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# Counseling Parents of Special Children: Insight from Resilient Parents

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## Abstract

Resilience is the ability to “bounce back” from adversity. Resilience research shifts our focus from the stress response to coping response. ‘Human agency’ takes center stage, which can be understood as making choices and taking actions intentionally. Defining resilience, as the ability of individuals to navigate their way to psychological, social, cultural, and physical resources in a culturally meaningful way to sustain their wellbeing, will be more meaningful in the Indian context. Factors leading to parental resilience are explored in the context of Indian society, with specific reference to Mumbai city, where the research has been done. This chapter summarizes the factors that both hinder and favor resilience and discusses the role of counselors in this process.

**Keywords:** resilience, special children, counseling, cognitive reappraisal, emotional support, socioeconomic status, social support, parenting, India

## 1. Introduction

*“I was pregnant with a lot of dreams like other mums. He was cute to look at ... all was okay, but still something was not up to the mark. He was slower than other kids of his age, I presumed. With eager anticipation, I took him to play school. Concerns from school followed by the diagnosis came like a jolt; I broke down. Why my son? Everyone around me enthusiastically spoke about their child’s achievements. I know I always wanted to be one of them ... Why me?”*

*I slowly realized that I am not in a horrible, disgusting situation as I imagined. My child is different, I need to slow down my pace and expectations. I took a deep breath, met people, read new parenting books. I had the choice of mourning or enjoying my special child! I made my choice ... Now I will do anything, whatever it takes me, I will do my best ... We shall overcome.”*

*Parent’s Voice*

It is a giant leap from ‘why me’ to ‘we shall overcome.’

Having a child with special needs can be a chronic strain for parents as the child care can cause relatively enduring problems in their day to day lives. These chronic strains differ from life events in that these occurrences are constant and prolonged over time. Caring for a special child is a doubly difficult situation, involving physical, financial and emotional stress. The stigma associated with disabilities

also increases the family's sense of isolation. Given the poor availability of support services (therapists, schools, rehabilitation, occupation), the parents carry the entire burden of responsibility unlike in developed countries where many social services are provided.

From a developing country context of poverty, inequality and multiple stressors, the ability to survive and flourish requires resilience. The concept of 'competence' describes the intrinsic need for human beings to adapt to the environment which leads to satisfaction or self-efficacy. The concept of human agency in the construct of resilience is important here. According to Hitlin and Elder [1] human agency is defined as intentionally making choices and taking action. Research by Luthar [2] who analyzed resilience research across five decades concludes that "resilience rests, fundamentally, on relationships". The availability of support systems ensures smooth adaptation even under severe conditions of stress and trauma.

This chapter illustrates the processes involved in this journey. The journey where human agency and support systems contribute to effective coping and resilience. It looks into the factors influencing the level of stress experienced by the families of children with specific disabilities and variables that aid coping. Professional counselors can help parents alleviate the stress of handling special children. They can also learn from parents who have successfully handled their special children.

## **2. Impact of a special child on parents and family**

The lives of parents take a drastic turn once the diagnosis is done. Their dreams and hopes are shattered and are filled with negative emotions. Parents of special needs children wrestle with multiple problems and unknown demands. The challenges faced are different as compared to experiences of parents of typically developing children. The emotional shock, self-doubt, blame, guilt and anxiety regarding the future, along with a lack of awareness about the child's disability and lack of parenting skills, are challenges faced by parents. Financial burden and lack of professional support make the situation even worse. Some of the shadow stressors can include marital conflicts, fatigue and loss of leisure time. Thus, the impact on a family with a special child is severe. Parents of special children also reported more physical symptoms than parents of normal children [3]. High parenting stress can worsen child behavior problems overtime, which in turn worsens parent's stress in pre-school children with intellectual disabilities according to previous research [4].

Every family is unique with its own patterns and experiences and is the primary and important social institution for every child. Family is "interacting communicative networks in which every member influences the nature of the family system and is in turn influenced by the system" [5]. Adversity can either strengthen family relationships or rupture the family bonding. Certain parents and families adapt well and stay resilient in the face of challenges [2]. However, not all of them manage to adapt. Adaptability according to Olson's Model [6] is defined as a family's ability to change its rules, roles, and power structure in response to situational and developmental stress. The systems theory in general stresses on circular causality – an idea that events are related through a series of interacting loops. An unhealthy pattern that emerges in these families can be 'fusion and triangulation' [7], which comes in the way of the family's mental health.

The emotional symptoms of a family member are expressions of the emotional symptoms of the family. Parental narrations share experiences similar to Bowen's findings. The diagnosis often is highly stressful and traumatic when parents experience a myriad of negative emotions. It is observed that parents deal with problems

associated with a special child, like how they deal with earlier stressful/traumatic experiences or how they have seen their parents dealing with such situations. Similar to “emotional fusion,” [7], parents often get caught up in the emotional connection with the child, react emotionally, without being able to think through or talk about choices they can enforce in stressful situations. Families going through anxiety show less flexibility in adapting to stress. They may take a longer time in accepting the diagnosis and reaching out to support systems. In highly stressful situations, parents seem to pass on these negative emotions onto their children in the family or to the special child. Research [8] confirms that more fusion was found in college students with disabilities compared to those without disabilities. Fusion and triangulation with family of origin were observed in children, who could not cope up with college.

Family adaptation is based on the interplay of experienced stress, available coping resources, and ecological contexts in which the individual family operates [9]. Parents are the pillars of the family structure and have a major influence on their children. This identifies the importance of working with families of special children. Having a special child is often a turning point for parents, which require a change in perception and a paradigm shift in expectations. Interviews with parents of special needs children share life stories that convey themes which have an obvious trauma (diagnosis of the child) followed by the parent moving ahead and solving/coping with these life situations or stagnating and at times regressing from the point he/she started off. It is important to recognize the unique group of parents who coped effectively in spite of multiple stressors and use this learning to guide and support those parents who need assistance and effective coping strategies.

### **3. Factors that prevent parents’ coping**

A typical scenario in a joint family (as shared by a parent).

*Akhil’s (name changed) mother suspected that her son (5years) is highly distracted and slower than her friend’s kid of the same age. His teacher was concerned that his worksheets are incomplete and he hates coloring. She informed mother about his lack of concentration in work. His father, however, felt he is playful and lazy. The father confirmed that as Akhil can concentrate while watching cartoons, his concentration cannot be an issue. Being in a joint family, Akhil’s grandmother confirmed that all her sons disliked school work.*

The above case elaborates lack of awareness as one of the factors that come up in parental narrations that impacts the child and eventually the family’s well-being. Parents tend to ignore developmental delays and attribute them to heredity, laziness or playfulness, which affects their understanding of the special child. Some parents attribute the reason for a child’s condition to metaphysical causation (one’s karma) and thus refuse to opt for remedial services.

Parent’s Voices

*“If God has decided that he has to be born to us, he will find a way out too. I don’t have to bother; God knows what needs to be done. He will take care.”*

*“It’s our destiny! My friends told me that marriage between first cousins can affect the mental health of the next generation. Our family did not listen. Nobody can change our fate now. This child is already born.”*

The above mindset delays parents opting for support services, resulting in blocking the child's progress. There is limited awareness about the causes of such conditions among the traditional, rural and lower socio-economic sections in the Indian society. Lack of awareness about the state's policies regarding the people with special needs adds to their burden.

#### Parent's Voice

*Mrs. and Mr. S shared "our son is bright as both of us are qualified and well placed. We both hail from highly educated families in the city. Our genes cannot become fragile and we cannot have a brainless child, he is just playful. He is just in the first standard; a little push can make him try harder to remember all alphabets. We don't want to accept the diagnosis".*

These parents sent their son to multiple tutors for extra coaching and refused to understand or accept their son's condition. The child was diagnosed with Fragile X syndrome.

Such a diagnosis often triggers stressors due to lack of acceptance, which contribute to imbalance in the family equilibrium. Many parents visualize the situation as a tragedy and are overwhelmed by their powerlessness to prevent it. The future seems depressing, as their child may not be able to achieve those age-appropriate developmental tasks. Grief about their child's lack of achievements and fear of stigmatization contributes to lack of acceptance. Parents feel that if they accept this diagnosis, they have to face the consequences that they fear. They believe that their persistence and teacher support will help them overcome whatever is mentioned in the medical reports. Some believe miracles to happen. Unfortunately, this attitude prevents the child from getting the adequate care required.

#### Parent's Voice

*"We believed God will take care, my wife was busy performing rituals told by the priest and I was busy with my work. I can find reasons, but I realize now that we didn't do our share. Support was around, we did not notice. Like the God who parted the Red Sea ... we believed miracles to happen, we were not practical, we can't say we did not get any support ... rather we did not opt for it."*

A parent shared his misfortune that he did not seek help at the right time. Now his daughter is 20 and is still dependent for managing her basic routines.

Some parents highlighted the role of the media for non-acceptance. The media often reflects the society's attitude, which either shows sympathy or stigmatizes special children, reactions which are not liked by many parents.

This research reflects that academic qualification and financial status do not influence the acceptance level. Lack of acceptance seems to be a factor across socio-economic classes, while the reasons for lack of acceptance vary across class. Parents from a high socioeconomic status expect more from the child, while parents from a lower socioeconomic status worry about the child's dependency and care requirements. Both these reasons prevent them from accepting reality. Anxiety about the future seems to be a concern across socioeconomic groups.

## 4. Other factors that contribute to stress

#### Parent's Voice

*"I have to travel every day by train (public transport), two hours both ways to reach the hospital where therapy is free, two days for speech therapy, three days for*

*physiotherapy and one day for meeting the doctor. All these happen at different parts of the city. We can't afford the center near our residence. Now I was told he needs to go to some special teacher for academics. Not sure how we will manage. I have two other normal children whose education is also important. Since I have to take our child everywhere, I have left my job. This adds burden on my husband. We hardly get time to talk to each other. He always comes home tired. I too am drained by the end of the day. Life is miserable."*

Children with challenging behavioral disturbances or complex physical needs add enormous stress to the family. Dependency of the child with respect to managing routine activities contributes to stressful parental experiences. Schools also require the parents to assist the child in school with their routine if the child is dependent. Children with severe behavior problems pose difficulties for parents in care giving, training them with self-help skills and monitoring their routine exercises at home which are mandatory for their progress (as suggested by therapists). Most parents are agonized at their child's physical health, treatment options and hospitalization.

In developing countries like India, public health resources are severely overburdened and parents are forced to access private healthcare. Parents from the lower socioeconomic status are not aware of the facilities available for special children. They have difficulty accessing special schools and fail to take assistance from professionals/therapists. Parents of lower- and middle-income households feel that they cannot afford private healthcare due to financial limitations. Special services like physiotherapy, occupational therapy, and speech therapy, which need to be accessed regularly for special children, become a luxury for them. Those who are ready to walk that extra mile and access public health care facilities report that they travel long hours to avail public health services and wait for a long time to get an appointment. So, child care becomes a crisis for many parents. When both parents are bread winners, lack of time also becomes an obstacle. Sometimes, families are economically strained, where the mother, the primary care giver, may not be able to return to work, which increases the burden of the working partner. Parents report that to manage the extra expenses in supporting the child, they work double shifts or take up additional part-time work. Poor access to services, lower social support coupled with the strain of poverty lead to lower levels of self-efficacy among parents from a lower socioeconomic status with regard to child care. Parents also report that financial strains, lack of energy and other resources create a lot of problems for family relationships.

Lack of support systems for parents can exacerbate stress. Support can be from professionals, schools, family and friends. Schools provide structure and a setting for the child to grow and develop skills. Schools also provide a context where there are other parents in a similar situation, providing an opportunity to meet and relate with other parents. Support from school authorities and staff members can alleviate stress, whereas a non-cooperative school environment creates stress. Parents report dearth of schools, therapists and special services. As discussed earlier, professional support is essential for parents to care for a special child. Professionals like doctors, paramedical professionals, counselors and special education teachers can help parents understand the child's condition and provide them hope about the child's future. Good therapists can be an important source of support, while encounters with unsympathetic health professionals can be very stressful.

Support from the partner, other immediate family members and children in the family can trim down stress. When partners do not actively contribute to child care and household chores, it can overburden the family, which results in special children being denied adequate care. Some parents single-handedly manage child care and expenses, which lead to health problems and emotional breakdowns for

the caregiver. Lack of support from the special child's sibling is seen as one reason for family conflict. In some families, siblings feel they are neglected, which can lead to repressed aggression or open fights at home. Parents report getting lost in these fights, which add to their emotional burden.

Emotional support to caretaking parents is mandatory for child care. Marital discord is also reported due to differences in opinion about what is best for the child. Switching roles as a primary caretaker can alleviate issues, but just one parent taking responsibility can lead to blaming and agony. Lack of time for nurturing the marriage is also reported as a trigger for marital problems.

Parents need space and time to accept and cope with the situation due to a myriad of negative emotions experienced at the time of diagnosis. Many parents are forced to take up jobs less demanding or have to opt out of a full-time dream job to take care of the child. They report feeling socially isolated from friends, extended family or social groups they wish to belong due to lack of personal time. Pessimism, anger and shame can be the emotional turnover parents face due to the child's dependency, behavior and health problems [10].

## **5. Resilient parenting and factors that support coping**

Despite problems, parents of special children show a lot of resilience. Parents who have coped effectively have narrated their experiences. The following section studies the patterns of successful coping. Parents have narrated their emotions and their inner struggles. These life stories all have an obvious trauma followed by the parents coping with this life situation (in different ways) and their interpretation of it [10].

Professionals working with special children and families may follow various models. This study does not discuss how efficient these models are, but a brief look at the models may benefit further discussions. The medical/biomedical model enumerates that these conditions exist within individuals and they are responsible for themselves. Environmental and functional models suggest that parents carry the stigma of having a special child and have to deal with societal prejudices and discrimination. The sociopolitical model aims at reducing discrimination and does not accept diagnosis aiming at full equality.

A model close to the current work is the peer counselor model, which assumes that people with direct experience with disabilities can be the best helpers, people who can assist and support parents whose children have been recently diagnosed. Counselors who work with the child and family need to understand what problems they face, social and financial. They have to assess the current level of functioning and environmental factors that either hinder or enhance functionality. Theoretical models can incorporate learning from those parents who have handled similar situations successfully.

It was seen that other than diagnosis, one's handling of the situation and support systems determine whether the situation is stressful or not. An effort is made here to understand the elements contributing to effective coping as evolved from parental experiences and professional support.

The most prominent theme in the narration is parental acceptance and awareness. Acceptance of the diagnosis and the child's condition helps in effective management of the child. Accepting the child's diagnosis emerged as the base for adaptation and resilience. The professional's role in conveying the diagnosis is extremely important. The way the diagnosis is conveyed has an impact on the parents' beliefs and expectations. It is important to clearly state the diagnosis and its impact on the child with clarity; it is important to be clear about the nature of

the condition and its implications. Realistic acceptance of the child's condition is equally important for effective child management.

Parents conclusively share how 'hope' helped them cope with problems. They reflect on their experiences and the role of the school, the doctor and other professionals, who instilled this hope. According to Snyder [11], 'hope' is a learned thinking pattern, a set of beliefs and thoughts, having very discrete ways of thinking. Having faith in achieving what one requires is important for coping and resilience. All parents who accepted the condition hoped to see progress in their child.

The ability to appraise the situation positively (Cognitive adaptation) paves the way for acceptance. It is an effective coping strategy seen in parents, who shared that they find meaning in their experiences with special children, which has made them more effective. Cognitive reappraisal of the situation helped parents in understanding the situation as more manageable, helped them to be optimistic and easily accept the diagnosis, thereby maintaining an optimistic outlook.

Many parents shared that they are the chosen parents, as they have the skill to handle special children. The tendency to reappraise the situation is sensed in terms of the parents' ability to see their inner strength and perceive the fighting spirit in them. They could perceive the situation from a different perspective, which sounds similar to the concept of cognitive illusions proposed by Taylor [12]. The Cognitive Adaptation Model proposed by Taylor [12] is based on the work done with the coping efforts of cancer patients. Taylor's model proposes that 'threats' induce adaptation by searching for meaning in the experiences, trying to gain mastery over the event and eventually life in general and by restoring self-esteem through positive evaluations. Taylor calls it 'cognitive illusions.' Adjustment is based on the ability to modify these illusions. The parents in these narrations could make a similar adaptation.

Many parents talked about esteem-enhancing cognitions. The importance of a positive outlook is shared by a parent – *"when children are small, we get to think how we will manage, but the faith that we will manage takes us ahead"* [10]. Parents share how the birth of the child changed the family dynamics positively. Spirituality aided adaptation in some narrations. Some parents mention the 'Karma' theory (sum of person's actions in one of his successive states of existence, viewed as deciding his fate for the next birth in positive light). Some parents see the birth of a child as a blessing.

Professionals and institutions working with special children can ease this process. The principal of a special school shared in her narration the importance of language used.

#### Professional's Voice

*"I realize language makes a big difference when I talk to parents. I often tell them that your child is differently abled. He/she is not their disability. He has a disability and we are here to help and streamline things for him. It is important for parents and society to become consciously aware that children are more than their disability."*

#### Parent's Voice

*"I have accepted that my son is special. Initially, I was reluctant, now I take him everywhere. ... sympathy from others at times hurts, knowing to handle those comments is important. I tell them I got a lot of luxury, money after he came, he is God. I started responding positively to questions raised by others about his conditions. This keeps those negative people away" [10].*

All the narrations and interactions with professionals working with special children confirm that higher levels of acceptance are associated with parents who either rely on themselves or seek help from support systems.

Other than parental acceptance, there are certain other parental traits that help in coping with the child's condition. *Parental perseverance* is the ability to keep pursuing their chosen paths despite difficulties. They often describe themselves in such terms as “*I am not a quitter*” and “*I never want to give up.*” “*I will do my best.*” These parents have a clear goal, which is the child's well-being. These parents put a lot of effort to learn more about their child, choose the best schools possible, and are willing to travel long distances every day for therapy sessions. These parents show the willingness to take support from others or relocate their residence and change their routines for the child.

#### Parent's Voice

*“You cannot say somebody else will help, you have to help yourself ... the amount of effort you put in, you will see that much outcome, and your effort will not go waste.”*

Parents' perseverance is not just related to how they handle their children. It is also seen in how they handle themselves – like eating on time, pursuing their hobbies etc.

The positive traits of parents seem to shield them from negativity. Parents often experience strong feelings for their child immediately after receiving the news of the disabling condition as discussed earlier. These include shock, anxiety, disbelief and disappointment as reported in narrations. Mothers often share that they wept for days together and few stopped interacting with others. However, after the initial phase of negativity, narrations had either positive or negative emotions taking over. The theme that emerges from these parental voices is *Trait Positive Affect*. Trait refers to a dispositional tendency that remains stable over time. Positive Affect is defined as the “level of pleasurable engagement with the environment” [13]. Parents who are initially negative turn positive, because they are inherently dominated by positive affect. Thus some narrations have mothers expressing positive affect, which are expressed as happiness in child rearing experiences. These narrations have shared optimism while enumerating the success stories of children. They were able to celebrate even the slightest improvement and also felt good about the effort put in by the child, themselves and family.

The role of positive emotions was illustrated by Folkman and Moskowitz [14]. When negative emotions are experienced due to a stressful event, positive emotions may provide a psychological break or respite, which support coping efforts and restock resources that stress has taken away. Thus, positive affect might help parents in strengthening psychological and physical resources during stress and protect them from depression. According to Lazarus and Folkman [15], “positive emotions reload resources that have been depleted by the stress by providing a psychological break or breather which supports coping.”

Most of the narrators who share experiencing positive emotions also share effective *emotional regulation*. They undergo negative emotions at times, which they are able to channelize instead of feeling burdened. They channelize their fears and anxieties by talking to the partner, family members or counselors. Parents also channelize their emotions by participating in routine exercises like yoga and engage in spiritual activities (visiting churches and temples, praying), thus distracting themselves from negative cogitation.

Not all narrations are positive. The narrations with dominant negative feelings are filled with feelings of pessimism, anger, shame, denial, guilt, grief, depression,

and self-blame. Parents who sound depressed and unhappy are very pessimistic in their approach. They either blame themselves, the family members, or the system. Guilt and depression affect the social lives of parents. A lot of anger towards self, significant others and at times towards their child was sensed. Some parents shared health hazards faced by them. They fail to take support, thereby failing to support their child like other parents.

#### Parent's Voice

*"I know my daughter is dependent on me for many things including self-care. I will be there and I want to be there ... I am constantly vigilant and learn/invent options to support her. Recently, I realized it has started showing on me. Lack of exercise, disrupted sleep and no time for self ... I am irritable and anxious most often and I am getting tired easily. Our marriage seems to be in doldrums too."*

Disability of a child can restrain the normal expression of emotions and thoughts of parents, as they believe that the child must be their priority. Parents share in their narrations that a negative affect results in accumulated anger resulting in outbursts, sadness and health concerns, which are often psychosomatic.

Early understanding of the diagnosis and awareness about the child's condition result in positive affect. Having adequate skills to handle the child and cognitive adaptations like finding hope and optimism facilitate positive feelings. Working with negative emotions is an important part of counseling parents. Accepting and normalizing these emotions is crucial in dealing with negative emotions. Parents are made to realize that it is not the child or the partner that is the cause of these emotions, but rather it is the condition or the disability. This helps them in handling emotions better.

Managing a special child necessitates the ability to handle countless issues. The quotes "*I can cope*" and *self-efficacy* are shared by parents, in multiple narrations. Parents who have handled previous stresses successfully, parents who are positive about handling a special child and get acquainted with other parents of special children are more confident about their current situation. Parents' narrations were similar to "mastery experiences" and "vicarious experiences from social models" as detailed by Bandura [16]. Observing other parents and listening to them enhance the belief that they can also help their own children effectively.

#### Parent's Voices

*"I lost my parents during my 10th grade. It became my responsibility to bring up my younger siblings. I managed well; both my brothers are educated and settled. I too managed a good degree in commerce and am employed in a bank. I can handle stress well. God had thought of it and has given me my child. I only can bring him up and in the process I can help others like him as well."*

*"I was lost when I heard about the diagnosis from the doctor during routine checkups. He doubted the chance of me having a child with delayed milestones and lower IQ. My husband felt we should abort this child, I was reluctant. I met parents who had children with similar difficulties, I spoke to professionals. I realized that if they can manage, I too can."*

*Assertiveness* seems to be a major factor in parents while taking decisions for themselves and their child. Their ability to say 'no' and the ability to "*stand for the child,*" while handling comments and criticism from family and society is very crucial. "*Being assertive also helps me handle negative emotions,*" says a parent. Assertion is important when it comes to spending for the child and choosing the

right school and professionals to work with one's child. Often, parents need to speak up for the child too. Parents share instances, where they may have to deal assertively with immediate family members to raise money for the child. Parents say they have to be assertive with family members, who refuse to give space to the special child in the family. Passive parents often become negative and develop guilt and anger.

*Decision-making skills* are important according to the narrations shared. The ability to assess the available options and the ability to envisage consequences of different actions along with knowing and protecting the rights of the child are shared as essential.

#### Parent's Voices

*"My son also would have done NIOS and I knew he can if I push him ... but he was not interested. I knew he needs to learn self-help skills and activities for daily living than a SSC certificate. If I prioritize exams, he would not be doing what he enjoys, nor would he be independent as he is now. He enjoys cooking and is now part of the finest hotels in the city".*

*"It was a difficult decision to relocate to Mumbai, especially leaving my husband who just had an attack, but I knew it's important for my daughter. My in-laws are there to take care of my husband, I decided. My family did not completely agree to my decision. I knew I have to manage both kids and their education and support expenses for my special child. I took it up and joined as a helper in special school and eventually completed a special education course. Now I am part of my daughter's school as a special educator. That decision to relocate to Mumbai helped our family to handle the crisis."*

Positive evaluations of situations, perseverance, assertive skills, decision-making skills and self-efficacy beliefs are all crucial for effective coping in parents. All these personal variables stem from cognitive reappraisals of parents, which lead to parents accepting the child's condition.

Parents showing the above-mentioned traits are able to come to terms faster with the child's condition compared to those parents who lack the above traits. These parents are motivated to seek information and approach professionals who could guide them to handle and nurture their child. Some of them prepare themselves by taking personal counseling.

An important factor that leads to positive adaptation in these parents is *social support*. Supports come from different levels and are seen as crucial for adaptation. Support systems for family can function at various levels. Support from the partner, children and other family members can alleviate stress and boost emotional support.

#### Parent's Voices

*"As parents, we work in shifts. My son is mentally challenged and also not very mobile. It's important that we both work, so that we can provide the best for our son. We can't afford a caretaker. My husband will be with the son after I leave for work at 8 am in the morning. My daughter who is 8 years old will reach home from school and take over the responsibility of my son. My husband will feed him and put him to sleep and leave for his night shift at 3 pm. She will take care of him till I come home from work. My daughter is our support. She is very patient with her elder brother. She is the one who taught him to sing and read alphabets. We as a family support each other."*

*“My husband without any complaints works double shifts so that I could leave my work and take care of children. There are days he comes home very tired but has a smile in his face. That smile gives me the energy to carry my child and walk to his special school and later to therapy. Now my son can walk with support. Thanks to my family and the support from my partner.”*

*“As a family, we share all responsibilities. All the chores of the family are shared by me, my in-laws, husband and my children. This helps us to give that extra time to my daughter who needs special care. My mother-in-law sees to it that I get adequate rest and I eat on time. There are days she gives me a break with my husband and manages my kids. My family is my biggest support. I am cheerful and so is my child.”*

## 6. Professionals as an important support

Professionals working with special children can support parents for all the factors discussed above. Interactions with professionals highlight that it is important to assess the needs of the family, available resources and support systems and make a tailor-made plan for each family. This will aid in identifying additional support and services crucial to improve the family's capacity to meet the developmental needs of the child and maintain family equilibrium. Research demonstrates that clients, along with what they bring to the session, are responsible for the success of counseling. So, understanding parents and their situations become important. Reflections from parent-counselor interactions as well as personal experiences of parents serve as a resource for developing, at times, unconventional styles of coping, based on 'practice-based evidence' as suggested by Egan and Reese [17].

Special schools with trained and sensitive professionals can ease the emotional strain of parents. Some schools take help from parents to speak about their experiences. These parents are trained to support other parents, who feel dejected with their child's diagnosis/disability.

### Parent's Voice

*“My child's school introduced me to a positive child, who is smiling despite his immobility and dependency on people around. He is dependent even to meet his basic needs. I was made to hear through his mother and how she is cheerful herself and could bring smile in all children in the special school. Here I learned to give space to every child and accept them as they are. Now I am not only able to accept my son with his diagnosis, but also give space to my daughter who is a normal child. My son taught me parenting and that helped me to nurture my daughter better. Parents usually decide what is good for the child, get good marks, do this do that ... my daughter is beyond all these. She is never worried for exams/marks, yet does so well in school. As a family, we are very cheerful. Thanks to the school and 'that' parent.”*

There are professional helpers to assist parents, who want to come to grips with problems in living with a special child. Every child is unique and so the requirements of parents are also unique. Parents need help in understanding the child's needs and managing them effectively, which can be achieved through counseling, family education and skilled training. Previous research also confirms that early intervention and psychosocial assistance are crucial protective factors [18]. Counseling parents soon after the diagnosis is made can work positively on the

family's belief systems. The ability to clarify and give meaning to a crisis is crucial for coping and family resilience. Counseling can strengthen family bonding and improve adaptability and flexibility in members, which will equip them to manage change. Family therapy can also aim at effective communication between family members and conflict resolution.

Often, parents require practical, informational, and educational support as soon as the diagnosis is given. Parents benefit from factual information about the causes of disability and ways of accessing resources to manage their child. Information support and services to locate professional services, including what can be expected from these services, are mandatory information parents need access to. Every state administration needs to have educational training platforms, which can be made available for all parents coming with concerns. With current technology, online programs, which are self-paced, can be made available to disseminate this information. Information regarding special schools in the locality, respite care services for parents who need a breather, and daycare programs for grown-up children can be made available. Services for children with disabilities are strongly influenced by government legislation. Professionals who work with special children need to keep themselves updated with the current government norms.

Proficiency in handling special children comes with skilled training, which introduces behavior management strategies. Parents and professionals need to work in unison.

#### Parent's Voice

*"I learned from my therapist that whatever I do with my son like helping him to manage routine or feeding, I need to do it with love and care. Also not to think of it as a task that takes 40 minutes, one hour and it is over. It should not be a monotonous therapy. My son needs repetition and I need to do it without feeling the tension that I have to do this ... Always I see to it that I am happy doing that. My child takes more than an hour to eat. As guided by my therapist, I eat first before feeding him. so I am not hungry while feeding".*

Professional support is mandatory to deal with emotions. Parent programs can help parents in dealing with stress, grief, guilt, fears and anxiety. Coping skills can be easily discussed once the emotional pain is handled. Changes in the emotional state affect the quality of parenting. Parents getting professional training, like cognitive-behavioral therapy and behavior management skills, help them cope with negative thoughts and non-productive behavior. Importance of parental programs has always been recommended in previous research [19]. Stress management interventions are found to effectively reduce the reported stress [20, 21]. Interventions of longer durations and addressing parental concerns and parenting skills have a greater impact. It can be confirmed that working with parents is a fundamental part of intervention for special children compared to letting parents working with the child alone.

Group counseling can be an excellent platform that enables parents to realize that they are not alone. Topics addressing the needs of both the child and parents are beneficial. These meetings can give parents the opportunity to develop a personal support network. Trained moderators are required to help parents handle their emotional well-being. Parents need space to vent out their anger and frustration. Group work, with a skilled professional, can address and alleviate emotional pain.

Some special schools have initiated parent support groups. As the child passes through various stages, parents need a platform to share and learn from other parents. Parents report that these support groups are seen as a place to share their fears

and find alternative solutions to their current concerns. It is a platform for parents to share feelings and ideas, where they can do physical exercises, yoga and pursue their hobbies with their children. It is a place where everyone can come together to pray to handle negativity. Some of these parent groups have started programs to make their children financially independent. Pickle making, painting, printing, making hand-made artifacts are some of the extension activities done by these support groups. Some cities in India have eat-out joints started by special children with the support of dedicated parents and Non-Government Organizations working for a social cause.

Professional assistance is required to address the special educational needs of the child. Special programs are required to address these needs, through the involvement of parents and professionals.

#### Parent's Voice

*"For others my daughter is dependent, but for me she is in the process of being independent. She started eating on her own! She has learned to button her shirt, she can signal me now if she wants to use the toilet! When she eats alone, I don't see how much she spilled, I see how much she could eat without getting tired. She started enjoying music, can sway her head with the rhythm, started smiling more often and responds when called ... my daughter is showing great improvement. I won't be talking to you this way if I had not met my daughter's special teacher. She is teaching her to be independent so patiently and also helping me identify her progress. This professional is amazing!"*

Special kids, who cannot handle sexual feelings, may require a psycho-educational approach to help them handle these feelings. Other emotional concerns like depression may require cognitive or behavioral interventions. Role play and psychodrama are used for kids who need to own up or take responsibility for their actions and eventually be more independent.

#### Parent's Voice

*"She is differently abled; her comprehension about worldly matters is poor. Her behavior bothers me, at times. She is hyper, stubborn ... she is 15 now. I recently realized that she is attracted to the opposite sex, something which happened in the school bus (parents shared the incident). I was upset, too emotional to handle but the therapist handled it well. She spoke to her like a 15-year-old; she educated her ... , explained to her without accusing and accepting her completely. Therapy to handle developmental changes is important. I am lucky to have the best one in the city to work with my daughter. I feel relieved."*

#### Professional's Voice

*"When I joined as a special educator in a regular school, I was asked to work with this girl with cerebral palsy. She was 7yrs old and got admission in this school with the class of 40 children – The so called 'normal' students. All her class mates were less than 5yrs old. With the support of class teacher, I made her pair up with one student in class each day. This friend assisted her to carry her bag, supported her with worksheet, played with her in class while others went to ground. This friend ate with her in class and sat next to her the whole day. Not only my special girl felt happy and confident, the whole class was proud and confident in assisting her. Currently she has cleared her 10th grade in flying colors. Her class mates were together in this journey. This class is known to be the most sensitive student group according to teachers. These students not only cared for their classmate but also were sensitive to all those needed support"*

This beautiful example highlights the role of professionals in not only supporting children with disability but also sensitizing the community. The point to be noted here is the trust placed on inclusion. Inclusion need to address infrastructural needs, curriculum development, suitable evaluation system and teacher training. Special educators have a major role to play in providing instruction tailored to meet the needs of the students. Diversity is a fact and inclusion is an art to support special children. Right for education is for all and cannot be denied due to any reason. Decisions about who can be educated or rehabilitated should not depend on classification systems. The classification systems will not provide the necessary information or guidance to understand child's learning pace.

There is hope with new education policy. The primary emphasis of education policy in India is to improve the quality of education for all. The Mental health care act, 2017 [22] and The Rights of Persons with Disabilities Act, 2016 [22] ensures every person have a right to live life with dignity and should not being discriminated. The New Education Policy [23] had come with more hope to children with special needs. The policy asserts that children with disabilities will have opportunities for equal participation across the educational system. Special schools will be known as alternate schools which will be equipped with trained staff to address children's educational and emotional needs. The need for humanizing education, encouraging self confidence and motivation in children with special needs is the need of the hour. This has come as a respite for parents and educators who were voicing the concerns since two decades.

Rehabilitation counseling, a specialty in the counseling profession, is particularly focused on serving individuals with disabilities [24]. These specialized counselors are not only aware of medical terminology related to a child's condition and its impact, but are also trained in skills to help the child and parents. They play a decisive role in the rehabilitation of these children towards independent living and employment, wherever possible. They are trained to do personal counseling to assist children in making social and emotional adjustments to their environment. They assist parents with educational and training resources. The recent polices bring hope to the system and the role professionals have in execution of this policies is incredible.

## **7. Conclusion**

Indian culture emphasizes the crucial role of family in the child's development. This is more pronounced in the case of family with special children, who require constant guidance and support. Parents can go through phases of denial, self-blame and stigma that prevent them from taking support for effective guidance of their child. Unrealistic expectations and anxiety about the future adds to the burden. Research suggests that adaptation by the family is based on the interaction between the stress experienced and the available coping resources.

It is the role of the professionals who work with these children to support parents and families to adapt and come out resilient. Families who emerge as resilient can be used as role models in the helping process. It is important for professionals to work on the family belief systems and nullify negative evaluations. The ability to clarify and give meaning to a crisis is crucial for resilience. Strengthening family bonding and identifying support systems outside the family can be another area professionals can work on.

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