching alone. In many situations, even in school parents with special needs often find it hard to keep their children in others' hand. This happens even in the relationship of professionals and parents; they are insecure while keeping their child in the hands of therapists, nurses and special educators etc. As a result, even in cases of slight accidents and minor mishaps, parents often tend to blame professionals and educators. Such negative attitude should be avoided as it creates difficulty for professionals to exchange their ideas and findings for the child's development.

Positive Parenting



Positive parenting includes using positive language or words while communicating with the child. Words can be an effective modeling tool for parents with special needs which can further influence their moods and strengthen their cognitive functions. Hence, when dealing with children positive statements should be used frequently.

Table: Negative and Positive statement in parenting

Sl.no	Negative statement	Positive statement
1.	Stop jumping on the bed	Sit on the bed, please.
2.	Stop fighting	I need you to get along now.
3.	Don't be so loud	Use a quiet voice
4.	Don't put that on the floor	Do you want to play with dough (use distraction)
5.	Don't break the line	Wait for your turn.
6.	Calm down, don't be angry	How can I help you?
7.	Stop yelling	Take a deep breath and tell me why you are upset.
8.	Don't throw that	Please hand it here.
9.	Don't run	I need you to walk now.
10.	Don't push	Keep your hands away.

Do's have better impact than don'ts, so positive parenting is to practice do's.

One of the main issues that hinder the development of children with disabilities is the excessive over protection which further hampers the child's overall development. Also, Baumrind theory states that parenting and behaviour of the child is reciprocal, and what is clearly highlighted in the study is that higher levels of support given by the parents to their disabled child influences behavioral and socio economic problems (Hastings, 2002)

WHAT I NEED TO KNOW AS A PARENT OF CHILD WITH SPECIAL NEEDS

The abilities of a child should not be shadowed by their disability. Some children might be bad at math while the same child who is bad at math can excel in reading stories. Likewise some children can be good in arts, dancing, music, sports etc. Knowing the child's abilities and the area where he/she excel can be a useful tool for learning other skills.

Identification of the child's interest

Interest simply means things a child prefers/likes to do. Knowing the likes and preferences of your child can be helpful in practicing interest based learning. Interest based learning is teaching your child using activity or things he/she likes. Promoting interest based learning helps learning more enjoyable which further helps in increasing the child's attention and concentration. Also, parents need to encourage their child to discover his/her interest, providing them with enough exposure and stimulation. Parents need to look at innovative ways of discovering what is best for their child.

How to identify a child's interest?

Making a checklist of your child's interest will help you to identify his/her interest. The checklist helps you in knowing your child better. After completing the checklist often parents reply, "I did not know my child like this".

Example of checklist-

Activity	Interest	Not interest
Listening to song		
Looking at pictures		
Colouring		
Going for a walk		

Practicing response teaching

Response teaching is interacting with the child, providing feedback using positive comments and actions. Being positive in our statements and response is very important as it can affect how the child thinks, feels and responds to different situations. If a parent displays negative attitude and behavior, it will reflect on the child resulting in bad mood and rebellious behavior. Response teaching also involves how we introduce the child to new places, things and people. This encourages the child to engage in the activity and helps him/her in learning through imitation. Response teaching should be practiced after identification of the child's interest and letting the child lead in the activity. Steps in practicing response teaching are as follows:

1. Involve your child in activities which he/she find interesting, which offer good opportunity for learning skills your child required.
2. Pay attention to how your child interact and communicate during these activities.

3. Give positive feedback/response when your child communicates so that he/she may continue to give you attention. You can praise your child for their actions and for interacting with you.
4. Instill your child in using more complex/difficult communication. This can be done by asking simple questions and giving new information to your child.

Parents can be effective therapists under the guidance and help of the certified therapist. Planning a flowchart similar to the figure below can be useful strategy in focusing and assessing the child's development.

Physical and psychological health is important among children with special needs like getting proper sleep, making time for physical activity, maintaining diets, establishing inter personal relationship. Monitoring their daily activities in a strict schedule is necessary so that the child will be aware of time. Many children with special needs have a problem in maintaining consistent sleeping routine.

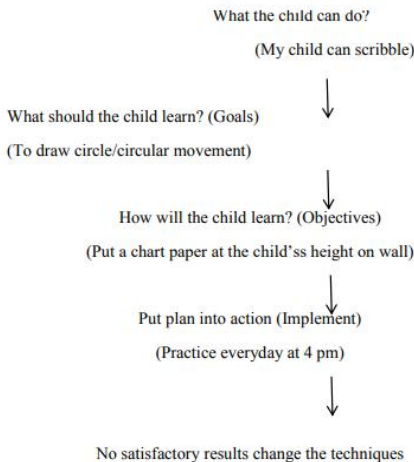


Fig: Process in setting goals for children

Some of the things to follow in maintaining a sleeping routine:

- Going to bed at a regular timing each day
- Make bedroom as restful and quiet environment as possible
- Avoid screen time and other stimulating activities just before bed
- Avoid nap in the day time.
- Do not take caffeine or other stimulants before bed
- Get regular exercise or engage in physical activity daily but not before bed.
- Regular exercise improves fitness and maintains weight, boost the immunity, prevents the child from many diseases
- Getting fresh air and sunshine as it gives vitamin requires for our body
- An exercise can include yoga and breathing exercise which is great benefit for children's health.

Making chart could be of great help for monitoring any learnt behavior

Activity	2.02.20	3.02.20	4.02.20	5.02.20
Going to bed at regular time				

Most children with special needs often go for a specific food. They are stuck with some particular dish daily, which results in imbalance diet and creates health issues. Also, there are some dish which should not be taken in large quantities depending on the condition of the child. Example: Intake of food rich in protein should be less with ADHD and some children with hyperactive.

- Replacing food with fun

Notice the time in a day when your child takes food mindlessly even when they are not hungry. During those times, engaging the child in his/her interest makes him/her forget about food and eat in the right time. This helps them in making a healthy routine in the timings for eating.

- Choosing a healthier diet

Knowing it is hard to change diet for children who choose a particular item for their daily meal and snacks. Many children with disabilities have difficulty in maintaining a healthy diet; a good solution is choosing food which has low calories. At the end of the day no one wants to stay hungry so even if the child ignores the food there will come a time when he/she takes the food you give. Consistency is an important key for changing any undesirable behavior.

- Restriction and reward

Here the child is restricted from going to the kitchen or other specific places where they store food, and sometimes some specific food are also restricted. After this, reward is given for positive behavior which does not include food.

The different techniques including the technique mentioned above are used and practiced under the guidance of a licensed clinical psychologist.

SUCCESSFUL JOURNEY OF CHILDREN WITH SPECIAL NEEDS

Story 1:

Miles was diagnosed with Down syndrome when he was born. His parents were not having hope that Miles will talk or able to understand like others and did not expect anything further for his development.

They were blank and lost, they did not know where to turn up to and ask for help as they clearly knew all the associated conditions of Down syndrome and that it was not curable. Fortunately, at the age of 6 months their pediatrician told them about Regional Centre a state funded organization which provides support to person with disabilities. The centre introduced them in a program for children under the age of three who have developmental delays. The family was introduced about therapy. After many therapy sessions, Miles was able to eat on his own, play with other kids and interact with his family (ECF, 2020)

Story 2:

Javed Shaikh was diagnosed with multiple disabilities (Cerebral Palsy with little control of his lower limbs, hearing impairment and a squint). After placing a special educator by Sarva Shiksha Abhiyan (SSA) in their locality in Sewri, Southern Mumbai Javed started schooling when he was 14 years. Before schooling he spent his days in front of T.V and bed and could not speak and ate only particular food. After going to school and for therapy for 4 consecutive years, Javed became a new person. He does not like missing school, started mingling with friends, eat and dress on his own, operate mobile phones, can lip read and even says a few words (Yadavar, 2017)

Story 3:

Suresh Reddy was the son of a farmer in Andhra Pradesh. When Suresh was a young boy, he fell from a building and lost his eyesight and had to discontinue his studies. At this time, Suresh found out that the attitude of society towards people like him, he always thought that he should earn, become economically self-reliant. With these realizations, he made up his mind to study again. He shifted school from one place to another as they did not accept blind students in regular schools and no facilities were available. In spite of many admission rejections, poor facilities and examination struggles he finished his post-graduation course in IIM, Kolkata. His strong determination against all obstacles and hardships brought about a change in the attitude and perception of many people around him on how they see people with disability (Disha, 2014).

Besides the above stories highlighted there were many successful stories which can be an instrument for many parents and children with special needs for inspiration and learning. These stories are available in many books, magazines and in internet sites.

Summary

- Capacity building helps the parents of children with special needs in self- awareness, giving them insights regarding their role in care-giving. This include training parents on various aspects such as self help skills training, pre-academic skills training, behavior modification training, training parents on self-esteem enhancement among PwDs, vocational training, documentation of skills by parents, speech-language stimulation, physiotherapy and occupational therapy interventions.
- Capacity building provides an insight of the current situation and development of their child.

- Choosing reliable sources of information should be practiced. One should check the details of the sources; check about the author, license of the website, whether the study/experiment is proved, publishing house etc.
- New information regarding health care should be applied or practiced only after consultation of health professionals.
- Getting support from others like health care professionals, family members, neighbours, school teachers, privileged and opportunities provided by the government and NGO's help in the development of the psychological and physical wellbeing of parents and child with special needs.
- The earlier the interventions, the more effective the treatment and therapy conducted.
- Today there is a paradigm shift from charity model to rights based model which encourage parents to utilize and voice out for their rights.
- Parents who knows the pinch of the shoe can relate and connect to parents of their kind.
- Maintaining a good relationship with other parents of special needs provide new learning, support, a useful tool for venting out stress.
- Participating and organizing different group activity provides insight and self-awareness to many parents having children with special needs
- Positive parenting which includes using appropriate reinforcement, eye contact, teaching with patience is an effective technique used by parents having a child with special needs.
- The ability of a child should not be shadowed by their inability to perform certain things. Everyone is unique, building the strength of a child through identifying his/her interest is of a great help for development.
- Parents with children of special needs should create consistency in maintaining routine for desirable

behavior of their child using different techniques under the guidance of professionals.

- Parents can get inspiration, motivation and learn new things from reading books, magazine, reports, etc. which contains successful stories, report of new information, research and studies related to the child's condition can be of great help in raising the child physically and emotionally.

Reflections

- The chapter is to provide information about the techniques and ideas in raising a child with special needs.
- It reminds the parents on the importance of understanding their children and information on the difficulties they are facing.
- Promoting the psychological and physical wellbeing of the parents by getting support from health professionals and other parents.
- It gives information on the importance of parenting and the effect of positive parenting style.
- It gives parents an insight on how they are raising their child.
- Providing information on exercise/activity to do for the development of children with special needs.

Chapter - 4

Advocacy & Self-advocacy in Parenting

- Cdr. Shrirang N. Bijur
& Purushottam S. Burde

Introduction

There are number of surveys and studies conducted by professionals regarding psychological, economic and social wellbeing of parents of persons with intellectual and developmental disabilities. The study results are on expected lines that these parents are more likely to have bouts of depression¹, more likely to have economic stress because one parent may have to look after the child full time, and more likely to be shunned by the neighborhood resulting in social discrimination. Given the above, most parents do come to term with the reality of their child's disability, adjust their life & routine and face the challenge. In this chapter an attempt has been made to put parents' perspective of types of challenges faced by them. The coping strategies are also spelled out by parents from their own experience and close interaction with other parents.

It is the worry of future uncertainty and responsibility of physical work (as caregiver) that causes life fatigue. And it invariably increases with time, and age of parents. In one of the Regional Parent Meets conducted by Parivaar in January 2020 there was a technical session on the wellbeing of parents with son/ daughter with intellectual and developmental disabilities (PwIDDs). At the end of the session there was a near unanimous view that the biggest worry in life of parents [age 50 years and above] of adult PwIDDs is 'who will look after my son/ daughter after parents are no more? Even parents who lived in joint family were uncertain. This response is totally different

from the worries of parents of mainstream adults where the concern is about job, marriage, grand children etc. The response also symbolizes the dire concern of parents of PwIDDS which goes beyond their life time, with acute uncertainty.

¹A Study on Psychological Well Being among the Parents of Children with Intellectual and Developmental Disabilities

The findings are that most of the parents do not have good psychological well-being due to their multiple responsibilities. To improve their psychological well-being the parents of intellectually challenged children should undergo therapies such as psychotherapy, relaxation and stress management techniques. And it is also applicable to the family members of the intellectually challenged children, referral services can also be given to parents and the family members to lead their life in positive way. Because referral service makes the parents to help their child in a better way.

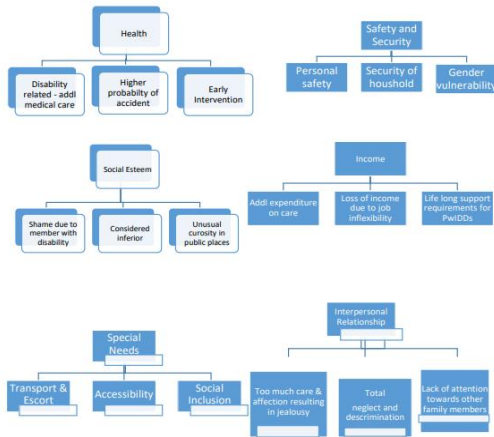
Wellbeing of Parents

A parent is not a parent till a child is born in his/ her family. Now as soon the news of disability of a child is broken to the parent the issues of non- acceptance, self-pity, snide remarks etc. set in the life of parents, specially the mother. This gets further accentuated by mystic and non-professional advice from near and dear ones which adds uncertainty and hope in the minds of parents. All this tends to alter and upset the working equation in the family. Therefore wellbeing of a parent is closely connected with

the wellbeing of the whole family. Such wellbeing of family has many facets. The facets may vary from time to time but generally the major factors that contribute significantly towards the wellbeing are; health, interpersonal relationship, income, safety and security, social interaction and family esteem. Needless to mention that these factors are interwoven and quantum effect of individual component is difficult to gauge.

Why me?

The first question that would come to the mind of parent is generally “why me” or “what did I do to deserve it”. As the day pass and parental instinct starts taking charge the question “There must be a way to cure the child, and what is that?” Over the time the initial desperation settles down and parents start thinking about “Do I know enough about my child’s needs to support his/ her development?” and “How do I keep myself going while helping my child?” and “Will caring for my child’s special needs strain my relationship with my spouse or other family members? Are they receiving enough attention? What will it take to make sure the rest of my family has what they need? During all this time, parents may blame themselves for the loss of that typical child they had dreamed of. Siblings may struggle with understanding why their little sister or brother acts differently and receives so much attention. Parents may feel a sense of guilt/ shame, sensing that some family members are judging their child or judging their parenting. And there are the stares from strangers when children are not behaving “up to expectations” in public places.



Learning to let go

The parents are not in control of their child's development beyond providing loving care and early intervention support. Further what is there in their control is that they can help, encourage, nourish, and pray for the

child. It is well known that all children have their own mind and their own timeline. We need to let go of our pre-supposed ideas of how our children will turn out. It's learning to let go! It often hurts when we realize all the things our child may never be able to do. But, when we finally let go of our preconceived expectations, it allows us to parent our child for *who they are*. One of the parents aptly put it "I used to think Sonu's disability was the issue that needed to be fixed till I realized that what required to be fixed was my 'anger, embarrassment and acceptance' of Sonu for what he is.

"Raised Eyebrows" of Family and Friends

It's amazing how often even well-meaning family and friends become anxious and short-tempered when exposed to a child with even mild special needs. A child with autism doesn't want to play in a group or do social talk, or a child with sensory challenges puts his hands over his ears, and everyone in the room seems to respond with judgmental surprise.

While the child himself may not be aware of the raised eyebrows and exchanged glances, parents certainly are. And while it's difficult to cope with judgments from strangers, it's much harder to let close friends' judgments roll off your back. And that require some heart to heart talk with such friends explaining them the simple technical and social aspects of the

disability and your expectations from them. The earlier it is done the better for parent as well the friends.

Seeking Support

There are also many genuine relatives, friends, volunteers and office colleagues who wish to support your special needs but do not know how to. They may not directly ask you because in their mind, it may not argue well. Many of them think that if they volunteer for your support the parent may think that “She considers me incapable or weak or helpless”. Therefore an initiative by parent, such as putting down the text box (shown) in a notice form, in your home, may be a solution.

SEEKING SUPPORT: How to Help the Parent of a Child with Special Needs	
1.	Offer to be Respite provider. If it's within your comfort and ability zone, give your friend a break by looking after their special needs child for an hour, an evening, or even a weekend. This is called respite care, and it's an extraordinary gift.
2.	Give siblings special attention. Many people with special needs kids have typically developing children who also need attention. These siblings often get overlooked by the relatives and friends out of pre-conceived notion that their disabled sibling may also insist. When you can, consider taking the siblings of a special needs child out for a social event or get together. It's a great way to build a relationship and let them have equal footing in social events.
3.	Be informed. Don't stare blankly at a child with special needs and wonders how to engage with them. Instead, read a book, watch a video, consult parent, or ask questions so that you be a company to the child with disability.
4.	Listen. That is one of the best way to provide solace to parents when things seem getting out of hand. Give company to the parent in the time of crisis (even your mere presence may help – but do not over stretch your presence).
5.	Be supportive and positive. It's all too easy to get into

negative talk when discussing a child with special needs. Instead of spiraling downward, do your best to accentuate the positive. Recount to the parent that they're doing a great job, and point to some of the very real positive outcomes they're almost certainly seeing.

6. **Avoid pity.** While it's sometimes hard to imagine the challenges of special needs parenting, pity doesn't help. In fact, pity can reinforce frustrations and feelings of isolation. Avoid it.
7. **Set an example for inclusion.** Show others how inclusion is done by finding ways to include your friend's special needs child in mainstream by ordinary activities and events. If the child with disability do not understand the happenings around it is still all right. But make the parents comfortable before hand.

Providing Care

All parents learn by experience regarding up-brining of their children. But that is the normal trend when the parent can look and think thru the mind of the child. It is easy when the child is as the parent was in his childhood. Even looking at siblings, friends and relatives of that age provides fair amount of insight about the mind. But when the abilities are different the challenges and struggles are also different. In case of children with intellectual disabilities even the mind (thinking & visualizing) be different. In such case expert or professional advice can help.

Be informed

- Take time to learn about your family member's condition and special needs requirements.
- Talk to therapist/ counselor/ special educator (care givers) and other professionals who work with families

with special needs.

- Understand the needs of you and your family, and work together to make good choices about housing, schools, health services, and more.
- Be aware of signs of emotional or physical abuse. Notice how others care for the person with special needs.

Get support

- Join a local or online (whatsapp, fb, linkdin etc.) group.
- Search for local, state and national groups that provide services, recreation, and information for families with special needs.
- Contact Anganwadi sevika, Serva Shiksha Abhiyan, PHC/ RHC to find out what type of Health care, Early Intervention, Inclusive education, Vocational training govt organizations and NGOs are in the vicinity of your stay.
- Find out about Panchayat, Zila Parishad, local/ state and Govt. of India programs that may be available.
- Parents of adults with intellectual disability can get a job card for their son/ daughter for doing soft work in MG NREGA scheme

Empower your son/ daughter to become a Self-Advocate

- Focus on what you and your son/ daughter with special needs *can* do.
- Recognize appropriate milestones to celebrate. Look for memorable events and achievements to honor your son/ daughter with special needs.

Self-Advocacy Training

- Self-Advocacy Training is a foundational life-skills

course that covers self-awareness, emotional literacy, independent thinking, problem solving, interpersonal relationships, responsibilities as a citizen and self-protection. In a number of countries (such as New Zealand and Canada) the Self-Advocacy movement among persons with developmental disabilities is well established, and those who do such training are called “Self-Advocates”. In some contexts, self-advocates have become mentors; carry out self-advocacy training and make a living out of it.

- Many persons with disabilities spend much of their lives not being listened to, and being told what to do. However, empowerment of persons with developmental disabilities only happens when they realize that they can change their situation, and begin to do so. It is a process that includes building awareness and capacities, leading to greater participation, greater decision making power and taking action for change. Change must start with persons with developmental disabilities shifting their mindset from being a passive receiver of services to an active contributor.
- Once person with developmental disabilities are at a point of leaving the classroom and entering the workforce, they need to advocate for their own needs and preferences, orient to workplace, social relationships, and counter discrimination.

Self-advocacy has now become a priority in India due to changes in the law around guardianship with the RPWD (2016) Act. Guardianship is now legally restricted and requires the active participation of the disabled person (the ward), in “supported decision making”. For this reason, it is now important for parents to advocate to institutionalize self-advocacy training and provide opportunity to special

educators, care givers and parents to become a mentor and further spread Self Advocacy like life skill or personality building training among persons with intellectual disabilities.

Take care of yourself

- Stay healthy for yourself and those you care for.
- Work to maintain your personal interests, hobbies, and friendships. Balance is key.
- Set reasonable expectations about caregiving. This may lower stress and make you a more effective caregiver.
- Take a break. Short or long breaks can be helpful.

Mentoring the Self Advocate

Due to inherent limitation in cognitive ability many Persons with ID do not acquire the capacity to enjoy their rights and entitlements. They need to be mentored to attain such capacity. Such mentoring remains their life time requirement (like braille/ Jaws for blind, and sign language/ hearing aid for hearing impaired). Having such mentorship that enables their social inclusion, decision making (however small), protecting own interest, independent living etc is but an essential assistive system for their life. A mentor coaches Persons with ID in groups to mitigate the effect of intellectual disability by infusing self-advocacy. Such coaching is not one time but is held periodically over the time.

Advocate for your son/ daughter

- Ask questions, and know the entitlements of your son/ daughter.
- Become familiar with Rights of Persons with Disability Act 2016, The National Trust Act 1999 and

important regulations of your state. Know how and when to apply them to your situation.

- Inform other Parents of any special conditions or instructions. Always remind Care givers, Medical staff and Samaj Kalyan Officials of this information each time you visit.
- Document the medical history and care issues of your family member with special needs, and keep this information current.
- Make sure your employer understands your circumstances or limitations. Arrange for flexible scheduling when needed.

What professionals & external care givers need to consider in their interaction with Parents

- Recognizing the parents as a constant in the child's life; caregivers and professionals will come and go
- Facilitate honest collaboration between parent and professionals
- Honoring and respecting family diversity in all dimensions (cultural, spiritual, and socioeconomic)
- Recognizing family strengths and the different approaches that parents may use to cope
- Sharing unbiased and correct information with parents on an ongoing basis
- Encouraging parent -to- parent support and networking
- Acknowledging and incorporating the developmental needs of the child and parents into your practice
- Appreciating and applauding parents who are high achievers and enabling their word in solving challenges – set an example to other parents
- Designing and implementing services that are accessible, culturally, linguistically and economically adaptable by parents. These should be responsive, flexible, and based on Parent/family-identified needs.

An Aware Parent Advocate

Nirav was in trouble for lifting eatables in a railway station stall. Fortunately Raghu, a passer-by parent, realized that Nirav was a person with intellectual disability. Raghu spoke to the stall owner, paid for the eatable and let go Nirav on his way.

As luck would have it Raghu found Nirav again near the railway station after 10 days, while he was returning home after work. The circumstances were grave this time; Nirav along with one more person were being escorted by two police constables to the police station. Raghu again intervened and asked the policemen about Nirav. He was informed that Nirav was caught peddling drugs in the nearby street and was to be booked in the police station. Raghu accompanied the police party and introduced himself to the Station House Officer. He further explained SHO about Nirav's disability by asking some simple questions to Nirav, to show Nirav's cognitive impairment. Raghu suggested to SHO that the best place to rehabilitate Nirav was to send him to a government home, till Nirav's relatives can be located. The SHO took Raghu's advice and completed the due process for his admission in state shelter home for persons with intellectual disability.

Nirav is less verbal and seems to have been abandoned by his relatives on the train. Nirav must have lived in a rural/ semi-rural environment because he has proved to be an excellent hand in gardening and loves to do gardening work. The government home in Mankurd, Mumbai, has a sprawling farm complex so Nirav has plenty to show his talent. He is very well behaved and helpful to others.

2. Advocacy by Parents

The age old axiom "God helps those who help themselves" is most relevant today, especially when empowerment of persons with disability is concerned. When it concerns Persons with intellectual and developmental disabilities it is equally applicable to the parents because majority of them (PwDs) are unable to articulate their needs and requirements due to inherent cognitive limitations and years of feeling of powerlessness that they undergo. Therefore the parents are duty bound to advocate for their PwD (children). Equally important for parents is to

transform their son/ daughter into a Self-advocate, to be able to derive purposeful benefits from the provisions and schemes and live a socially inclusive life.

Documents for Person with intellectual & Developmental Disabilities to avail Govt Schemes

- A - Adhaar card with address and linked to a mobile
- B - Birth certificate
- C - Cast certificate, if applicable
- D - Disability UDID certificate
- E - Economic status [PAN card, IT return]
- F - Funds [Bank account]
- G - Guardianship certificate [if adult]
- H - Health Insurance card [Niramaya]

Empowering Parents

Parents will be empowered when they have a voice. The voice of parents has to be a collective voice, backed with collective wisdom arising out of collective necessities. This has led to formation of Parents' organizations. These enterprising parents have set up facilities in many cities and towns to fulfill the gap (in special needs) of their children. These include Early Intervention & Respite centers, Special schools, Vocational training centers, Assisted workshops, Training for Open employment and Group homes/ Residential centers. Most of the rehabilitation centres, across the country were initiated by parents in early 1950's till date. The state and central government centres are supplementary and complimentary to the existing NGOs. These are kind of community enterprises by parents who run them with dedication since the need generally arises from their own child. But fulfilling the gaps in life cycle requirements of Persons with intellectual and developmental disabilities is only first part of the above quoted axiom. The second and important part is to usher in necessary awareness and sensitivity in the neighborhood, society, service providing

institutions and at various levels of government. The first and second part together can make the progress of empowerment of Persons with intellectual and developmental disabilities sustainable and benefits reaching the lower economic group of Persons with intellectual and developmental disabilities. Besides the population of Persons with intellectual and developmental disabilities is much scattered in rural areas and therefore requires the on-going government programs to cater for the needs of Persons with intellectual and developmental disabilities in the rural areas.

The requirements of individual parents vary and change according to the age of the child and economic status. There is a strong catalyst in the form of Rights of Persons with Disability (2016) Act, The National Trust Act 1999 and their schemes. In addition there is plenty of helpful literature available with National centers (NIEPID, NIEPMD, NIMHANS), Parivaar – National Confederation of Parents’ Organizations and NGOs working in the sector. This could support parents in terms of:

1. For younger parents: To provide guidance towards overcoming initial shock/ worry, Early Intervention, cautioning against myths/ dubious advice. Awareness regarding health and education schemes and concessions, making right choice. Getting the required certificates for the child.
2. For Senior parents: Creating awareness about education, skill building, employment schemes that can benefit their son/ daughter. Encouraging formation of parent group, parent association, parental self help groups to share experience and setting up facilities.
3. Facilitation of correct and complete documentation required by Persons with intellectual and developmental disabilities to become entitled for the schemes and provisions of the government.
4. For parent groups: Options for setting up schools/ workshop/ group homes etc. and to make them economically and socially sustainable. Capacity building of parent leaders, sharing best

- practices among the organizations, generating funds and motivating volunteers.
5. Receiving necessary facilities for inclusive education, social inclusion, home stability (avoiding transfer of residence), social support and provisions related to legal capacity.
 6. With Government: Coordinating and bring up the voice of Self Advocates and parents to the government for formulating requisite laws, rules & regulations, policies, schemes and feedback on implementation. Grass root effectiveness.
 7. Ensuring that parents are Aware Parent Advocates. In each of above function the Rights of Persons with Disability Act lays down entitlements of Persons with intellectual and developmental disabilities which if implemented can give big boost to the efforts of Parent Organizations. But laws remain in the book if the beneficiaries are not aware of it. Here comes the role of awareness and advocacy to be undertaken by parents of Persons with intellectual and developmental disabilities.

What is Advocacy? There is a general lack of awareness about rights and empowerment of persons with disabilities. The lack of awareness, many times, results in insensitive behavior towards the Persons with intellectual and developmental disabilities. This remains a major impediment to the inclusive development of Persons with intellectual and developmental disabilities. Advocacy basically is a step to build a common awareness among different stakeholders about how to empower and achieve inclusion for Persons with intellectual and developmental disabilities. In addressing the needs for people with intellectual and developmental disabilities, advocacy is particularly important because there is little awareness, knowledge and skills about this population among the community, service providers and decision makers. Therefore one of the key components of advocacy strategy is making sure that decision makers have the right information, data and grass root facts for making well informed decisions and schemes. The endeavor is to make people with intellectual and developmental disabilities get counted by community and decision makers, while planning schemes and services for the

mainstream community/ citizens.

For effective advocacy there has to be a group of likeminded parents with a clear vision and objectives and fire in the belly to empower their children with intellectual and developmental disabilities.

Vision

To empower, secure rights and improve the quality of life of persons with intellectual and developmental disabilities and their families in the country.

³SUPER MOTHERS

Way back in 1970s when people kept their children with intellectual disability behind closed doors, few brave mothers got together and worked tirelessly to create awareness in the society about mental disability. Thus in 1974, AWMH (Association For Welfare Of Mentally Handicapped) came into existence.

As the children became adults and could no longer be accommodated in special schools, these mothers planned Sheltered Workshops. Here the persons with intellectual disabilities worked with support & guidance during the weekdays. Going to work with a bag just like other adult family members, gives them feeling of importance and satisfaction!

What about some relaxation with friends to unwind themselves on weekends? Mothers found a way out and in 1994 came up with RAC- Recreation Activities Centre!

It's only the untiring efforts of these visionary ladies that the sapling planted as an advocacy unit has grown into a large banyan tree, branching into 5 Early intervention centers, RAC center, Sports wing that regularly coach students with intellectual and developmental disabilities and conducts state level tournaments for special schools. The list of activities is still growing!!

The coordinator of RAC center aptly put it "I strongly believe that all these institutions share one common foundation - A mother's love for her child and determination to make most from his ability! Such a mother recognizes that her child- whether four years old or forty- will always view the world in a special way. For her, the child's intellectual disability is not a limitation but an opportunity for her. This she accepts cheerfully to find ways to encourage her child to reach his/her full potential."

These women are perfectly described in the article, 'The Special Mother' by Erma Bombeck. My favorite lines, where God tells an Angel why He chose this woman for the child:

"I will permit her to see clearly the things I see...ignorance, cruelty, prejudice... and allow her to rise above them. She will never be alone. I will be by her side

every minute of every day of her life because she is doing My work as surely as if she is here by my side” “And what about her Patron Saint?” asks the Angel, his pen poised in mid air.

God smiled, “A mirror will suffice.”

My salutations to such Special, Super Mothers!

- By Suman Kodial

Main Objectives

To lobby, plan and execute advocacy strategies for:

- Creating awareness among the parents about empowering persons with intellectual and developmental disabilities and the families.
- Support building of parent network across India for advocacy, and supporting each other.
- Building Self Advocates Forum across the country
- Forming partnership among various stakeholders; Parents, Civil society, Cross-disability organizations
- Gaining access to policy planning and implementation mechanism of governments at National, State and local levels
- Advocating for equity, opportunities, social justice and human rights of Persons with intellectual and developmental disabilities
- Sensitizing the public, government officials, community leaders and service providers towards the rights of Persons with intellectual and developmental disabilities.

Key components

- i. Get together to form parents’ organizations and nurture the volunteer and their capabilities towards advocating rights of Persons with intellectual and developmental disabilities in the community as well as at local government.
- ii. Create awareness among the parents about the means to empower their son/ daughter and utilization of schemes and benefits offered by the governments at different levels.

- iii. Training and capacity building of parents' organizations
- iv. Assist parents in setting up Self Help Groups for vocational training/ skill building and providing occupation and employment to Persons with intellectual and developmental disabilities (PwIDDs)
- v. Enable Persons with intellectual and developmental disabilities to train as Self Advocates to assert themselves as responsible citizen with equal rights.

Parents' Responsibility

The first step towards advocacy undertaken by Parents for their son/ daughter is to participate in surveys (by enumerators or on-line) undertaken by different governments (central, state, local bodies and Civil society) and spell out their special needs. The survey needs to be answered faithfully. This would ensure greater availability of information for policy makers and program decision makers; improved access to information for people with disabilities themselves, their carers and families and finally; improved self-efficacy and life skills for people with disabilities and their parents.

3. Empowering adult sons/ daughters (wards) as Self-advocates

Until now, parents have been their son or daughter's (PwIDDs) best advocate - protecting them from harsh realities of life. But the earlier parents empowered their wards to advocate for themselves. The more social inclusion, opportunities and independence they will attain in their life. In other words PwIDDs must be equipped to become self-confident, articulate their needs in whichever way/form, and generally get over the powerlessness that they had been subjected in the past.

It is imperative to understand the meaning of terms "Powerlessness" and "Empowerment" in context to Persons with Intellectual and Developmental Disabilities.

Powerlessness

The persons with Intellectual Disabilities have negative attitudes towards themselves. They think that any action by them would not make any impact or influence the community or organization or even parents. This is because they are not taken seriously; they are devalued, marginalized, neglected, isolated & segregated. They are seen as incapable and not having their own opinion, desire & wish. They are left out of decision making process and not allowed to decide how they should live their lives. They are perceived as dependent on others so they are not provided necessary services. This attitude of society in general makes them powerless.

Empowerment

This is an interactive process through which persons with Intellectual and Developmental Disabilities experience personal and social change and learn to take care of their requirements and achieve influence over the community and organization and even parents. They need to be provided information about themselves and the environment. This can be done by giving them exposure, freedom and bringing them into mainstream. Empowerment means giving PwIDDs power to make decision. Empowerment is a lifelong process.

What is Self Advocacy?

Self-Advocacy is about independent groups of people with intellectual and developmental disabilities working together for justice by helping each other, take charge of their lives and resist discrimination. It teaches them how to make decisions and choices that affect their lives so that they are more independent. It teaches them about their rights, but along with learning about their rights they also learn about their responsibilities. The way

they learn about advocating for themselves is by supporting each other and helping each other to gain confidence to speak out for what they believe in. As a verb, self-advocacy is about advocating or pleading for self. As a noun, it generally describes the grassroots, civil rights movement of self-advocacy including its associations and groups.

There are five parts to becoming an effective self-advocate: These are 1) Understanding own strength and weakness, 2) Knowing own needs 3) Identifying personal goals, 4) Knowing rights & responsibilities and 5) Communicating to get what one needs.

These are applicable for persons with intellectual and developmental disabilities with entire range of functioning levels. To elaborate these parts it is appropriate to say that Self Advocacy is – PwIDD speaking-up for oneself and things that are important to them, speaking for those who cannot speak, asking for what they need, expressing their thoughts & feelings, speaking for rights, fulfilling responsibilities, doing their own thing, helping each other in the group, being presentable, understanding appropriate and inappropriate, taking control of own lives, protecting self from danger, being able to take life decisions without influence or control by others, being able to develop and carry out a plan, sharing problems, being part of a support group, being part of the real world, knowing the life skills like practical life skill, social skill, academic skills, vocational skill, skills for employment, and above all getting rid of words like, ‘Mentally Retarded’, ‘Crippled’, ‘Handicapped’ etc.’. This does not mean that the Self Advocates need to have all the skills; at the same time Self Advocacy is not limited to above skills and aspects of life. Self Advocacy includes innumerable skills and aspect of life. Asking for support is also self advocacy. Every individual living under the sun needs support. Its degree of support may vary, quantum of support may vary or its methodology may be different. Self-Advocate too needs help and support. Rather asking for support is the right of Self Advocate.

What is not self advocacy?

Self Advocacy does not mean getting everything one want, revolt against family, society or Government, being uncooperative, being slang being awkward, being bad-tempered or being rebellious

Why is Self Advocacy important?

It is important for PwIDDs to learn self-advocacy skills because it helps them decide what they want and what is possible for them to expect. When they have good self-advocacy skills they can have more control and make the life decisions that are best for them. Self-advocacy helps to empower PwIDDs, to speak-up for themselves and make decisions about their life.

Importance of Self Advocacy in context of RPwD Act, 2016

Disability movement has been through different models viz. traditional model, medical or charity model, social model and human rights model. It is in this human rights model that Persons with intellectual and developmental disabilities started to struggle for their rights. It is recognised that they have the rights to be included in school, college, job, etc.

With enactment of RPwD Act, 2016 Persons with Disabilities are empowered with legal capacity - means they have right to enter into any contract and own and inherit the property and control their financial affairs. Another aspect is Limited Guardianship - means mutual understanding between the guardian and Person with intellectual and developmental disabilities which is limited for specific decision and operates in accordance with the will of Person with disabilities. The Persons with disabilities may modify any support arrangement and seek the support of another. In this context Self Advocacy has paramount importance in the lives of persons with ID.

Myths v/s Facts about self advocacy

- Myth – The first and foremost myth about self advocacy is that “standing in court & pleading/arguing or fighting against something or someone”.
- Fact -- Self Advocacy for PwIDDs covers wide range of aspects of life including taking small decisions like what to eat, what to wear.
- Myth – Another myth about self advocacy is that self advocacy is an event for short period like duration of program and event.
- Fact – In reality self advocacy is a continuous process to be followed on day to day basis and lifelong.
- Myth – Many parents and professionals think that self advocacy is for PwIDDs who can speak and communicate.
- Fact – In fact self advocacy is for all including those who can't speak. All people, even those with severe intellectual disabilities, can communicate and express themselves as there are many other modes of communication like sign language, body language, facial expression, eye contact, writing and other Augmentative and Alternative Communication Systems like Picture Exchange Communication System.
- Myth – Parents often think that self advocacy is only for High Functioning PwIDDs.
- Fact – Self Advocacy is for Low Functioning PwIDDs also as needs or expectations of low functioning PwIDDs may be limited to his capacity.
- Myth – Many parents think that PwIDDs don't understand their needs.
- Facts – It is nature's gift to every individual to understand his/her needs. Every individuals understand their own needs better than anyone else.

4 Self-Advocacy Pioneer becomes a member of UN Committee

Robert Martin, one of the founding members of the self-advocacy movement for people with intellectual disabilities in New Zealand and Life Member of People First New Zealand, has become the first person with an intellectual disability to be elected to serve on the United Nation's committee responsible for monitoring the UN Convention on the Rights of Persons with Disabilities. This election makes Robert the first person with an intellectual disability to have a seat on any UN Committee in history. Robert was among nine new members elected to the committee June 14th, 2016 at the 9th Conference of State Parties at the United Nations headquarters in New York City. He will serve a three-year term. The Committee is the body of independent experts that monitors implementation of the UN Convention's goals.

Robert is a leader in New Zealand's disability community and is a professional evaluator of disability support services, funded by the NZ government. A biography of Robert, *Becoming a Person*, recounts he suffered physical, emotional and sexual abuse during a childhood spent in large institutions and foster homes. He now lives in his own home in a small town in New Zealand with his wife Lynda and has become an advocate for the right of people with disabilities to live independently.

*This is a true example of the UN principle "Nothing about you, without you".

- Myth - Generally people without IDD think that PwIDDs don't have decision making capacity.
Fact - Nature has given every individual including PwIDD decision making capacity.
- Myth - Professional are of the opinion that self advocacy is only for adults.
Fact - Self advocacy is for all age groups. It has been observed that children as young as 10 year old with IDD have been much benefitted when they undertake training in self advocacy. Many opined that self-advocacy should be practiced in school at very primary stage.

Mentoring Who is mentor?

Mentor is someone who believes in the cause, supports mentee in struggle, engages minds of mentee, facilitates thinking of his/her mentee and inspires & empowers the mentee. Mentor is a friend, a guide, a motivator, a person who has patience, an excellent listener, a connector, a trusted & reliable advisor.

A mentor is someone who provides support through listening and offering information about community and local supports systems or resources. Mentor delivers an important service by modelling a positive attitude toward their mentees by demonstrating through example that it is possible to live a happy and productive life. They also provide emotional support by sharing a common experience so that PwIDDs know that they are not alone and understand that their feelings are natural.

Summarising - A Mentor is a supportive individual who voluntarily accepts the personal and professional responsibilities to guide the self advocate, using his/her knowledge, communication skills and patience to enable the Self Advocates to move on to higher levels of functioning in their lives on day to day basis.

Who can become mentor?

Mentoring is not a rocket science. Mentoring doesn't need high intelligence. But it needs a Big Heart. Mentors are necessarily volunteers from the community who wish to support PwIDDs towards their empowerment. Prospective mentor should be able to read and write at least one of the languages known to mentee. Potentially there are three types of volunteers who opt to be a mentor.

1. Volunteers not connected with disability sector or PwD: These potential mentors may not be much aware about the type and extent of discrimination, deprivation and denials faced by PwIDs. They are required to understand about the rights of PwIDDs and how their empowerment can takes place. Such volunteers must know about level of cognition, learning process, associated behavioural disturbance and also strengths PwIDDs possess.

1.Parent volunteers: The first mentor of any individual is his/her parents. Parents know strengths and weaknesses of their ward. But most parents treat their PwIDD wards like a child and over protect them and provide extra care and above all extra love. These create barrier in the development of their wards. It may be best to choose parent volunteers having neuro typical children, but having knowledge about child development and having qualities like commitment, dedication, being impartial, etc. So parents must unlearn such practices that limit the personality building of individual.

2.Professional volunteers: To-date most of the professionals in the sector are not fully conversant with concept of empowerment of PwIDDs. The classical way of teaching in special schools or behaviour management in schools, workshops and group homes leaves much to be unlearned and learn. Professionals who undergo Mentor training are much better mentors and professionals.

What is the role of mentor as mentor, not as teacher or parent?

Mentor should be confident that Self Advocates have an inherent desire and ability to progress, and trust that they know what to do and how to go about whatever they wish to do. The role of mentor is to unearth the latent potentials in PwIDDs, aid them in making life decisions, assist in trouble shooting personal and social barriers, and introduce them to new opportunities that provide extended support. Mentor should enhance knowledge and understanding of self-advocates about the opportunities available in community and guide them in handling of specific situation and should let Self Advocates take the final decision.

Mentoring is not teaching and coaching, not telling them what to do, not telling them how to do, not doing things for them. Mentoring is not about providing them everything that they want. Mentoring is not about sympathy.

“Mentoring is a win approach for everyone.” Mentoring is more of an attitudinal change in self as well as in self advocates.

Mentors play the role of “ROLE MODEL” to their mentee.

With a mentor by his side, PwIDDs have the opportunity to have a listening ear allowing PwIDDs to express honest emotions. It is important that mentors listen with acceptance, remain open-minded and non-judgmental.

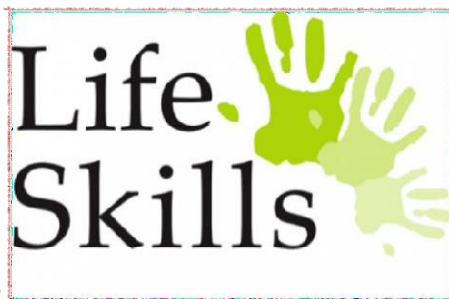
Mentors offer encouragement, emotional support, and information. They guide PwIDDs in learning how to make informed consent, responsible choices by providing direction and guidance as needed while allowing them to make his/her own decisions. Mentors are also sensitive to the feelings and privacy of PwIDDs. Mentors keep the conversation focused on feelings and perception of the situation.

Qualities of good and successful Mentor

Mentor must believe in self advocacy movement. Mentor should view all people as valuable regardless of their (dis)abilities. Mentor must have the leadership qualities, trustworthiness, good rapport in community, interest of others at heart, good at encouraging others, be able to energize through enthusiasm, be non-judgmental. Mentor should maintain confidentiality, should have deep commitment to fostering self-sufficiency, should respect for the mentee's right to make his/her own decisions, should sharpen their leadership skills in the mentoring process, maintains mutual respect and should be impartial. Mentor should not have intimidating nature, should not jump to the conclusion and should possess a positive and ‘can-do’ attitude. Mentor should be prepared all the time, be honest with diplomacy, has inquisitiveness and should not have any hidden agenda. Mentor should be compassionate and genuine. He/she should listen well and with an open mind and above all should be satisfied with his own life.

Importance of Life skills⁵

Self advocacy is not limited to aspect mentioned above. Understanding and learning life skills for PwIDDs is very essential. The term '*Life Skills*'



refers to the skills one needs to skill that is useful in life can be considered a life skill. Life skills are usually associated with managing and living a better quality of life. These help PwIDDs to accomplish their ambitions and live to their full potential. The other term "*Living Skills*" refers to wide range of skills like food preparation, eating nutritious food, personal hygiene, dressing & clothing, health care, home management like housekeeping, helping at home, safety and security, medication management, financial management and community access. These living skills are the part of life skills as PwIDs need to perform on a regular basis. These skills make them a contributing member of the family.

There is no definitive list of life skills. However certain skills are relevant to PwIDDs. The Ten core Life Skills as laid down by WHO are explained as follows:

1. Self-awareness: Self-awareness includes recognition of "self", own character, own strengths and weaknesses, likes and dislikes. It is often a prerequisite to effective communication and interpersonal relations, as well as for developing empathy with others. Self awareness is the capacity for introspection and the ability to recognize oneself as an individual. Self awareness is the first step in creating what one wants and mastering own life.



Activity to learn self awareness: Self advocates sit in circle and play game of passing the parcel. On his/ her turn each self advocate introduces himself, what he/she likes and does not like, how he/she helps at home, how he/she greets the guest, how he/she maintains safe distance with strangers.

2. Interpersonal relationship: This means being able to make and keep friendly relationships. A close association between individuals who share common interests and goals is called interpersonal relationship.

Interpersonal relationship is the ability to build rapport with individuals having similar interests and goals. Through friendships and peer relationships, one receives (and gives) support. People who have supportive and lasting relationships



tend to feel more connected to their communities and have people available to assist them when challenges eventually arise. To live a truly self-determined life, PwIDDs should have a circle of friends and supportive people who care about them and are available to exchange needed supports.

Activity to learn interpersonal relationship: self advocates randomly stand in circle and move in circle with the music. When music stops each self advocates introduce himself to self advocates next to him/her, shake hands, etc.

3. Empathy: To have a successful relationship with loved ones and society at large, one needs to understand and care about other peoples' needs, desires and feelings. Empathy is the ability to imagine what life is like for another person. Without empathy, communication with others will amount to one-way traffic. Every individual grows up in relationships with many people – parents, brothers and sisters, cousins, uncles and aunts,

classmates, friends and neighbors. When one understands others, he/she is better prepared to communicate his/her needs and desires. At the same time, he/she will be able to elicit support from others.

This activity is demonstrated by trainers by playing drama. One trainer is sad because of some trouble, other trainer inquires with him and try to understand the cause of trouble, why he is sad and try console him. The drama is played by self advocates as role play.

4.Critical thinking: Critical thinking is that mode of thinking about any subject, content, or problem in which the thinker improves the quality of his/her thinking by skillfully analyzing and assessing it. It is self-directed, self-disciplined, self-



monitored, and self-corrective thinking. It is the art of taking charge of own mind. If one can take charge of own mind, he/she can take charge of own lives.

Activity to learn critical thinking: this activity is demonstrated by trainers by role play. Mentor lost in the market/station. Trainer defines the problem, identifies various available options like making telephone calls to family, availing private transport etc. and choses the one which is most viable to reach home. This drama is played by self advocates with different situations.

5.Creative thinking: Means looking at something in a different and new way. Creativity in a sense involves what is called lateral thinking or the ability to perceive patterns that are not obvious. Creative thinking is a novel way of seeing or doing things that is characteristic of four components - 1. Generating new ideas, 2. Flexibility - shifting perspective easily, 3. Originality - conceiving of something new and 4. Elaboration - building on new ideas.

Each group of self advocates and mentors are provided with loads of old newspapers, scissor, cello tapes, adhesive and ask to make objects of their choice. They make various objects like bridge, temple, mosque, church, caps, hats, shirts, etc.

6.Decision making: Is the ability to consider possible solutions and select the one best suited to one's individual needs, while considering how the decision affects oneself and others. Decision making helps PwIDDs carefully weigh all



possible options in order to reach a desired outcome. It also provides a base for problem solving, goal setting, and self-management. Here, decision making is focused on decisions having an impact on one's life and future.

While forming groups a bowl containing beads of different colors is passed around self advocates. Each self advocate picks up one color bead of his choice. This way they learn to choose and take decision on their own.

7.Effective communication:

Communication is a critical component of everyone's lives. Everybody has needs, wants, and feelings, and he/she needs a way to express these to others. Communication is a two way process, so communication involves both how



we send and receive messages. Listening to others, empathizing and encouraging are few components of effective communication. Recent technological developments have led to many strategies for enhancing the communication of PwIDDs. By learning effective communication PwIDDs may be better able to practice self-expression and participate more readily in activities that foster self advocacy.

Self advocate in the group chooses picture or object of his choice from the lot. He/she tells the importance and use of the same.

8. Listening skill: Listening skill is key to receiving messages effectively. It is a combination of hearing what another person says and psychological involvement with the person who is talking. Listening requires a desire to

understand others, an attitude of respect and acceptance, and a willingness to open one's mind to try and see things from another's point of view. It requires a high level of concentration and energy.



During the training of self advocates a group of self advocates and mentors play musical chair. Players are asked not to sit once the music stops but stand in front of the chairs and wait for instruction like, "sit with an empty water bottle or old newspaper". Players look around for empty water bottles/old newspaper placed around, pick up the same and sit, one who is late to find the bottle/newspaper is out of the game. In this activity self advocates can improve their listening skill.

9. Problem Solving: Is a process of working through details of a problem to reach a solution. Problems are the barriers that prevent the achievement of goals. Problem solving involves working through numbers of steps. One has to explore possible avenues to a solution one by one which comes across. Here are steps for an effective problem solving process: 1. Identify the issues, 2. Understand everyone's interests, 3. List the possible solutions/options, 4. Evaluate the options, 5. Select an option, and 6. Agree on contingencies, monitoring, and evaluation.



To develop problem solving skills following activity is conducted during training of self advocates. Groups of 5-7 self advocates are formed. Pictures of various situations like fire in the house, drowning boy asking for help, car accident, thief enters in the house, etc. are kept on the floor. Each group picks up one picture of its choice. Each group discusses the situation for 5/10 min. and explain show they have solved the problem.

10.Coping with emotion/managing emotion: Emotion is often defined as a complex state of feeling that results in physical and psychological changes that influence thought and behaviour. Everybody has emotions. The ability to realize, accept, and control feelings in oneself is known as the emotion management skill. Emotion management is the ability to master own emotions.



Mentors role play and explain how to cope up with emotion. One mentor falls down and gets hurt. On this other mentor laughs. The mentor who gets hurt is sad. Trainer explains that this kind of incident may happen with anybody including the one who laughs. Therefore we should control emotion and be kind to others, be open and accept what is going around because this stops us worrying about us. Huge numbers of activities are available in order to make self advocates aware about life skills and living skills. During a single activity self advocates can be made aware about multiple life skills and living skills.

The life of a person with intellectual and developmental disabilities will be transformed after he/ she becomes a self-advocate. This would bring about the social inclusion which is so much necessary for rehabilitation and living a life with dignity, and independence to his maximum potential. The resultant effect on the life of parents will be as much remarkable as of the self advocate.

Summary

1. The parents of a person with intellectual and developmental disabilities have to undergo stress and physical exertion which may have a telling effect on their well-being. Since the wellbeing of parent is intrinsically linked to the wellbeing of his/ her child therefore it is critical that parent pays attention to remain physically and mentally strong.
2. The initial trauma and subsequent stress of parents will be much better managed by communicating with fellow/ senior parents. Such parents must provide balanced information.
3. Parents should not hesitate to accept support from relatives, friends and volunteers as long as it is well meaning and complies with their requirement.
4. A strong parent network will enable parents to share their concerns, and exchange information useful for each other.
5. The parent network should eventually result in Parent organization. The parent organizations can advocate for provision of necessary facilities and satisfying the life cycle needs of their children by local government.
6. The parent organizations should also advocate to bring awareness about the rights of persons with disabilities in the society for effective social inclusion of their children.
7. The parent organization can advocate to bring awareness among the policy makers. The parent organizations should ensure that its members provide correct and reliable information during data collection and census so that creditable information is available to policy makers for making required policies.
8. Parents should also encourage their son/ daughter to train as Self advocate. This will empower them to participate in social activities and attain independence to their maximum potential.
9. A self advocate is coached by mentor – parent and enables social inclusion and living life with a purpose and dignity.

10. Parents can train as mentor to add value to their efforts to make their son/ daughter independent and socially inclusive, as much possible.
11. There are many success stories of self-advocates transforming their life by honing their life skills.
12. A positive attitude and self-advocacy training of person with intellectual and developmental disabilities can add to the well-being of son/ daughter, family and parents.

Chapter - 5. Resilience Building

- *Srigowri Rajesh*

Taking care of child with disability is often a stressful experience to the parents. Although, this is the fact, that the many families are able to adapt, cope better and even thrive in such situations. So what makes some individuals respond to such situations in a more positive manner?

Understanding Resilience Ability to bounce back

Resilience is the term used and described in various ways. However, there seems to be some commonality existing among the various definitions of resilience. They describe resilience as surfacing in the face of hardship or adversity and demonstrating the ability to “bounce back”, that is, to regain or surpass pre-adversity levels of functioning.

Resilience can be understood as a quality of living organism that helps to them to recover from destructive forces such as encountering trauma, injury, or stress. It is a healing process through which the individual usually regains some measure of former “health” (Corcoran & Nichols- Casebolt, 2004)

Resilience can also be defined as the process of adapting well in the face of trauma or tragedy, threats or significant sources of stress. It’s about how you handle negative feelings and move forward in a healthy, positive manner (Southwick et al., 2014)

The concept of resilience is a complex one. In reality, resilience is more likely to exist on a continuum that may present itself in differing degrees across multiple domains of life. (Southwick et al., 2014)

Moreover, there is increasing interest among researchers in understanding the importance of focusing on evaluating and teaching methods to enhance resilience rather than focusing on or examining the negative consequences of trauma or stress. This signifies a move away from deficit based model of mental health towards inclusion of strength and competency based models. This allows greater focus on prevention and building strengths apart from addressing to other mental health issues.(Southwick et al, 2014)

In short, developing skills of resilience can help to face challenges and difficulties in life which can help feel better and cope better. i.e resilience helps handle stress more positively . Life is not always easy to go but at the same time it is not always hard to stay. It's natural to have a tendency to try and control things. There are things you can control in life but there are also things you cannot.

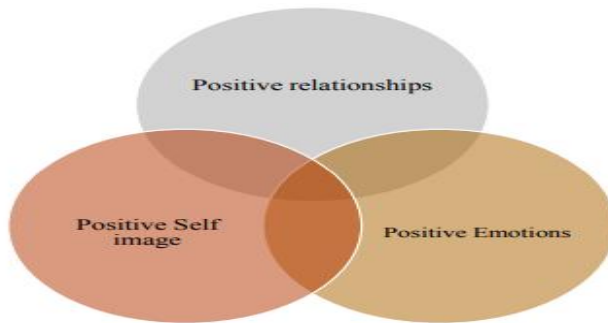
Developing resilience is a very personal process. Each of us reacts differently to stress and to trauma. Some people bounce back quickly while others tend to take longer. There is no magic formula. What works well for one person may not necessarily work for another, which is one of the biggest reasons to learn multiple techniques for enhancing resilience.

What is not resilience?

While certain factors might make some individuals more resilient than others,

- Resilience is not necessarily a personality trait that only some people possess. On the contrary,

resilience involves behaviors, thoughts and actions that anyone can learn and develop



- The ability to learn resilience is one reason research has shown that resilience is ordinary, not extraordinary.

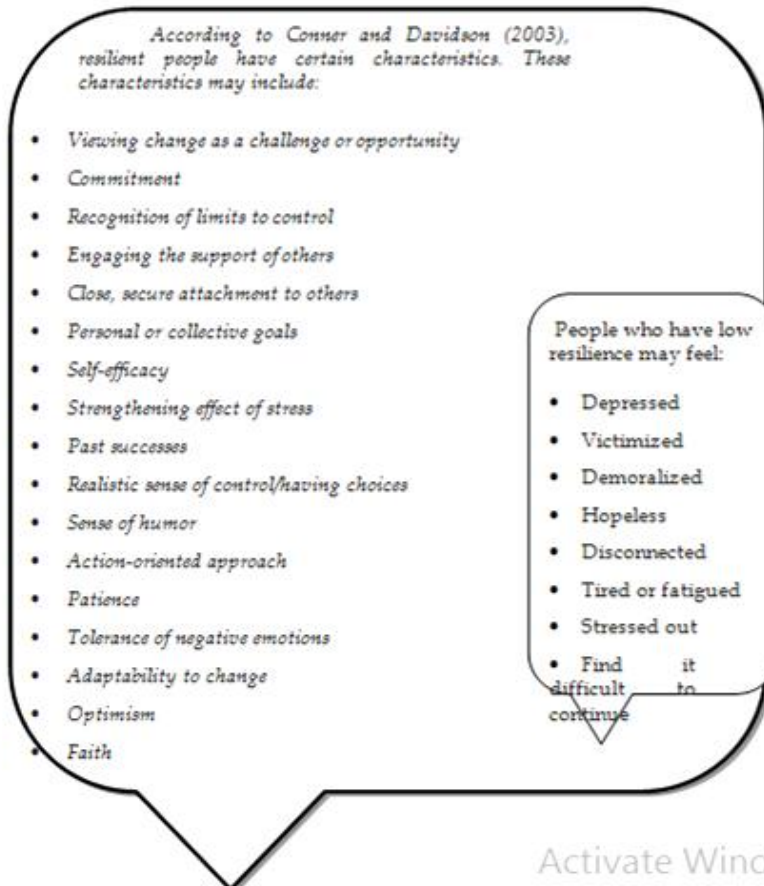
What contributes to Resilience?

□ Positive Relationships: To have a supportive family & friends and community resources, willingness to reach out and accept help from others is important for enhancing positive relationships

□ Self Image: Optimistic view of oneself and life and positive resilience is also associated with the experience of autonomy, mastery, and vitality (Shing, 2016). This can help you be more effective at managing challenging tasks and help you live life with more energy and enthusiasm.

□ Positive Emotions: positive emotions help you build up social, psychological, and physical resources over time, which could help you develop coping skills during future times of stress.

Qualities of resilient people



Different Types of Resilience

According to Genie Joseph, M.A. adjunct professor at Chaminade University in Hawaii, and the creator of the Act Resilient program, there are three basic types of resilience.

1. Natural Resilience

Natural resilience is that resilience you are born with and the resilience that comes naturally. This is your human

nature and your life force. Those with natural resilience are enthusiastic about life's experiences and they are happy to play, learn and explore. Natural resilience allows you to go forth and do your best even if you get knocked down and taken off track.

2. Adaptive Resilience

This occurs when challenging circumstances force you to learn, change and adapt. Learning how to roll with life's punches can help you build resilience and grow stronger as a result.

3. Restored Resilience

This is also known as learned resilience. You can learn techniques that help build resilience, and, as a result, restore that natural resilience you had as a child. Doing so can help you deal with past, present and future traumas in a healthier fashion.

Stress and trauma tend to lower resilience over time, especially multiple repeated incidents of trauma. Trauma tends to get stuck in the brain leaving you on high alert or fight or flight mode. This can continue to manifest, even if the trauma is no longer present.

Can Resilience be built?

It is important to remember that resilience is something that is developed over time through thoughts, behaviors, and actions. Children with special needs and their families experience greater stress and need help building their resiliency. Like building a muscle, increasing your resilience takes time. To build resilience it is important to focus on four core components – **connection, wellness, healthy thinking and meaning.**

Ways to build resilience

According to American Psychological Association (APA) resilience can be built through following strategies:

□ **Build connections**

□ **Prioritize relationships:** Good relationships with close family members, friends, or others are important. Accepting help and support from those who care about you and will listen to you - strengthens resilience.

□ **Join a group** that could offer you support and a sense of purpose or joy when you need it. Some people find that being active in civic groups, faith-based communities, or other local organizations provides social support and can help reclaim hope.

□ **Foster wellness**

□ **Take care of your body.** Self-care is an important aspect for enhancing for mental health and building resilience. Promoting positive lifestyle factors like proper nutrition, ample sleep, hydration and regular exercise can strengthen your body to adapt to stress and reduce the toll of emotions like anxiety or depression.

□ **Practice mindfulness.** Mindful journaling, yoga, and other spiritual practices like prayer or meditation can also help people build connections and restore hope, which will help them to deal with situations that require resilience.

□ **Avoid negative outlets:** Avoid taking alcohol, drugs or other substances to mask the emotional stress instead focus on giving your body resources to manage stress, rather than seeking to eliminate the feeling of stress altogether.

□ **Find purpose**

□ **Help others.** By helping others you can develop sense of purpose, foster self-worth, connect with other people and tangibly help others, all of which can empower you to grow

in resilience.

□ **Be proactive.** It's helpful to acknowledge and accept your emotions during hard times, but it's also important to help you foster self-discovery by asking yourself, "What can I do about a problem in my life?" If the problems seem too big to tackle, break them down into manageable pieces.

Taking initiative will remind you that you can muster motivation and purpose even during stressful periods of your life, increasing the likelihood that you'll rise up during painful times again.

□ **Move toward your goals.** Develop some realistic goals and do something regularly, even if it seems like a small accomplishment that enables you to move toward the things you want to accomplish. Instead of focusing on tasks that seem unachievable, ask yourself, "What's one thing I know I can accomplish today that helps me move in the direction, I want to go".

□ **Look for opportunities for self-discovery.** People often find that they have grown in some respect as a result of a struggle. For example, after a tragedy or hardship, people have reported better relationships and a greater sense of strength, even while feeling vulnerable. That can increase their sense of self-worth and heighten their appreciation for life.

□ **Embrace healthy thoughts**

□ **Keep things in perspective.** How you think can play a significant part in how you feel and how resilient you are when faced with obstacles. Try to identify areas of irrational thinking, such as a tendency to catastrophize difficulties or assume the world is out to get you, and adopt a more balanced and realistic thinking pattern.

□ **Accept change.** Accept that change is a part of life. Certain goals or ideals may no longer be attainable as a result of adverse situations in your life. Accepting

circumstances that cannot be changed can help you focus on circumstances that you can alter.

□ **Maintain a hopeful outlook.** It's hard to be positive when life isn't going your way. An optimistic outlook empowers you to expect that good things will happen to you. Try visualizing what you want, rather than worrying about what you fear. Along the way, note any subtle ways in which you start to feel better as you deal with difficult situations.

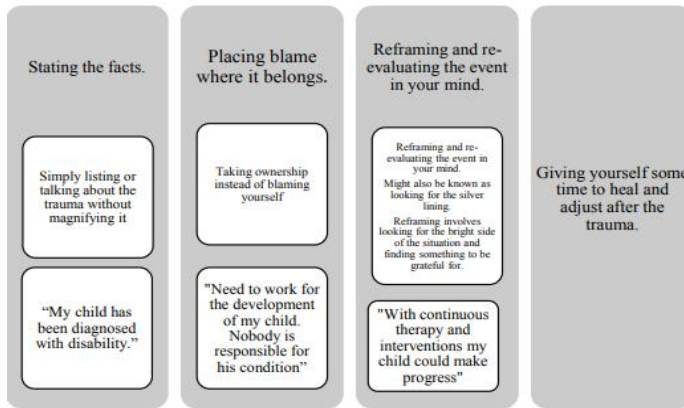
□ **Learn from your past.** By looking back at who or what was helpful in previous times of distress, you may discover how you can respond effectively to new difficult situations. Remind yourself of where you've been able to find strength and ask yourself what you've learned from those experiences.

□ **Seeking help**

□ Getting help when you need it is crucial in building your resilience. For many people, using their own resources and the kinds of strategies listed above may be enough for building their resilience. But at times, an individual might get stuck or have difficulty making progress on the road to resilience. It is important to get professional help if you feel like you are unable to function as well as you would like or perform basic activities of daily living as a result of a traumatic or other stressful life experience.

4-Factor Approach

This approach was created by Deborah Serani, clinical psychologist. The 4-factor approach is a great option for helping people better understand the concept of resilience.



Use of Relaxation Techniques

Benson recommends several techniques that can help elicit the relaxation response, which includes:

1. Deep abdominal breathing.
2. Focusing on a soothing word like *peace* or *calm*.
3. Visualizing a tranquil scene like a beach or a park.
4. Engaging in repetitive prayer.
5. Doing something physical like Yoga

Many people find it hard to manage stress, because stress has become a way of life. A certain amount of stress can serve as a motivating factor, but a little goes a long way.

Your body is well-equipped and even hardwired to handle most types of stressful situations but too much stress can cause you to break down. In a sense, stress is your body's warning system and a signal that something needs to be addressed.

The relaxation response is a simple technique that you can learn that can help you counteract the toxic effects of chronic stress. It slows your breathing rate, relaxes your muscles and can even help reduce your blood pressure.

Chronic stress can take a toll on your mind and body. According to the Harvard Medical School, low-grade chronic stress can even lead to things like high blood pressure, increased muscle tension and an increased heart rate. (According to Harvard Medical School, 2011)

Building Resilience in Families

The birth or diagnosis of a child with a developmental disability represents a major and unique stressor to the family unit. The family as a unit, as well as its individual members, has to deal with feelings of shock, grief, guilt, and uncertainty about the future, as well as having to institute major changes to the family's functioning in order to accommodate the unique needs of the child (Beckman, 1991; Gatford, 2007; Quine & Pahl, 1987; Weisner, Beizer, & Stolze, 1991). This process is strongly influenced by the socio-cultural and developmental context the family finds itself in, since these factors influence the family's perception of disability and the resources it has available to cope with care-giving demands and the resulting emotional and also financial strains (Garwick, Kohrman, Titus, Wolam, & Blum, 1999; Walsh, 2003; Xu, 2007). A lot of research to date has focused on this "negative" impact of disability on the family,

Resilience emphasizes the strengths families employ to overcome adversity rather than focusing on deficits (Hawley, 2000).

What is Family Resilience?

Coping with and overcoming adversity through: 1. Open and effective communication 2. Collaboration and problem solving 3. Development of a shared sense of meaning 4. Effective mobilization of support

➤ **Family Education:**

The families of children with special needs may be prone to risks of family dysfunction due to incomplete understanding of the impact of the stressor, inaccurate developmental expectations, disrupted family communication, strained parenting/co-parenting practices, impaired family organization and lack of guiding belief systems (Saltzman et al, 2012).

Therefore, the family education focuses on the following

- Emphasize the child's unique strengths to the child and family (if applicable)
 - Empower parents
 - Learn more information about the child's unique strengths (especially if working with the family)
 - Help parents use praise
 - There may be a wide variety of reactions from the parents to a diagnosis (e.g., grief/loss, anxiety, relief)
 - Help parents be aware of their own emotional reactions
- **Family Emotional Regulation:** The family member and children with special needs need to develop to appropriately express a wide range of emotions and to be responsive to the emotional needs of others.

- **Learning about Feelings:** Help the families to identify the feeling through feelings -thought connection and feeling -body connection in themselves and others, encourage empathy among family members.
- **Family Problem Solving:** To allow the family to address challenges in an organized, step-by-step manner and to focus more on the process of finding effective solutions.
- **Family Communication:** To allow for one to express their own experiences and preferences while also listening and understanding those of another person.
- **Family Narrative Timeline:(Walsh, 2007)**
 - **Perspective Taking**
Understanding another's point of view, imagining how another person has experienced the same situation.
 - **Meaning Making**
Understanding how the family's experience has helped them to overcome certain challenges and made them stronger in unexpected ways. In other words, how the family is able to "find the silver lining." developing sense of purpose and meaningful bond to others and helping others
 - **Helpful Beliefs**
Enhancing Spirituality& faith among family members through engaging in family rituals such as prayers, meditations & ceremony,
- **Managing Trauma:** Families should learn to recognize their emotional distress and learn to deal effectively.

- **Family Goal Setting:** Allow families to set and achieve appropriate family goals.

Conclusion

Parents of children with special needs go through stress and turmoil while raising the child, apart from dealing with other life challenges. Resilience helps them to develop the competency in handling the stress not only as an individual but also as a family. Building resilience is a complex process and can be achieved by everyone with intense practice of managing & fostering positive emotions and finding meaning in life.

Chapter -6 Psychological Well-Being of Parents

- N. Mangaleshwari Manjari

*'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

INTRODUCTION

Parenthood of children is an awesome responsibility and that too being the parents of children with special needs, gives even more trust. Indeed, it is a life-long adjustment and it would be apt if we mention such a parent as an 'Exceptional Parent'. Our cultural heritage says, "Madha (Mother), Pidha (Father), Guru (Teacher), Deivam (God)" indicating Godly status to parents and they are considered as the first and best teachers. They have a key role in providing early intervention for the infants with special needs.

Each and every parent is molded as a new expert when he/she receives the gift of a child. Unfortunately, the parents of children with special needs feel the situation as 'a curse' or 'a punishment'. They lack the mind to accept the child with special needs. This denial makes the parents to face many psychological problems depending on the type and severity of the child's disability.

Parents of children with various disabilities have multiple problems in their life including physical, psychological and social level compared to the parents of neurotypical children. They are facing lots of negative emotions like stress, anxiety, depression, worry and fear about their future and their child's future which will have adverse effect on the well-being.

The Psychological health or mental health is considered to be the most important dimension of a healthy well-being. It doesn't mean that absence of distress alone might lead to a healthy psychological well-being. Instead, it is a relative state of mind in which the individual who is healthy, is able to cope with and adjust to the recurrent stresses of everyday living in an acceptable way. It is actually about feeling happy and doing well.

People with high psychological well-being would feel capable, well-supported and satisfied with their life. It is attained by achieving a state of balance between both challenging and rewarding life events. It is a subjective term that means different things to different people.

It's been identified that people with higher psychological well-being are more likely to live healthier and longer. They are also more likely to enjoy a better Quality of Life. Earlier, Professionals were focusing only on the immediate requirements of the children and the family in alleviating the problems but now, the demand is on the total rehabilitation which should focus on the extended environment of school, work place and the whole community.



Fig: 1: Picture Source
https://www.rnceus.com/CHF3/pos_constructs.html

EMOTIONAL REACTIONS EXPERIENCED BY PARENTS

In the developmental process, even the neurotypical children exhibit some amount of emotional and behavioural problems. In children with special needs, these issues are multiplied and exhibit in a wider spectrum with more severity as they advance in their chronological age.

The parents are bound to adapt themselves to the pressing needs of challenges in their children. The situation of diagnosis of the child

with a particular disability disturbs the mental health of the parents and they pass through different phases of adapting to their child's difficulties. The various reactions experienced by the parents are as follows (Seligman, 1979, Wright, Granger and Sameroff, 1984).



Fig: 2: Picture Source- <https://www.verywellmind.com/five-stages-of-grief-4175361>

1. **SHOCK:** Parents report feelings of confusion, Psychic numbness, disorganization and helplessness soon after they were told about the condition of the child. This typically lasts from few hours to few days.
2. **DENIAL:** The parents tend to develop a disbelief or denial of the reality. This might be used as a temporary coping mechanism but, if followed for a prolonged duration it might bring in an added damage to the child's improvement. The best proverb which explains this phase is "A stitch in time saves nine" - "Early the intervention; better the prognosis".
3. **ANGER:** Parents put in a lot of struggle to find out the cause of their child's problem. They may blame themselves and feel guilty for giving birth to a special child. The anger might be expressed either inward or outward. The parents would displace their

anger towards the Almighty, their spouse, neighbours, relatives, and the child or onto the professionals involved because of not diagnosing at early stages of the child's life.

4. **SADNESS:** The parents may feel depressed and they start developing symptoms of low mood, decreased interests even in doing their favourite tasks, crying spells, helplessness, hopelessness, etc. There are also parents who start developing thoughts about harming oneself because of the thought that they have lost the 'meaning of their life'.
5. **REORGANIZATION:** This is the bouncing back phase. Here, the parents accept the reality of their life and find new ways to enjoy with their bundle of joy. They start to explore about the possibility of making their child the best individual to his/her maximum level of potential.
6. **ADAPTATION:** This is the phase where the parents of children with special needs take a rebirth in understanding what has to be done for the child in a matured emotional way. They plan for their therapeutic intervention, to teach the life skills and if possible to train them to attain basic academics and put a lot of efforts to make the best out of their life.

The adaptation process is regarded as a normal and healthy reaction for the parents of special children. The duration taken by the parents differ from one another. Few parents would miss certain phase and adapt themselves much better with the reality; whereas, some parents might take longer time to move on and few others might also be fixated to a particular phase. Parents do experience these phases in a different order and manner depending upon the type or severity of the problem.

WAYS TO IMPROVE PSYCHOLOGICAL WELL-BEING

Even though we all go through many difficult times in our life, there is always a chance for us to have a positive outlook by incorporating several ways in which we could feel and function better. Here are some ways for you to improve your psychological well-being.

- ❖ Creating Purpose: Living a meaningful life and understanding its purpose are the key components for improving our mental well-being. To find the purpose of life we have to work on reaching the goals which we fix for ourselves. The goals should always be “SMART” (i.e.):
 - S - Specific, M - Measurable, A - Achievable, R - Realistic and T - Time bound.
- ❖ Positive Thinking: To think positively is a way of life. Optimistic thoughts will improve our mind and body to work in an effective manner.
- ❖ Recall Positive Life Events: Taking time to think about the best memories of our life and recalling the same will bring more positivity within us. It serves as a reminder of the fullness of life, especially when the bad circumstances pull us down.
- ❖ Perform Act of Kindness: Helping others will make you feel great in making a difference in someone’s life. Kindness is considered as a self-reinforcing habit which takes less effort to perform.
- ❖ Gratefulness: Practicing to learn to be grateful will make the individual to enjoy even small things in our life. This in turn brings happiness to oneself and helps us to have a high psychological well-being.
- ❖ Identify your Strength: Feeling capable and confident is important. Identify the things that you are good at and work on them to sustain in your life. Try reflecting the past achievements and the qualities that helped you to succeed. Improving yourself will make you busy with the current situation than worrying about the negative events.
- ❖ Build Relationships: Loneliness is the most serious issue which affects the emotional and physical health. Being connected with people will improve their psychological well-being. It’s actually easier to practice a healthy lifestyle emotionally by habituating ourselves to the above explained domains.

ADAPTATION BY THE PARENTS

The primary task for parents is to enhance their child’s

development. They can help them to gain control over normal developmental milestones and in their activities of daily living. Parents also help in alleviating the fear in children, to teach them about sexuality, and in adjusting with siblings and peers. Each child is unique and the parental adaptation varies because of numerous variables like:

- Unwanted pregnancy of the problem child,
- Birth order of the child,
- Similar problems in other siblings,
- Single parent rearing the special child,
- Non-acceptance of the child among the other family members,
- Lack of social acceptance and support,
- Parental education,
- Financial constraints and other socio economic factors,
- Planning to have another child if the first one is affected,
- Non- identification of the child's problem,
- Inadequate child care resources,
- Chaotic home event,
- Insensitive or unresponsive parenting,
- Low expectations from the child,
- Mental/Physical Illness in parents,
- Low intelligence in parents.

The coping mechanisms have two widely recognized functions:

1. Emotional – Focused coping for regulating stressful emotions. It involves trying to reduce the negative emotional responses associated with stress such as embarrassment, fear, anxiety, depression, excitement and frustration. The individuals tend to

use this type of coping style, only when they feel that the source of stress is outside the person's control. The various emotion-focused coping techniques are:

- Distraction - Keeping themselves busy to avoid thinking about the disturbing issues,
- Emotional disclosure - Expressing one's strong emotions by either talking or writing about the disturbing events,
- Praying,
- Meditation, etc.

Emotion - focused coping does not provide a long term solution and may have negative side effects as it delays the person dealing with the problem. A Meta-analysis revealed emotion- focused strategies are often less effective than using problem - focused methods in relation to health outcomes (Penley, Tomaka, and Weibe, 2012).

2. Problem - Focused coping for changing the situation which is causing distress. It targets the causes of stress in practical ways which aim to remove/ reduce the stressor. The methods used in problem - focused coping are:
 - Problem Solving,
 - Time Management,
 - Obtaining instrumental social support, etc.

Optimistic people who tend to have positive expectations of the future are more likely to use problem - focused strategies, whereas pessimistic individual are more inclined to use emotion - focused strategies (Nes and Segerstrom, 2006).

Parents shall also use many other different coping mechanisms for handling their distress and some of them are as follows:

- ✓ self-controlling,

- ✓ seeking social support,
- ✓ accepting responsibility,
- ✓ effective problem solving,
- ✓ planning and
- ✓ positive reappraisals.

EARLY NEEDS OF PARENTS

As parents of special children there are few early needs which they expect.

- Early Identification or diagnosis of the child's condition,
- Communication in a sensitive and constructive manner,
- Obtaining information about the condition,
- Suggestions on facilitating the child's development,
- Receiving an emotional support,
- Helping them in understanding feelings and reactions and
- Meeting other parents of children with similar disabilities.

Parenting is the toughest job; that too parenting a special child requires more energy and time because strict schedules has to be followed, extra time has to be spent planning and implementing for the day. Parents are the first person to give the prompts, encouragements, praise and feedback.

CHALLENGES OF PARENTS

The current work in the area of parenting practices has focused on the determinants of parenting styles. The three possible influence on parenting as proposed by Belsky (1984) is Characteristics of the parents, Characteristics of the child and Characteristics of the environment.

The parents need help to solve the problems at home or school. They have to face many challenges in removing the undesirable behaviour of kids at home and in public places. They may have to face the wild criticism and strange looks of the society. Taking care of toileting and sleep needs of these children particularly during travel, the parent's sleep deprivation and their unexpected health issues pose critical times. Unexpected medical expenses, purchase and maintenance of assistive devices like wheelchair, hearing aids, prosthetic appliances etc., can lead to financial crisis, losing their private time and space for leisure, are few among many personal challenges which every parent faces with a huge amount of stress leading to burnout especially for the mothers who are homemakers.

For most families, the depression decreases as members develop a routine of care, gain access to early intervention, and begin seeing progress in their child's development (Turnbull et al., 1993). As the child grows older, parental depression may re-emerge in the family of children with special needs who may have an increased behaviour problems, new health care issues and physical needs in particular to the child and also to the other family members.

Both parents face the difficult situations, but the mother (in most cases) who is at home is affected the most because, they spend a lot of time with the special children and they do not have any other opportunity to vent their problems. Even after these many odds, ultimately the basic need of every parent is to see their children being independent to the maximum extent possible once they become adults.

Once the special child reach his/her milestones, however small it may be like maintaining an eye contact/ potty trained/ saying a first sentence/ responding to his or her name call, etc., the rewards are more than incredible in which the parents forget their stressful or taxing experiences which they had in the past. They start to develop a sense of achievement or satisfaction and

feel motivated to work further more intensively for the child's betterment.



Fig: 3: Picture

The parents have to reinforce the desirable behaviour and do not attend to the child for an undesirable behaviour (E.g. If the child with speech difficulty cries for his needs using gestures, but you insist him/her to communicate through language - do not attend to him/her when they cry or throw temper tantrums).

THE REQUIRED PARENTAL ATTENTION TO THE CHILDREN WITH SPECIAL NEEDS:

During Infancy and in pre-school period, we have to focus mainly on motor, cognitive and communication development and in improving self-help and social behaviour. The child with disability particularly in the early years may not realize he/she is different from other children. The parents should give proper support to the child by helping him/her to cope up with the disability. If the parents have the acceptance, the child's self-image is usually good. Discussing and modeling how to handle the different situations at home improves the child's ability to

cope with his society as well. The child should be counseled by the parents to manage the bullying and teasing by his peers/friends, he should also be taught to develop communication strategies to compensate his difficulties/limitations. Academic mainstreaming also should be planned by implementing early identification and intervention.

Adolescence is a difficult time for all children. For a child with special needs it's the period of more emotional and behavioural difficulties. The children start to develop sexual interests and at times may act in an odd manner in social interactions. They should be encouraged to discuss issues of sexuality with parents in a way and at a level they feel comfortable and understandable. The parents should focus on providing help to reinforce children/ young people's rights to physical and emotional safety, Promote the reporting of inappropriate behavior towards them, and to promote help seeking behavior.

As family progresses through life, there are lots of changes and challenges. It's much tougher for the families with special children. Especially, the siblings can experience more stress and strained feelings that can increase their risk for significant deviant behaviour. The child, parents, siblings, relatives and significant others undergo many difficulties and find their own ways to cope up with their situations over a period of time.

IMPORTANCE OF PSYCHOLOGICAL WELL-BEING

Only when you have a positive mental health, you will have the physical energy to work better, accept the reality well, and cognitively strong to face the challenges of life. The depressed parents perceive their children more negatively, which leads to increased criticism and punishment, resulting in child's behaviour problems.



Fig: 4: Picture Source- <https://www.focusonreproduction.eu/article/ESHRE-Meetings-Campus-Psychology-and-Counselling-Sexuality-2>

It is suggested that stress has a negative effect on parent's mood, which leads to poor parenting and subsequent adverse child outcomes (Kendziora & O'Leary, 1993). Thus, providing the parents with '**Supportive Therapy**' allows them to ventilate concerns and may help the family adapt to their new life circumstances. The parents experience a lot of doubts about the child's future, what will be the prognosis of their condition? How will they manage in the society? Who will take care of the children after them? and so on.

The best method to adopt for a good mental health is '**Mindfulness Training**' which helps them to reduce the stress. Instead of focusing on the negative burden some aspects of past period of their life or being apprehensive about their future, it is always essential to focus on the present activities. Parents have to proceed with a clear mindset leaving back all negative thinking. Mindfulness helps them to increase their confidence and to be bold to face any challenges in their life.



Fig: 5: Picture

The parents should maintain their log of daily tasks by keeping up an '**Activity Schedule**' which will help them to work in a systematic way. Prioritizing their work according to the importance and urgency of the task will help to work one by one with decreased amount of stress. Parents usually focus more attention to their children and other family members than really taking care of themselves. They should often insist on having their own time whenever possible or required. These strategies will definitely enhance their energy level both physically and mentally. Even mothers can maintain a log about their care - health, physical outlook, nutrition, hobbies, etc.

Fig: 6: Picture Source- <http://www.get.gg/docs/BACEdiary.pdf>

Activity

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Body care Exercise, Healthy eating, Treat illness, Rest & sleep			
Achievement Work, Hobbies & Study			
Connect with others Friends, Family, & Community			
Enjoyment Play, Fun, & Pleasure			

Being a **‘Supportive Spouse’** itself bring in a healthy mind state for the partner. The parents may express disagreements on many issues including the up-bringing of the child. A thorough discussion only will bring the desired bright plan. They may have difference of



opinion about disciplining the child, in deciding the cause for the failure, in deciding the type of academic set-up including medium of instructions / residential vs day care, etc. Giving protection to the special child and planning for next pregnancy also may require lot of discussion among partners.

Fig: 7: Picture

When already the mother experiencing more emotional disturbance due to the child's condition, the father not being empathetic towards her and the child will put her under a loads of stress. So, being understanding and empathetic, creates a better bond between the parents.

Their emotional support will definitely increases their attention in bringing up their children in a better way.

Amanda (2012) says, "You Should Take Care of yourself; So, You Can Take Care of Him". Taking time for practicing the '**Relaxation Training**' will help them to overcome the hurdles and view life in a positive way. The relaxation techniques could be of any type which is feasible for the parents like exercise, yoga, meditation, gardening, painting, continuing with their hobbies, music and so on. A caution of note is given on meditation for people with depression.



Fig: 8: Picture Source - <https://nimbusweb.me/blog/the-art-of-rest-learning-to-relax/>

The negative automatic thoughts will leave the parents to form a negative cognitive triad i.e. having a negative thought about oneself, the significant others and the future. To overcome these negative cognitions, '**Cognitive Restructuring**' will help the parents to overcome their problems by altering/ modifying the negative cognition into positive ones. The parents are helped by the Clinical Psychologists to convert their negative thoughts into an acceptable positive thought by providing them the reassurance and possibility to bring in a change in their children with special needs.



Fig: 9: Picture Source- https://www.successconsciousness.com/index_000009.htm

It has been learned from various studies, that the parents of children with special needs do not have good Psychological well-being due to their multiple responsibilities. Proper '**Counselling services**' by the professionals are also found helpful for the parents to lead their life in a positive way and have a good psychological well-being.

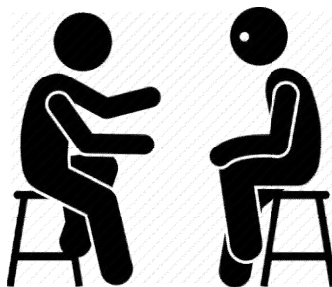


Fig:10:PictureSourcehttps://www.iconfinder.com/icons/2957532/advise_advisor_counselor_counseling_counselor_psychologist_psychotherapy_icon

PERCEIVED SUPPORT FROM THE COMMUNITY

Although parents remain important sources of support, other adults and peers play an increasing role in the child's socialization. The parent of special children frequently receives criticisms for being too lenient/ demanding/ neglectful/ overprotective. The parents and children receives stare and make unkind comments/ complaints about the child's behavior being a disturbance in the surrounding or even refuse other normal children to play with them.

Making an attempt to understand and integrate the children and their family members as a part of the social group will enhance the quality of life of the parents. The parents should be encouraged to get involved in group, neighbors and community as a whole along with their children. Positive perceptions of social support are associated with parent's physical and mental well-being, which in turn affects parenting behaviour (Cutrona, 1984; Heller & Swindle, 1983). So, community support is a welcome gesture from the society.

PARENT - PROFESSIONAL RESPONSIBILITY

- The goal of the Professional is not only to assist the children with special needs, but also to help the parents and significant others to manage the stressors.
- The Professionals are expected to be honest, direct and non- technical while sharing the diagnostic information to the parents. Do not give them the false hope, which might develop over expectations in parents about their special child.
- The Professionals must have the knowledge of the normal sequence of skill acquisition, in order to plan appropriate training/ treatment for the child because, behaviour common at

one age may be considered significant problem at another age, and many childhood problems may change both qualitatively and quantitatively as a child develops.

- The problems faced by special children during infancy typically come to the attention of Pediatrician rather than a Professional dealing with special children. So, it's the duty of the parents to watch their child's behaviour keenly and get the apt Professional help from the correct discipline at the right time.
- The Parents should maintain a journal for themselves and also for their children regarding their emotions, stress factor, documentation of the child's improvement on any skill development so that, the professional will get the clear idea about the child in detail.
- Talk freely with the professional dealing with your child, get the latest feedback, and keep updating about his/her daily schedules or tasks at school.
- As the parents are considered the most important people in the special child's life, they have to spend more time together.
- Grandparents may not accept the diagnosis or may assign blame to one of the parents. Thus, psychoeducation has to be provided for the significant group of people who is in close acquaintance of the child.
- Never isolate from the social group. The parents might feel uncomfortable in the presence of the child in a family function or a community gathering so, they avoid going there. Talk to your professional about the setback even if it is something considered really very silly.

SUMMARY

1. Accept the children as they are and nurture them properly.
2. Plan for intensive and continuous training.
3. Parents should have the updated knowledge of the

legal rights of their children.

4. Focus on the early intervention of the child and never have too much of unrealistic expectations.
5. Parental mental health should be taken care seriously in order to take care of the child.
6. Maternal depression may indirectly affect children's development.
7. Lack of interpersonal attachment leads to depression in parents thus, appreciate a supportive family environment.
8. Parents should be encouraged to engage and grab a "ME TIME" to entertain themselves with their favourite task.
9. Schedule the tasks and work on them one by one, depending on the prioritization.
10. Love the PRESENT - Don't brood over the PAST or be apprehensive towards the FUTURE.
11. Be thankful for the blessings and stay connected with others in the society.
12. A Healthy mind produces great ideas; which might bring in the best for the child.

Chapter 7

Physical Well-Being of Parents

- Jaya Krishnaswamy

NOTE

The term, “Parents” is both expansive in its use, and role specific. The activity of parenting therefore is also on a wide range of definability. In its biological definition it refers to the parent who has conceived, the (biological mother) or sired (biological father) and whose genes are therefore transmitted to the child. (Also called: birth parent) Adoptive parents are those who adopt a child and bring it up as their own. Foster parents are people who officially take a child into their family for a period of time, without becoming the child's legal parents. The child is referred to as their foster child. A surrogate parent is one who stands in the place of a child's parent, but who is not that parent. Either by virtue of voluntary or court-appointed status, that person assumes all rights, duties and responsibilities of the child's parent. A care giver, in the role of parenting may be a family member or paid helper who regularly looks after a child or a sick, elderly, or a person with disability.

INTRODUCTION

In an Indian setting, generally, any child in the family, with special needs or otherwise is raised in an environment where apart from the biological parents there are others participating in their respective “parenting” roles - close relatives, caregivers, and also neighbors. This tremendous human resource support system is available to the mother in most households. However, an important factor that of the “well-being” of the mother in its totality is often disregarded, by the family members and often even by the mother herself taking it casually.

Reasons are many:

- Cultural taboos
- Imbalanced socio economic conditions
- Fragility in family relationships

are a few striking ones observed, in many households.

Where the family faces severe day to day economic problems, the mother's "physical well-being" is much compromised. With meals continuing to be made available just for sustenance, the needs of the other members of the family, particularly the aged and the sick, becoming the priority, mother's personal needs are put aside. The grieving mother of a child with special needs also neglects taking care of herself. In due course, her weakening physical health gives way to illnesses, chronic as well into serious ones, but by then the damage has already been done.

"*Well-being*" is not just providing nutritious meals to the mother for a physical and infection free state of health but also means caring for her "*mental well-being*" enabling her in fulfilling her responsibilities as the primary care giver of the child.

This chapter will address specific issues that commonly pose as challenges to physical well-being of the mother, in areas of her daily activities. A note of caution. It should however be noted and considered that, in current days, with exposure to the changes happening around, the father's role is expanding beyond the rigid confines of conservative thinking. Fathers are now playing a responsible role in parenting partnerships, and this positive practice has indeed immensely contributed in the developmental processes of the child as much as it has also strengthened family relationships as well. This chapter will therefore address also issues that pertain the role of the father. Any issue jointly addressed on time, will benefit the well-being of the mother, her health condition would improve, family harmony will be sustained, and parenting values strengthened, with the "family" unit remaining well grounded.

PHYSICAL WELL-BEING OF PARENTS

This chapter will refer to the biological parent, the mother, unless otherwise stated. The significance of “motherhood” is well emphasized in all cultures over the world, in the Indian context, she is extolled as divinity incarnate, “*Matru Devoh Bhava*”. The mother is not just a female being, in physical form, also capable of generating enormous physical energy from her specialized genetically endowed biological resources, but also one with an infinite emotional capacity to express in action, unconditional love, compassion and patience, endowed with the strongest will to deliver, sustain and succeed in all the ways adopted to nourish her child, physically and mentally in to a well balanced human being. As the child’s natural teacher, she plays the role of an educator for all time, addressing diverse needs rendering in different forms.

Eat well and stay healthy (maintaining healthy habits). This statement is pertinent to the father as well. It is common in households, a continuing practice still that the male member’s food needs (particularly as a head and earning member) is the priority over and above every one else’s. When the father clarifies his role as a “partner” rather than as, the “male head” meal times will be shared moments and priorities will only be decided on the health needs, of the most vulnerable person, could be a pregnant wife, the lactating mother or the convalescing wife.

Physical “well-being” includes maintaining, “Good health”, and feeling well. That is:

- wanting to do what one wants to do’ easily, comfortably
- performing the activities with a balanced state of good health, free from any physical discomfort or illness
- enjoying a life style with a positive outlook

Physical health is basic to an optimal state of well-being, which also includes emotional and mental well-being. It is a state of the body, free from disease or any abnormality, the mind contented

and unconfused. If one has to be healthy, it is necessary to protect the body from any infection or illness as much as possible. When any unforeseen problem arises disrupting the general state of health, it is important to take action at the earliest, preventing it from becoming a crisis.

Basic to maintaining good health with “right eating” are the following factors:

- choosing the right type of balanced food
- cooking it hygienically, maintaining its nutrients
- eating at the required times, not less not more, allowing time between meals, aiding proper digestion, and absorption
- relishing the food eaten

The, “ nutrition well-being” of the mother is dependent on the:

- Economic conditions in the family, how much the family can spend on food
- Accessibility to items and their availability, when needed
- The choice of food items, the cooking preferences, and also the
- Traditional, cultural and family practices It is possible to find some guidelines, in
- accessing items from one’s own backyards
- buying locally produced affordable items from nearby *shandies* –(*open wholesale street markets*)
- using long term proven traditional methods in cooking

Eating alone is not enough to maintain a state of physical wellbeing. Being active is as important. Following a well planned physical exercises schedule, will help in avoiding illness, and the “balance” of well-being intact. These exercises can be built into one’s daily chores which involve physical movements in their performance.

In rural areas, sweeping, washing, drawing water from wells, preparations in cooking have built-in physical movements, and they also help the mind to relax. In the urban areas, where walking, jogging routines are usual, gardening is another activity that involves physical movements. In the normal family pattern, the responsibility of ensuring the “physical well-being” of the parent, the mother, has been laid on the members of the family, making it appear that the mother is a totally dependent person to the decisions of the family elders. This is true only to some extent. However, much of the onus rests on the mother as well. This means that the mother should be aware of the need to address her health care herself, and take her own physical well-being with seriousness. Much information on health care, eating healthy, on being active, has been made available educating the general public, families included. With mother and father, both serious on eating well, and in exercising as needed, or with one helping the other, sharing chores, the health of the mother is well care for.

For any benefit to reach the beneficiary, and for it being utilized in its purpose, there is a continuing need for:

- Creating awareness on the, details of the schemes, publicized through the different media, reaching out to all in need
- attracting the public to utilize them, guiding them in the process
- compiling the data on the distribution and reach out
- getting feedback from the benefitted persons and
- implementing follow ups for taking on further

This is done through reaching out the awareness programs to as many households as possible, through:

- Media, television, radio, newspapers, street plays posters
- Home to home visits by social workers
- Grass root level, (Panchayat) gatherings
- School education and so on

As persons working for the families and ultimately reaching out to them, we need to:

- deliberate over the inputs:
- analyze the needs at ground levels, where each family faces day to day unique problems
- and arrive at practical solutions to make, "physical well-being" for the mother, especially with a child with special needs a reality.

Reality checks, introspecting and reaching for practical solutions Exercise: Situation 1

A parent with her child availing the services at a city based early intervention centre.

(Name changed for confidentiality)

- Mother, named, Salma, age about 28 years, 3rd child with special needs, the older two also with special needs passed away as infants, all boys, now pregnant, first trimester, with the fourth child.
- Lives in a 600 sq ft tenement, in a crowded lane in the city, shares water and electricity supply, with co tenants, poor sanitation, and unhygienic condition
- Husband, tailor by profession, hardworking, only earning member to support his own family, his parents and two other adults

During the preliminary medical examination of the child conducted at the centre, the doctor noticed the mother's emaciated condition and prescribed clinical investigations for her. The result was – Salma is anemic, with high blood pressure, and on the threshold for diabetes.

Salma was:

- referred to an affordable and accessible medical facility
- given practical advices, on her daily diet, regulation of her daily routine to include enough rest, and exercise and,

- visited at home as needed, when the family members, were also counseled

In the given family circumstances, do you think that:

- this remedial measure is sufficient for a long term benefit
- the mother and the family members are now aware on the importance of “Eating well and being Healthy. How much is the father well informed?
- the resources suggested would be accessed by them for their benefit
- it is also important to advise the mother on the feeding practices for her special needs child and provide the needed nutrition
- simultaneously providing early intervention services will help the child to gain health and also show development

All the questions have answers, but for practical solutions a framework of schedule is needed. Work it out as a project study.

Ponder on the questions, and from the information in the bullet marked statements,

- cull out answers by referring to the benefits of the different government schemes available
- work out an individualized solution referring to the background information of the mother as reference
- plan counseling sessions, with the mother, including the father and other family members into confidence, noting their ideas
- evolve a model initially, follow it up, get feed backs and arrive at plausible answers

SUMMARY

- Eat well and stay healthy (maintaining healthy habits)
- Physical “well-being” means “good health”, and also, “feeling good”.
- Basic to this optimal state of well-being lies in the emotional and mental well-being also.
- Choosing the right type of nutritious balanced food is important

but not easy given the economic conditions in each family

- Basic needs can be met, using easily available items from one's own backyard, accessing locally produced affordable items from nearby shandies, (open wholesale street markets) and using long term proven traditional methods in cooking.
- Eating alone is not enough to maintain a state of physical wellbeing.
- Being active is as important, following a well planned physical exercises schedule
- The responsibility of ensuring the "physical well-being "of the parent, the mother, is on the family members and on the mother as well

Much information on health care, eating healthy, on being active, has been made available through government health schemes, educating the general public, families included, in the Government National Health Mission website. Yet there is a continuing need for creating awareness on the, details of the schemes, publicized through the different media, reaching out to all in need.

REFLECTIONS:

- The Government of India recognizing the importance of maternal health as," central to the development of the country in terms of increasing equity and reducing poverty and building social capital" and committed to the realization of the Millennium Development Goal (MDG) in reducing maternal mortality rate, launched the Reproductive and Child Health (RCH) programme under the umbrella of the Government of India's (GoI) National health Mission (NHM) in 2005.
- The NHM recognizing that, "child survival cannot be addressed in isolation" has "intrinsically linked it to the health of the mother, which is further determined by her health and development as an adolescent.

Self Care

The importance of eating well and being healthy has been described in the earlier unit of this chapter. The section on the importance of exercising will follow but both the activities are indeed a pair of the same area, that of Self care. Self care activities with eating well and exercising are built in to the “physical well-being” each for its own importance. They are to be viewed holistically for they pervade all aspects of one’s daily activities.

Self care activity is common to all living species

The animal kingdom, practices self care as a natural activity for survival, thriving, saving themselves of extinction, and maintaining the ecological balance. The plant kingdom too has its own ways of self preservation through its own self care practices. Human beings evolved self care practices suited to the environmental needs, climatic conditions and economic demands.

Self care is practiced, as a:

- Grooming activity
- Cleansing routine
- Right eating for staying healthy
- Leisure, resting when tired, sleeping routinely
- Protection in health and for safety
- Body hygiene routine to keep free from infections

Exercising for tuning up the body is also basic to a state of well-being for any person. Self care can be practiced only with one’s own will, with the right attitude and giving time for any activity.

Personal hygiene, a basic to self care:

There are well laid down ways for practicing personal hygiene,

evolved over the years, common to all cultures.

Oral hygiene:

- Vital for digestion and for prevention of many infections transmitted through breath
- Teeth when decaying hoard germs and generate several infections. Keeping teeth clean, bright and strong is a self care requisite

Maintaining teeth health, by

- brushing teeth regularly morning and evening
- rinsing mouth after every meal
- avoiding chewing items which can cause ulceration in the mouth or
- retaining items for too long in the mouth, such as tobacco or “paan”, which can also discolor the teeth, are some of the ways in which teeth health can be maintained

Brushing of the teeth does not require elaborate items in the type of brush to choose or in the brand of tooth paste that is needed. What is still practiced in some of the villages and which has been scientifically proven for its merits holds good in many situations. It is the use of the “neem” stick for cleaning teeth and in the use of a homemade tooth powder, with specially chosen home ingredients.

Daily bath is another absolute need in the practice of self care for health and safety.

In India water availability is a major problem

- there is a severe water scarcity in many places
- inaccessibility is a major difficulty in some areas
- water when available, is often erratic in its supply timings, or in short supply and inadequate
 - often water quality questionable Much awareness is being created on how to:
- conserve water,

- save from wastage and also
- reuse for several other purposes, such as the garden, toilets and so on

In any given circumstance, body cleanliness has to be maintained towards a lasting physical well-being. One should distinguish between bathing for cleansing one self and bathing for pleasure. Washing hands, feet after any an external exposure or any unclean transaction is a must. The mother, in close contact with her child, intimately often, particularly with special needs, should diligently practice hygiene, for her physical well-being as well as that of her child. Traditional cultural practices emphasize social distancing for any one not directly concerned in handling the infant, and the practice of rules of hygiene for the mother when breast feeding or when engaged in many other intimate child care activities for the first 45 days after birth. Over the years, many of the valuable practices have been lost from usage.

Some positive traditional practices relevant to today's needs may be restored and adapted for use.

A few of the positive traditional parenting practices are mentioned below, which among the many, are easy for practicing even today.

The mother's health is taken care with utmost diligence, with special bathing routine, exercising for restrengthening the womb and the abdominal muscles, specifically prepared easily digestible, but nutritious meals, for regaining health and being able to offer enough breast milk for child. Home isolation and social distancing practiced.

Handling of the infant only by a designated helper, a close relative, well wisher or a trained care giver for at least 4 5 days after birth, strictly following rules of hygiene , social distancing from casual visitors, and observing child's needs closely and attending to them. In modern times, paternity leave is also offered to the father in many work places. Many fathers slip into the new designations with ease.

Apart from care in hygiene and the practices related to it:

- the practice of self observations and alertness to any set back in

health, indicating the onset of any infection or illness and

- taking preventive action is of vital importance to the physical being of the mother

Self care does not mean undue fussing over oneself. It is self reliance in following related practices:

- the mother while taking care of herself is also protecting her child
- a social responsibility part of one's nature towards the child, family and community

Bathing practices with the needed massage, with carefully prepared bath oils and fragrances, with the infant in close physical proximity on the stretched legs of the bather with scope for infant to, "look " at the bather, respond suitably to the stimulating caresses and endearing rhymes and tunes.

Mother trained to maintain hygiene before putting infant to breast, "looking ", "caressing" and "talking to the child" as if offering the "world" around, waiting to get the "cooing" responses, and establishing communication.

Celebrating milestones, as family traditions, where every member has a role to play, creating social relationships for the child.

Weaning foods, introducing each one with ceremony, and continuing to follow close meal time relationships between the person feeding and the infant. Mother's role is now that of every one in the household, elders, father, and others.

Decorating child, with specific selected jingling jewellery, usually handed down heir looms, not expensive, made out of special amalgam of metals, for the ankles, wrists , waist, at different events, cradle ceremony, first official out door visit, introduction of semi solids, first birthday and so on, introducing child to the world of sounds.

The father's role as a parent is significant, at every event, every relative has a role to play, every artisan , craftsman and the priest is in one way or the other involved in the making of the events. A world of very important people and events emerge for the child at every ceremony.

Reality checks introspecting and reaching for practical solutions Exercise: Situation 2

A reality check on self care practices, two different styles, by two persons each at a different socio economic level. Nirmala, a city bred college educated girl, now mother to a premature baby, about two months old. Delivery was through a Caesarian section. Baby underweight at birth, presented a cleft lip, difficulty in sucking and swallowing breast milk, and crying incessantly. Nirmala had been working in an Information technology firm on day shifts, her husband also in the same profession and working on alternate shifts of day and night. Nirmala has sufficient domestic help, in addition to her mother being with her.

Nirmala's reactions and routine:

- Shocked that her child was having a problem. Not able to get over her grief even when assured that surgery can set things right.
- Does not like eating the special meals prepared for her, saying they were insipid and asking for her usual favorites of fried dishes.
- Takes assistance in her bathing and grooming activities.
- Takes her medicines regularly follows doctor's orders correctly.
- Attends to baby at all times, feeding and cleaning.
- Husband also shares baby time with her, changing nappies, attending to other needs.
- Restricts her movements to minimal activities, preferring to lounge in bed reading or taking calls on her mobile or watching television shows.
- Expresses her anxiety even over trifles, refuses to accept reality and to look for solutions.

Situation 3

Ammani sells flowers to households and at the temple on festival days. Her husband works at construction sites as a brick layer. He brings home his earnings but also indulges in drinking when domestic harmony gets upset. Ammani has three children,

two boys and the youngest a girl with spinal bifida.

Ammani's routine:

Her day begins early, collecting water from the nearby pump, preparing her morning gruel of millets "kanji," helping her daughter in her morning toilet needs, and getting ready the packet of mixed rice, or her sons to take to school and rushing to sell her flowers.

- Her husband leaves home only when called by his contractor. He eats outside.
- Strings flowers until late night, leaves in the afternoon to buy the flowers from the whole sale markets.
- Buys idlis and snacks for her children on their return from school.
- Her bathing has no routine, depends on the availability of time and water.
- She eats when there is food, otherwise manages with tea from wayside shops.
- Ammani takes her daughter regularly to the government hospital for post surgery checkups catching the bus and walking the distance to the bus stop.

Conduct a SWOT Analysis, its pluses and minuses of each one's self care levels, arrive at suitable solutions where needed and appreciation where due. Enter the SWOT, data, tabulate, study the presentation and analyze the result with comments and remedies.

SUMMARY:

- Self care activity is common to all living species.
- It is part of daily living activities, including eating, exercising and spending leisure time.
- Basic in personal hygiene, one should distinguish between bathing for cleansing one self and bathing for pleasure.
- Some positive traditional practices relevant to today's needs may be restored and adapted for use.

- Self observations and alertness to any set back in health, taking preventive action is of vital importance to the physical being of the mother. It is protection to child, mother and a social responsibility.

REFLECTIONS:

- Self care means proper grooming, cleansing, right eating, adequate leisure and protection of health and safety.
- Self care means self reliance to protect her child, social responsibility towards the child, family, and community.
- Self care means being aware of proper sanitation, proper hygiene and proper alertness by preventing illness.
- Role of Government of India:

The women in the villages have been habituated to easing at night times, whereas the men folk could do so openly during the day. The woman had no choice even in weak health during pregnancy or after delivery or when sick. They could not assert themselves for their own intimate personal needs, their urgency and convenience which affected their decency and self pride. "Self Care" was difficult in such conditions. Recognizing that the mother's health has always been side lined and it being directly linked to the availability of drinking water and hygienic sanitation facilities the Government of India has put several health schemes in place.

- Swachh Bharat Abhiyan (SBA): "Swachh Bharat Mission (SBM) or Clean India Mission (CIM) and Swasth Nagarik abhiyan.

RECAPITULATION

Exercise

I. Fill in the blanks:

- Self care activity is common to all living.....
 - Basic to self care is personal
- c) Body cleanliness has to be maintained towards a lasting

well-being.

- d) There is a difference between bathing for cleanliness and for pleasure, so in..... scarcity it must be conserved and used carefully.

II. Give one word for each of the following statements

- a) The balance maintained by all living species with self care to survive, thrive
- b) Practices in self care, handed down from one generation to the next.
- c) Being responsible to one's own health and, child care and the family and the community around.
- d) Self care practices build up the self of the parent in due course

III. What do these acronyms stand for:

- a) SBA
- b) SBM
- c) CIM

SUBUNIT 3

Importance of Physical Exercise

Physical Activity is vital for the upkeep of the body. It is any movement where the body uses the muscles and the energy required which again is got from one's body. Even sleep is an activity. Physical exercise, in a daily routine, whether structured or naturally built into the daily living activities, gives strength to the body, builds up the stamina and keeps the body free from illnesses.

In western countries and in countries in the Far East too much importance has always been given to daily physical exercises,

almost as part of one's daily life. It is a part of the school curriculum, and includes all outdoor recreation activities too such as swimming, trekking, mountaineering and so on. In the Indian scenario, historically there did exist a pattern with:

- rigorous physical body building up regimen, like wrestling, for strength to defend oneself and combat any enemy
- physical prowess, with training in specialized skills for agility and alertness such as archery, sword fights, as part of the then prevalent, "gurukulam" system of education
- games for developing physical stamina such as "Kabaddi", "Gilli Danda" and so on

Yet not all of the population was included, and the women folk were normally kept out. In the modern Indian school system, physical exercises were addressed as just "drills" or "physical training" (PT). Many students did not take to them with enthusiasm because of the rigidity in enforcement and lack of motivation. Physical exercises were considered more for body building rather than as a health need.

In such a situation, which continued over several decades, physical exercises for good health was not taken up seriously until independence, and even a few decades afterwards. Now, with much awakening, schools nurture their students, also girl students in the various aspects of physical exercises making them health conscious. However, women tied down to household chores are still not part of the inclusion of the training. This unit will deliberate on that issue. Activities, such as eating well and healthy, exercising, giving proper self care, allotting "me time" for oneself and practicing simple yoga and meditation help build up a healthy physical state of well-being. Eating well and maintaining all practices towards good health by caring for oneself have been dealt with in the earlier units.

This unit will describe the importance of physical exercises and will be followed by units of "**Me time**" and "**Yoga and Meditation**". All in one way or the other are related in importance to the physical well-being of the mother. Physical

exercises lead to body strength and good health.

While eating, the food ingested is stored as energy in the body in the form of calories. Physical activity burns the calories, and prevents the formation of excess fatty deposits in the body. With well patterned physical exercises and proper nutrition, the positive health benefits are:

- illness free life and a
- sense of physical well-being

Physical fitness is assessed by the five coordinates for any activity to be performed. They are:

- overall health of the body
- speed of performance
- balance maintenance
- alertness and
- agility for skilled performances

Like starting an engine, physical exercises gives the “power” to the muscles towards their easy movements, which then start to perform the activity, thereby aiding the functioning of the various organs in the body. When the physical strength gets built up, immunity is also safe guarded, and the person becomes fit and enjoys being active. Physical exercises show both immediate and long-term health benefits.

They are:

- lowering of blood pressure
- boosting levels of good cholesterol,
- improving blood flow (circulation)
- keeping weight under control
- preventing bone loss that can lead to osteoporosis
- And certainly keep your medical bills low. They reduce:

- risk of developing several diseases like type 2 diabetes, cancer and cardiovascular disease
- stress, anxiety and the resulting outcomes

Most importantly, regular exercise, helps developing a positive attitude towards life, improves one's well-being and, therefore, quality of life too. A lazy body is an easy abode for any set back in health to happen. Lack of exercise leads to

- obesity and thereby inefficient functioning of the different systems in the body, digestion, respiration, evacuation and so on leading to the setting of life style diseases
- physical systems in the body getting affected, the body weakening and leading to the day to day essential physical activities getting slowed down or becoming more and more tiring or even difficult to perform
- complications in health set in

A typical example is that of the condition called diabetes or hyper tension. Hence the importance of exercise cannot be stressed more. Not all understand the serious consequences of an inactive daily life with sedentary habits and lethargy. Many of the parents either out of ignorance or over confidence and many because of lack of motivation, give up exercising. In a rural setting, in a normal village household especially in one's daily life exercising was a built in system, that is, walking for water or drawing it from a well, as a necessity, performing household chores involving physical movements.

In the modern context much of the household chores have been reduced and are not much of drudgery due to the introduction of home aid appliances, where even in small towns and large villages they are becoming easily buyable on monthly remittances. While technology must be adopted to reduce drudgery and saving of time which could otherwise be better used it should not replace the needed bodily exercises for keeping fit.

What could be the physical exercises any parent can afford to perform in the home situations, and whether they are simple enough to practice, given the life style of every parent is what needs to be considered. One should start with caution, not over do and strain the body.

REALITY CHECKS introspecting and reaching for practical solutions

Exercise: Situation 4

Sashi a young college going girl in her early twenties used to a pampered life style.

- Apart from her parents, her aged grandmother is there who always active, has recently become confined to bed after a fall and a hip fracture.
- *Sashi feels it a chore to attend to her grandmother when ever her mother asks her to do so.*

Mother always reminds her of her duties to her grandmother who had taken care of Sashi through her child hood years. Worried that she may not turn out to be a good wife, mother or daughter in law!!

However when ever the grandmother is hospitalized Sashi takes care to be with her through and through uncomplainingly.

Her morning wake time depends on whether she has to attend college that day or not.

Watches movies over the television through a good part of the night and sleeps till almost afternoon.

Her bathing routine depends on her appointment with her friends for an outing to a movie and a visit to the restaurant.

She complains over the meals at home and orders online almost every day for her choice of snacks.

She however has a wide circle of friends with whom she is on phone calls forgetting the world around her.

She performs very well in her studies and is regular in attendance.

Conscious of her becoming over weight she registered herself to a fitness program in a gym which she soon stopped attending saying it showed no results.

Kokila, eldest of four girls, lives in a village almost 6 kms from the nearby town where she goes to college.

Her mother herd's goats and her father supplies milk, bicycling to the cooperative society located almost 10 kms away from his place of work.

They have brought up a child who they discovered as an unclaimed infant after the Tsunami had hit their village. The girl child, named Aishwarya, now a ten year old is a child with Down Syndrome, with limited means of communication.

Kokila's day begins well before sunrise every day. She cleans up the animal shed, and uses the dung mixed water to wet the ground in front of the house. *Keeps her foster sister with her while on her chores, talking to her, and making her assist in small jobs.* Relaxed, she decorates the area and lights the earthen lamp near the tulsi pot.

Little by little she has trained her sister in her toilet needs and feeding practices

She fetches water from the nearby common pump for the daily needs and for bathing.

Once a week she takes clothes for washing at the field pump where water flows forcefully. *She trains Aishwarya to apply soap to the clothes, also rinse the light ones.*

She helps her mother in her morning chores, bicycles to college with a packed meal.

She tops her class and is a full scholarship student.

Has very few friends, prefers to spend time in the library rather than chat.

In the evening she helps her sisters with their school work and at night helps her father with his milk accounts.

Over the weekends she helps out at her uncle's grocery store and earns money which she saves for any need.

Read the two descriptions, and carry out the following exercise.

If Sashi and Kokila happen to meet with each other and become friends, they are likely to chat on their respective daily routine and on their different life styles. Analyze, in not more than a paragraph of ten sentences, each one's daily routine, on how the economic status of each, their environmental compulsions, and personal attitudes have had their influences on their physical well-being *and their commitment to the special needs of the family.*

SUMMARY

- Physical Activity is vital for the upkeep of the body
- With well patterned physical exercises, along with proper nutrition, the positive health benefits are, illness free health and a sense of physical well-being
- When the physical strength gets built up, immunity is also safe guarded, and the person becomes fit and enjoys being active
- Physical exercises show both immediate and long-term health benefits
- Regular exercise, helps developing a positive attitude towards life, improves one's well-being and, therefore, quality of life too.

REFLECTIONS:

- Simple exercises that can be practiced by the parent at home situations must be done with caution.
- While technology can be adopted to reduce drudgery it should not replace physical exercises in daily life.
- Physical exercises show short term and long term benefits.

RECAPITULATION

Exercise

I. Fill in the blanks

- a) is vital for the upkeep of the body
- b) The fiveform the basis for assessment of physical fitness.
- c) A sedentary life style can lead to diseases such as
- d) Your physical well-being, will give you a life of

II. Give one word for each of the following statements

- a) Any movement where the body uses the muscles and the energy
- b) In the modern Indian school system, physical exercises were addressed as just “.....”
Or “... ..Training”, (PT).
- c) must be adopted to reduce drudgery and saving of time but should not replace
- d) the needed exercises for keeping fit

IV. Answer briefly in one or two words only.

- a) Two village activities which build up the physical stamina in a person.
- b) Energy stored in the body from the daily food intake.
- c) Blood pressure raised beyond the normal limits.

Importance of “Me time”

In the earlier sections in this chapter emphasis has been on the ways and means towards a state of physical well-being in matters of eating well, exercising, and in self care. In this section, “me time” will be described, for what it exactly means, how it can be culled from one’s daily routine, and how it is of value to the mother .

“Me time” as an important component of “Time” is recent, though the idea that everyone needs some time for oneself has been basic to human requirement. It has also been an underlying factor in practices in all cultures, though not necessarily defined or designated as such or reckoned as one’s rightful need. It was but natural for the women, whose personal needs themselves were considered with indifference, that “me time” was usually, ‘lifted’ out of the usual routine time leaving them ridden with guilt for having had such, ‘indulgences’. The mother, and if mother of a child with special needs was always expected to keep other’s needs above that of hers, and hence could only dream of, “me time” for herself, not realize it. “Me time” was usually considered as time for personal reasons such as the time for prayers, worship, decorating oneself on festive occasions and catching up “free time” to nap, to feel relieved from any work of drudgery. The “me time” of those days was not personal, private or exclusive.

Given below are some quotes on “me time”

- “Prioritize self-care & incorporate a MINIMUM of 60 minutes 'ME TIME' into your daily routine - “YES THERE ARE enough hours in the day, NO EXCUSES.”
- “Spending time alone in your own company reinforces your self-worth and is often the number-one way to replenish your resilience reserves.”
- “It is never too late to make a change and taking some much needed alone time for yourself to reflect is not selfish.”
- “Intelligent living” simply means focusing only on what matters most to you, on what you love doing. By investing in your “me time”, with what you are deeply passionate about, makes you come alive! When you do create that one hour for yourself, you will, magically, see how you gain control of the remaining 23 hours of the day!”

“Me time” is more important to the mother with special needs

because of the different types of demand on her time:

- attending to daily chores
- giving special care to her child and
- looking after the family routine

Her tasks would quite often be over whelming, exacting and exhausting. Many mothers break down in despair. It would be an ideal situation, if understanding the gravity of such household situations the husband, close family members, friends and neighbors, cooperate and coordinate to work out practical solutions for the mother to have her leisure and plan for time for her own relaxation through enjoyable pastimes. This positive attitude by persons, who care for her, will soon help in “me time” getting evolved for the mother, by and by. The “me time” spent by the mother could then be:

in the performance of any activity which she does for her own satisfaction

under no compulsion from anybody else, and which

she chooses doing, without any interference, and which gives her relaxation

“Me Time” will not only maintain the physical being of the mother, but will also build up her sense of self and, self confidence. “Me Time” is therefore an important aspect of one’s life. It means time for oneself. Oneself means giving time to attend to one’s own specific needs, physical, mental and spiritual.

The physical needs are:

- hunger, sleep and rest when needed and its
 - associated activities, such as meal preparations, observing a sleeping pattern and resting, when the body demands
- Mental time refers to time to
- think, plan, contemplate

- observing silence where needed
- analyze situations, take decisions, and act accordingly.

Spiritual time means:

- time for thinking beyond one's mundane activities, not just eating sleeping, earning and so on
- thinking of the environment around you, of nature, observe and enjoy how calming it can be
- offering prayers and following simple spiritual practices of daily life

"Me time" is precious for the mother, when she spends it just for herself, being herself, and relooking herself with her own choices, living the time entirely on her own equations. "Me time" is sometimes associated as time for physical fitness, though it is not often available, When available it is only because of compelling reasons or when in a state of urgency, for health reasons.

Mental time is given, not for contemplation or deliberation but more for hasty decision making. With no real, me time, additional negative factors that of stress and tension result.

Spiritual time is the usual casualty in the hectic daily life of the individual, particularly in the city life of the parent. Even in the villages, spiritual pursuits though part of cultural life earlier have become ritualistic and pompous.

It is not simple to format a time table for "me time" and follow it. The reasons:

- The daily life of an average Indian parent is beset with problems which may become permanent too
- Male domination with decision taking denied to the female partner, temper outbursts, antisocial habits - smoking, alcoholism, gambling, infidelity are some of the stress situations that abound in many homes.
- Managing crisis after crisis for the mother becomes more

urgent than seeking “Me time for solace.

But “me time” is still essential. “Me time”, is an individualized time. Each one must work out the daily routine simplifying each activity, so that “me time” for chosen pursuits can be culled out easily. They could be, a hobby, knowledge enhancing activity, both specific and general, outing with friends, engaging in productive earning activities, and such others. Simple daily activities can also give “me time” to the mother, as relaxation as well as for self improvement.

Enjoying the activities of daily life:

- Bathing, washing clothes, which when not a drudgery give satisfaction, relaxation and calms the mind.
- Cooking, when not an obligation, as also any small job in the household, become a time for contemplation.
- Reaching out to people in need of help is also a “me time” service
- Rest time every day is also one’s own time.
- Pursuing hobbies, music, or any other, reading, participation in the community cultural activities also mean getting your “me time” yours entirely.

In the villages many mothers are members of the self help groups and the gram sabhas or Panchayats. Some are leaders too. Some earn working in small scale home based industries and agricultural activities. In the towns and cities parents go out to work as professionals in the different areas in urban enterprises. The self confidence gained from becoming an earning member makes the woman more and more confident of spending the “me time” with pride and happiness. Any time that is spent on an activity that makes one relaxed and calm is, “me time”.

REALITY CHECKS introspecting and reaching for practical solutions

Exercise: Situation 5.

In the earlier sections of the chapter, Eating well and Staying Healthy; Self Care; Importance of Exercise; “ Reality Checks” were given at the end of each unit as introspective and analytical exercises.

Revise each of the descriptions, cull out from them the statements which indicate whether any of the characters has used the time from one’s day as “me time”. Note them down. Draw out 6 part column list in column 1 , the names of all of the main characters; in column 2, against each of their names write down the statements; in column 3 their respective locations, whether urban or rural based, in column 4 each one’s status , single or otherwise, in column 5 the economic background of each, upper level, middle level or lower level; and in column 6 , the analysis , whether each of the activities is on “me time” or not , and if so whether each is self satisfying, a worthwhile pursuit, and has a long term benefit. Summarize your analysis on how “me time” can be redefined in the context of physical well-being, mental harmony and, creativity of the mother.

Example :

	2			5	6
	Statements			Economic background	Analysis

Nirmala	Expresses her anxiety even over trifles, refuses to accept reality and to look for solutions	Urban	Married	Middle class	Though she has time, does not use it for introspection or as 'me time'; and on the contrary is agitated. There is no long term benefit for her in this situation
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SUMMARY

- “Me time” as an important component of “Time” is recent
- “Me time” was usually considered as time for personal reasons
- “By investing in your “me Time”, with what you are deeply passionate about, makes you come alive!”
- The positive attitude by persons who care for mother, will soon help in “me time” getting evolved for her, by and by
- “Me Time” will not only maintain the physical being of the mother, but will also build up her sense of self and, self confidence.
- “Me time”, is an individualized time. Each must work out the daily routine simplifying each activity, so that “me time” for chosen pursuits can be culled out easily
- Any time that is spent on an activity that makes one relaxed and calm is, “me time”

REFLECTIONS:

- “Me Time” will not only maintain the physical being of the mother, but will also build up her sense of self and, self confidence.
- Me Time” is therefore an important aspect of one’s life. It means time for oneself. (Oneself means giving time to attend to one’s own specific needs, physical, mental and spiritual.)

RECAPITULATION

Exercises

1. Pick the odd word out (and underline it) from among the statements given with reference to “me time”
 - a. Chosen activity, sense of self, individualized, physical exercises, household chores.
 - b. Personal, selfish, valuable, practical, essential
2. Write down naming a simple activity in the mother’s daily routine for each of the following phrases to clearly define what, “me time” exactly means.
 - a) just for herself
 - b) being herself
 - c) relooking herself with her own choices, and
 - d) living the time entirely on her own equations

Yoga and Meditation:

Yoga and Meditation are terms now familiar in our day to day affairs. Even though yoga and meditation originated in the Indian soil it had lost its status for several centuries. It was only after the West recognized its worth, as an extraordinarily

valuable practice in the enlightenment of the mind and fitness of the body that it began to be re known in India. In recent years, yoga and meditation has gained the status it deserves for its simplicity, easiness for practice, and benefits towards stress relief and good health. Yoga practices and meditation techniques are now becoming so popular, and many seek teachers in yoga and meditation for proper initiation and for the resulting benefits. It is important a right teacher is identified, who would, with dedication, direct the pupil on the correct methodology for practice towards its outcomes, physical health, calmness of mind and clarity in thinking and action.

Definition of Yoga:

“yogash chitta-vritti-nirodhah”

Yoga is the cessation of the fluctuations, or whirling, of the mind. (Patanjali’s Yoga Sutras 1.2.)

When there is yoga, “chitta” the mind, “with its fleeting, ceaseless thoughts will come to a stop

- “vritti” and there will be no self identity of one with the body, “nirodhah” - but a state of happiness, bliss and ecstasy.

Yoga means union with the Self, the Aatman: the higher Self - the Divine/eternal/limitless Self. Patanjali who codified yoga for humanity affairs says that yoga must be experienced, and so it is with continuous practice that results are achieved. Meditation is a practice where an individual uses a technique - such as mindfulness, or focusing the mind on a particular object, thought, or activity - to train attention towards awareness, and achieve a mentally clear and emotionally calm and stable state of self. While meditating, one sits in a quiet place, eyes closed, gently calming the mind to stop getting distracted, and, focusing attention on breathing. When the mind is calm, fears recede, the mind, becomes compassionate and relaxed. The day presents as purposeful. Yoga and meditation go hand in hand, with focus on

breathing emphasized in both the practices.

The Yoga Sutra is the codification by Sage Patanjali on the science of yoga, who has also given us a treatise on Sanskrit grammar and on Ayurveda - the ancient medicine system of India. It is one of the six orthodox philosophies of ancient India. Patanjali's sutras are general guidelines for spiritual growth through right living, and are not specifically about Hinduism. They are not beliefs, but methods that can be tested by each practitioner to personally discover actually, the benefits claimed.

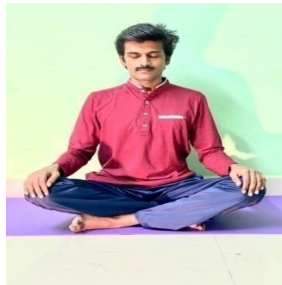
Components of Yoga (refer www.jivamuktivyoga.com)

There are 8 limbs of yoga Yama, Niyama, Asana, Pranayama, Pratyahara, Dhyana, Dharna, and Samadhi. Of these Asana and Pranayama prepares one for meditation. Breathing is an activity as long as life exists in any living being, breathing continuously day in day out. The body, in a living state, breathes involuntarily whether awake, in sleep, or in any activity. Breathing is therefore a vital function of life, the life force. Regulated breathing in yoga and meditation is Pranayama.

Pranayama is a yogic practice. In yoga, this life force is referred to as "*pranayama*", a Sanskrit term, "prana meaning, "life force" and "ayama," meaning, extending or stretching. It is also known as the extension of breath. Every cell in our bodies needs oxygen to function properly. *Pranayama* breathing is basic to the physical practice of yoga, leading to mindfulness in breathing. Results of several studies show that a regular practice of pranayama decreases the effects of stress on the body and increases overall physical and mental health; also aids in digestion, improvement in sleep, and reducing anxiety.

How to Do Pranayama Breathing in Yoga
(www.yogaoutlet.com) The following are the steps:

1. Sit in a comfortable cross-legged position such as Easy Pose (Sukhasana).



2. Close the right nostril with your right thumb.



Sukasana Mrigi Mudra



Anulom – inhale



Vilom – Exhale

3. Inhale deeply through the left nostril.
4. Close the left nostril with the ring finger of your right hand as you release the right nostril

For the mother with a child with special needs, the practice of this simple technique helps calm the nervous system and enjoy a restful night's sleep. By increasing the amount of oxygen taken into the body, it's believed that this breath can also purify the blood, calm the mind, reduce stress, and promote concentration. As it can be performed any time of the day, it will be easy for the mother to do it whenever she is stressed. With the exacting and stressful demands of living styles in the modern world, depression, anxiety and chronic stress are the outcomes affecting the individual. Yoga and meditation are becoming more and more sought after for stress releasing techniques, by more and more persons who face psychological and physical health issues. Many studies conducted in India and elsewhere show positive results on the effects on the mental, physical, and emotional health in the practitioners of yoga and meditation.

Extreme stress in a person strains the nervous system resulting in high blood pressure, increase in heart rate, and cholesterol levels, hormonal imbalance, weakening the immune system, energy levels

and sleep loss.

When the body and mind are relaxed:

- the nervous system is also relaxed, and with energy level raised, blood pressure, heart rate and oxygen levels are stable
- Positive traits appear, such as focusing and decision making
- Negative traits such as tensions caused out of fear, anxiety, and hopelessness cease

With such positive results from several studies in yoga and meditation, it is but natural to conclude that parents of children with special needs would also be the beneficiaries. Even basic and simple practices are beneficial to them in the long run. One complete and simple yoga practice, integrated with breathing techniques, is the **Surya Namaskar** which the parents can be trained in, under proper guidance. **“Surya Namaskar” or Sun Salutation is a sequence of 12 powerful yoga poses.** Besides being a great cardiovascular workout, it is also known to have an immensely positive impact on the body and mind. It is best done early morning on an empty stomach. Each round of Sun Salutation consists of two sets, and each set is composed of 12 yoga poses. Besides good health, Surya Namaskar also expresses gratitude to the sun for sustaining life on this planet.



REALITY CHECKS introspecting and reaching for practical solutions
Exercise: Situation 6.

Let us once again look at the families of Nirmala, Ammani, Kokila, Sashi, Salma. Each one comes from differing home backgrounds, economic conditions, locations, family practices and exposure to the happenings in the world outside. Yet they all need to be introduced to the value of yoga and meditation. As a Rehabilitation Professional, you have to make them understand the value of yoga, learn and practice simple yogasanas amidst their daily chores. You may choose, at least two of the persons, and write how you will go about the task.

Note:

The steps given below are jumbled in sequence and hence, in priority also. Rearrange them correctly, and in a few sentences, state, how you would go about your task, whether workable or not and if not how to overcome the challenges.

- Contact the organization concerned with taking yoga practices to

grass roots levels for volunteers.

- Arrange for classes through the many voluntary organizations working in this area.
- Work out an individualized daily practice schedule.
- Conduct a basic health check up with the local physicians.
- Counsel the parents individually and also with their family members.
- Show video presentations and have discussions.
- Follow up periodically the consistency in practice.
- Arrange coverage through the media of how such an effort was possible, by just the conviction of the women folk.

SUMMARY

- Yoga practices and meditation techniques are now becoming so popular that it is important a right teacher is identified by the seeker.
- Yoga means union with the Self, the Aatman: the higher Self.
- Yoga must be experienced, and so it is with continuous practice that results are achieved.
- Meditation is a practice where techniques are used in focusing the mind, training the attention towards awareness, achieving mental, and emotional stability and thereby a stable self.
 - Yoga and meditation go hand in hand, with focus on breathing emphasized in both the practices.

REFLECTIONS

- Special mothers must be encouraged to take up yoga that is easy, simple affordable and needs no special infrastructure.
- With positive results from several studies in yoga and meditation, it is but natural to conclude that parents of children with special needs would also be the beneficiaries

RECAPITULATION

Exercises

1. Fill in the blanks suitably.

- a) With the right teacher and right practice yoga is said to give the

following benefits: physical health, calmness of mind and in thinking and action.

- b) Yoga must be.....to achieve the desired outcomes.
- c) As yoga has eight limbs it is called... Yoga.

2. Complete the answers in the following statements.

- a) Pranayama, increases oxygen intake, the blood gets purified, calms the mind, reduces stress, and
- b) "Surya Namaskar or Sun Salutation is a sequence of ...
..... Poses.

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Acronyms

- SWOT: Strengths, weaknesses, opportunities and threats.
- SBA - Swatch Bharath Abhiyan
- SBM - Swatch Bharath Mission
- CIM - Clean India Mission
- SWM - Solid Waste Management

Quotes from Google Search

- Miya Yamanouchi - Embrace Your Sexual Self: A Practical Guide for Women

- Nyki Mack
- AVIS Viswanathan
- Kyod Maqupe an international DJ, Author, Producer and artist.

Glossary

- Aasana – postures
- Aatman – derived from Sanskrit word Atman, which literally means spirit, soul or essence.
- Ability- A capacity to accomplish a task at the present moment.
- Accusing: Blaming someone for some fault
- Acquaintance: A person whom you met but not a friend
- Acquisition- Gaining or incorporating something new.
- Adaptation- The action or process of adapting or being adapted.
- Adhering: Sticking or following something
- Allied health professionals- Allied health professionals are health care professionals other than doctors, dentist, medicine and pharmacy who provide a diagnostic, technical, therapeutic and support services in health care system.

- Anuloma - Inhaling through one nostril while the other is closed with fingers,
- Anxiety- A fearful mood that has a vague or no specific focus and is accompanied by bodily arousal.
- Apprehension- Anxiety or fear that something bad or unpleasant will happen.
- Ashtanga- A type of yoga based on eight principles and consisting of a series of poses executed in swift succession, combined with deep controlled breathing
- Ayurveda – A system of medicine with historical roots in the Indian subcontinent.
- Behaviour- All the activities that living organisms exhibit.
- Bivalent: A pair or two
- Bully- Seek to harm, intimidate, or someone perceived as vulnerable.
- Cerebral Palsy- A congenital disorder of movement, muscle tone or posture due to abnormal brain development, often before birth.
- Coexist: Live or exist together

- Cognition- A general term for all forms of mental processes
- Cognitive Restructuring- A technique of examining one's beliefs as embodied in automatic thoughts and substituting more accurate beliefs for those found to be distorted or inaccurate
- Cognitive-of relating to, being, or involving conscious intellectual activity (such as thinking, reasoning, or remembering)
- Constraints- A limitation or restriction.
- Contagious: One which is likely to spread and affect each other
- Coping Resources: Abilities to manage stress
- Coping skills: The methods a person uses to deal with stressful situations.
- Counselling- The process of helping people make adjustments in normal developmental processes across the life span, including educational, vocational, and marital adjustment and planning; family dynamics; aging; and rehabilitation after disability.
- Denial: Not accepting or rejecting something
- Depression- A state of mind characterized by negative mood, low energy, loss of interest in usual activities, pessimism, unrealistically negative thoughts about self and the future, and social withdrawal.
- Despair: Feeling sad or hopeless
- Dharana - means holding concentration or steady focus. Binding the mind to one place, idea or object
- Dhyana - a training of the mind, commonly translated as meditation to withdraw the mind from the automatic responses to sense-impressions and leading to a state of perfect equanimity and awareness.
- Disability- A physical or mental condition that limits a person's movements, senses, or activities.
- Disability: Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions.
- Down syndrome- A congenital disorder arising from a chromosome defect which causes intellectual impairment and physical abnormalities including short stature and a broad facial profile. It arises from a defect involving chromosome 21, usually an extra copy (trisomy-21)
- Emotional regulation: It is an ability to control one's own emotions.
- Emotions- A strong feeling deriving from one's circumstances, mood, or relationships with others.

- Empathy- The capacity to understand the point of view of another person.
- Exemption: Getting free of or exclusion
- Fear- An unpleasant emotion caused by the threat of danger, pain, or harm.
- Gilli Danda – A Indian game in which players try to strike a small stick called gilli sharpened at both ends, to fling it far with a longer stick called danda that is thick and heavier to hit the gilli.
- Gurukulam – A type of education system in ancient India with the Student or Sishya living near or with the Guru in the same place.
- Hassle: Problem or struggle
- Hostility: Bitterness or being aggressive
- Hurdle: A problem
- Hyperactive: Over or extremely active

- Impulsive: Acting without thinking or instinctive behavior without filter
- Kabbadi – A game played in rural India between two teams of seven players, in which individuals take turns to chase and try to touch members of the opposing teams without being captured by them.
- Mainstream- The ideas, attitudes, or activities that are shared by most people and regarded as normal or conventional.
- Mathru Devo Bhava – A quote from the Taittiriya Upanishad meaning “Honor thy mother as God ”
- Meaning in life: A feeling that a one’s life has a meaning and purpose and it is derived from things we do in our daily life.
- Mental Health- A person’s condition with regard to their psychological and emotional well-being.
- Mindfulness- The quality or state of being conscious or aware of something.
- Mindfulness: It is an ability to be fully aware of the present moment, i.e. being aware of where we are and what we're doing,
- Mrigi Mudra : Deer Sign
- Multiple Disabilities- Multiple disabilities is when a person have a combination of two or more serious disabilities (e.g. Intellectual Disability with Cerebral Palsy)

- Nausea: Feeling sick and feel like one is about to vomit
- Neural circuits- Connection of neurons which carry out specific functions when activated.
- Neurotypical Children: Children with no neurological difference or without any disability.
- Niyama - observances
- Nurture- Care for and protect (someone or something) while they are growing.
- Perception- Awareness of something through the senses.
- Perceptions: The opinion of something after being understood and interpreted
- Potentialities: Possibility of something happening in future
- Pranayama - regulation of breath through certain techniques and exercises
- Pratyahara - derived from two Sanskrit words - Prati and ahara, with ahara meaning food, together they mean weaning away from ahara
- Psychoeducation- It refers to the process of providing education/information to those seeking or receiving mental health services.
- Psychological- Relating to the human mind and feelings. Affecting or arising in the minds; related to the mental and emotional state of a person.
- Rehabilitation: The process of helping a person who has suffered an illness or injury restore lost skills and so regain maximum self-sufficiency.
- Relaxation Training- It is the program in which a person is taught to relax his/her entire body.
- Resentment: Feeling of anger and disappointment
- Resilience: It is a process of adapting well in the face of trauma or tragedy, threats or significant sources of stress
- Resilience: Resilience is the ability to mentally or emotionally cope with a crisis or to return to pre-crisis status quickly.
- Safeguarding: Protecting from harm
- Samaddhi - a state of intense concentration achieved through meditation. In yoga this is regarded as the final state at which union with the divine is reached
- Scant: Limited or not available
- Scribe: A person who copies or writes said things

- Self-Esteem: Person's opinion about oneself and his/her abilities
- Self-image- The idea one has towards his/her own abilities, appearance, and personality.
- Self-Pity: Feeling sorry for yourself
- Siblings: *Sibling* is a person who shares the same parents as you.
- Socialization- The process of learning to behave in a way that is acceptable to society.
- Socialization: Mixing with people around or society
- Squint - A squint is a condition in which the eyes do not align properly. One eye turns inwards, upwards, downwards, or outwards, while the other one focuses at one spot.
- Stemming: Starting or causing
- Stereotypic Behaviour: Repetitive and purposeless movements or gestures
- Stress- A prolonged state of psychological and physiological arousal leading to negative effects on mood, cognitive capacity, immune functions, and physical health.
- Stress: Response to a stressor
- Subtle: Difficult to find out, not obvious
- Sukhasana - wellness or comfort, translated in English as Easy pose
- Surya namaskar - Salutations to the Sun, a practice in yoga as exercise incorporating a sequence of some twelve gracefully linked postures together
- Swasth Nagrik Abiyan proposed in the National Health Policy 2017 has an ambitious target of improving health seeking behavior of the population through increased awareness and enhanced uptake of health services.
- Swatch Bharath Abiyan or Clean India Mission, was started by the Government Ministry of Water and Sanitation in the year 2014, to construct toilets in households in both rural and urban areas
- Tailoring: Preparing something according to certain requirements
- Tedious: Tiring or bothersome because of its long duration
- Temperament: Person's basic nature or behavioural trait

- Verge: On border
- Viloma - Exhaling through one nostril while the other is close with fingers, the two processes together make the process of Pranayama.
- Wellbeing: *Well-being* is the experience of health, happiness, and prosperity.
- Worry- The state of being anxious and troubled over actual or potential problems.
- Yama - abstinences
- Yoga - A Hindu spiritual and ascetic discipline, a part of which including breath control, simple meditation and the adoption of specific bodily postures is widely practiced for health and relaxation
- Yoga Sutra - Yoga sutras of Patanjali are a collection of Sanskrit sutras or principles on the theory and practice of yoga.
- Yogash Chitta-Vritti-Nirodhah - meaning Yoga stills the fluctuations of the mind

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