

## PSYCHOSOCIAL SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

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### ABSTRACT

*This paper draws attention to the stress levels and coping strategies used, in the families of children with autism. Differences in the stressors perceived and coping strategies adopted by the father, mother and siblings of a child with autism have been discussed. Given that pre-intervention parental stress levels predict the success of early intervention programmes and determine the prognosis, the paper highlights the importance as well as the lack of providing psychosocial support to the families of children with autism. The authors have illustrated various ways of delivering effective support services for parents. The article progresses from child-centred, professional dependence for service delivery to developing strategies that are family centred and encourage active participation of parents of children with autism themselves. The paper also draws attention to the prevailing scenario of autism in India.*

### INTRODUCTION

Research tells us that parents of disabled children are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children (1). In addition, both the general psychological literature and specific studies of disabled children show that parental distress and family functioning impacts children in numerous ways, affecting their cognitive, behavioural and social development. Although there are many other developmental disorders, which also present parents with ongoing grief, autism is unique in several ways. First, this disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation, deafness, blindness, and aphasia. Without a definitive test, the diagnosis of and prognosis for autism is fraught

with uncertainty. This ambiguity makes it extremely difficult for parents to accept the child's condition. Second, because it is characterised by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood. As a result, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. In fact, research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children (2); than parents of children with other physical or learning disabilities (3); or parents with children with other developmental disabilities (4).

Characteristics that are common among children with autism and contribute to parenting stress, include scattered intellectual abilities or isolated skills and pervasive problem behaviour such as self-stimulatory behaviors (5). The deficit in emotional expressiveness of autistic children may lower empathy between mother and child, and thus induce greater parental stress. Existing studies of families of children with autism suggest that behavioural, social, and cognitive dimensions of the disorder are associated with stress in parents. It is true, that the more severe the child's symptoms, the greater will be the degree of parental stress (4). Furthermore, the more the negative characteristics a child has, the more socially isolated the family will be (6), and more the feelings of stigmatisation that they will experience. Gray (3) found that almost all parents with children with autism have felt stigmatised in public situations (for example at the supermarket or a shopping mall), and that parents of younger and/or more severely disabled children felt more stigmatised. Other important factors associated with parental stress in families of children with autism, include, feelings of loss of personal control, absence of spousal support, informal and professional support. Adjustments to the reality of the child's condition, housing and finance are some of the other factors that influence parental stress. In the cases of families with aggressive or violent children, the parents experienced high levels of stress and had few resources in terms of treatment or residential placement to deal with their situation (7).

As a result, family members of children with autism, are often perceived to experience negative psychological effects. Studies have found parents of autistic children to be at a higher risk for depression, social isolation and marital discord. Some parents go through periods of disbelief, deep sadness and depression and self-blame and guilt whereas others

experience helplessness, feelings of inadequacy, anger, shock and guilt. It is clear from the available studies, that the impact of the disability is borne by the family as a unit. However, while the mother, father and the siblings get affected together as a family, the effects of autism are felt individually as well. The brunt of caring for the child with autism has been shown to fall predominantly upon the mother, who may as a result, experience low parenting competence, less marital satisfaction, family adaptability and significant levels of chronic stress and fatigue (2). Also, mothers of children with autism were found to be easily upset and disappointed with their child; greatly concerned about their child's dependency; lack of vocational activities to keep their child busy, and very aware of personality problems in their child. According to Gray (7) mothers were much more likely to claim that their child's autism had severely affected their emotional well-being. It also had a significant effect on their careers. For those who did manage to work, they were often forced to miss work, perform below their normal level or drop back to part-time status. It was also found that for some mothers, this caused resentment. Mothers were also the parent who was most likely to be held responsible for their child's behaviour; both by their husbands and by people outside the family. Mothers were also significantly concerned about the effect of their child on the integration of the rest of the family. Mothers with an adolescent with autism, reported presence of significant levels of family problems, behaviour difficulties, and limitations of physical abilities and self-help skills. Moreover, these mothers were found low on ability to cope by maintaining their social system, self-esteem and psychological stability.

There is considerable and consistent evidence that mothers experience greater impact than fathers. Gray (7) found that the most striking difference between mothers and fathers was the differing personal impact of their child's autism. Although most fathers noted the severe difficulties that their child's autism presented for their families, they usually claimed that their child's condition did not have a significant effect on them personally. For fathers, the most serious effect of their child's autism was the stress experienced by their wives. The relatively less severe impact of the child's autism on most of the fathers appeared to be at least partially due to the gender roles connected to work and child rearing (7). In this regard, fathers may have seen helping their child to reach financial independence, as being consistent with their role. It was noted that the fathers felt that their sacrifice was in having to work harder to support the extra demands on the family, as a result of the child's disability. Burke

and Cigno (8) concur with these gender differences in the perceptions of and participation in parenting. Fathers were found less involved with physical care and domestic tasks, but can, and do provide a high level of support. Also, the fathers experienced considerable stress due to continual disturbed sleep and the need to take time off work, to support their partner in managing the child's behaviour.

Mothers and fathers also cope differently with emotional distress, with fathers typically suppressing their feelings, often at the cost of anger (7). A perceived lack of support from predominantly male partners has been described (8). It is also suggested that fathers sometimes 'coped', by working away from home. Mothers tend to vent their feelings and had a wider range of emotional expression, feeling grief and sadness in addition to anger and crying. They rely on talking to friends and family as a way of dealing with their emotions, particularly with other mothers with a child with autism. Gray (3) also found mothers to be more stigmatised by their child's disorder. Stigma was exacerbated among those with children who were more severely disabled or children under the age of 12.

Research indicates that siblings of children with autism are also at risk of bearing the psychological and emotional brunt of growing up alongside a child with behavioural difficulties. Many siblings have felt that their parents perceived their needs as being secondary, with more time and attention given to the child with autism. Whilst they may have a deep love for their sibling, they may also harbor feelings of resentment at the amount of time their parents are spending with the child with autism, and feel that they are being treated unfairly. Feelings of anger, embarrassment and guilt are also normal, as is feeling very protective of their sibling (9). It has been reported that the siblings of children with autism have high levels of loneliness and problems with peers. Kaminsky and Dewey (10), found loneliness to be related to a lack of social support from friends. Social support from classmates was also significantly correlated with academic problems. Siblings of children with autism are significantly more likely to experience depression than the general population. Along with psychological problems, exhaustion may affect siblings who may be responsible for domestic tasks and physical care. Problems can also be there when the increased parental expectations are not accompanied by increased parental time or attention.

There is research evidence that family stress can contribute to unfavorable prognosis. Family stress associated with limited financial resources, lack of appropriate services, and insufficient support systems are examples of family system risk factors that can contribute to poor prognosis (11). Environmental risk factors such as lack of services and negative attitudes can also have an adverse influence on the prognosis of the child with autism. One research finding of particular importance is that pre-intervention parental stress levels may be one of the strongest predictors of the success of early intervention programmes (12). However, adaptive coping strategies, informal social support sources and beliefs about the efficacy of the interventions were associated with lower levels of stress (4). Thus, the combined effects of individual, family, and systems risk factors influence the development of the child.

### **IMPORTANCE OF PARENT-SUPPORT-SERVICES**

Epidemiological reports suggest that the number of children who are receiving diagnosis of autism and ASD is rising (13). This higher prevalence could be partially attributed to better assessment procedures or better understanding of autism and pervasive developmental disorders and of the heterogeneity of behaviors of individual with autism. Additionally, many children are receiving diagnosis at earlier ages. While in the past, children typically were diagnosed around the age of 5 years when they entered school (14), there is now a great deal of knowledge about how to service preschool-age children. Consequently, children as young as 2 to 3 years, who exhibit behaviour associated with a diagnosis can qualify for early intervention services. This alarming rise in the number of children, clearly calls for additional services to meet the needs of these children and their families.

Prevalence estimates indicate that there may be as many as 2 million people in India with autism (15). Yet, autism as an area of research is still emerging in the Indian sub-continent. Aluri and Karanth (16) found that most parents reported that they initially consulted pediatricians regarding their child's problem. Professionals such as psychologists, speech language pathologists and special educators were often consulted later. Parents reported that early referrals to these professionals for appropriate intervention, would have helped and stressed the need for this information being made available to medical practitioners. In his work, Peeters (17) noted that on their lists of priorities, the association for parents' of children with autism emphasised the creation of specialized diagnostic and home-training services, classrooms for children and

adolescents with autism, living and working facilities for adults with autism, crisis intervention centres and weekends devoted to developing social skills.

Kohler (18), cited some of the problems and concerns, as reported by families, related to quality service provision for their 3 to 9 year old children with autism; these concerns included difficulty in accessing services, limited involvement in interventions, services that are not effective in meeting the needs of the child or family, and a lack of interagency collaboration. In India, where the rehabilitation of children with autism is relatively new and consists of scattered and isolated efforts, Aluri and Karanth (16) collated information on rehabilitation services available for children with Autism/PDD in Bangalore city. They found very few centers providing rehabilitation services specifically for children with autism. Also, in spite of the fact that the maximally availed services are behavioural, communication, special education programmes, and medical management services; but these services were not available at any one center.

From the developmental systems perspective, children are participants of many interacting systems. Those systems generate and are affected by sociocultural ideologies. In his work with individuals with developmental disability, Vygotsky (19) maintained that the principles of development do not differ for those with mental retardation or other disabilities. He viewed the primary difficulty for the child with developmental disabilities, as the lack of acceptance within the sociocultural milieu. He considered collaboration as essential for the development of higher psychological processes, and he emphasised the importance of children collaborating in a diverse group.

Vygotsky's view was that children compensate for their disabilities. The task of the collaborative community, then, is to aid in that compensation. He considered the compensation to be "round about developmental processes," that restructure and stabilise psychological functioning. Thus, although Vygotsky considered the fundamental processes of development to be same for children with developmental disabilities, he maintained that support from sociocultural superstructure was essential for optimal development (20).

### **DEVELOPING PARENT SUPPORT SERVICES**

Conventionally, intervention for children with autism usually involves a therapist who is usually the sole developer and implementer of training programmes. Instead of a natural

environment, therapy is conducted in a clinical setting for a designated number of hours per week. Alternatively, an expert in a given area (education, communication, physical therapy, etc.) conducts observations and assessments either in a clinic or in the child's natural environment and provides written and/or verbal recommendations for programme development. This may then be followed-up to see whether the programmes are being implemented smoothly.

Attempts are now made, to involve the parents in the intervention programmes being designed for the child. In India, the demand for service providers far exceeds the supply of available professionals, and the cost attached to accessing these services can be high. The professionals can therefore train parents in setting up their own individualised treatment programmes for their child. An expert may provide an initial short-term, hands-on training to the parents and then monitors student and trainee progress with a follow-up when as necessary. Parents are increasingly being taught the implementation of the programme through modelling and rehearsal; and the parents practise the programme with the expert's feedback (21). This method has been reported to be successful in training parents to teach a number of skills to their children, including play skills and communication (22). Involving the parents at this level, by providing more information and making them an integrated part of the child's education programme not only enhances the child's skills but is also instrumental in reinforcing belief in their own competencies (14).

### **INTERAGENCY COLLABORATION**

Families seeking to be an integral part of service-delivery process face many difficulties (21). Given the fact that autism is a spectrum disorder, it follows that a child with autism benefits from the presence of a variety of special educators (e.g. sensory therapist, occupational therapist, speech therapist etc.). A key worker or a link person is assigned, whom the parent approaches for advice about any problem related to the child (23). The key worker in turn, maintains regular contact as needed with the family, and has responsibility to work together with professionals from a range of services, and coordinating support for the family. Particularly important aspects of the service are the key worker's knowledge of and ability to access information and services from a range of agencies. Some of the positive effects in families with key workers include higher parental morale, receipt of more practical

help, greater satisfaction with respite facilities, and less isolation. The greatest value of the service was seen as having someone to talk to, whom parents could turn to for help whenever they needed (24).

Sloper and Turner (25), found that families who did not have a key worker had significantly more unmet needs, and that this was particularly the case for families with the most problems and fewest resources. Beresford's (26) survey indicated that families, who received a key worker service, did report better relationships with professionals, but not necessarily less problems with services. One of the significant reasons was suggestive of this role being taken on in an ad hoc way by a particular person, rather than it being an official part of their role. Thus, changes in service personnel or increasing demands of 'official' roles may result in a cessation or decrease in the key worker function.

#### **DEVELOPING EFFECTIVE COPING RESOURCES**

Coping with stressful situations that are beyond one's control is one of the greatest challenges of life. With no scope of reducing or eliminating the sources of stress, such situations require strategies where one changes the self to fit the situation. Understanding the ways of family coping is very important, as these are central to cognitive models of stress and coping often applied to families of children with disabilities (27). Studies have also shown that coping resources and strategies used by the families has a more decisive effect on the stress experienced by them, than the child specific variable (e.g. age, sex and severity of problem); and socio-demographic variables (e.g. social class, income and domicile) (28). Randall and Parker (29) suggest that often there are two general ways of coping, that the families use. Firstly, they make the autistic child the center of the family's attention and efforts and secondly, subjugate natural and spontaneous emotional expression, in order to show greater patience and understanding towards the child with autism. Though these strategies may be helpful in the short term, they prove detrimental to the mental health of the parents in the long run.

Gallagher, Beckman, & Cross, (6), identified the following as important coping strategies that influence the stress felt by the families: expectations, attributions, parent's view of the causation of the handicap, nature and quality of daily interactions with the child, parent's notions about their child's efficacy as 'changing agents' in facilitating child's development,

attitudes and social support. Other mediating factors that have been identified, include family beliefs and perceptions, religious and moral beliefs, overall philosophies and ideologies held by the families, family lifestyles and extent of harmony in the family (28).

The way in which a family functions, is influenced by the parent's perception of their child's difficulties. Dunn (30), studied children's close relationships and suggested that a family's response to this type of stress influenced the siblings' perception of the situation. If parents react positively to their child with special need, then the sibling relationship tends to be more positive. If the parents took an optimistic and caring view, then the sibling was more likely to do the same. Thus the parent's ability to accept their child's difficulties influence the ways in which a family functions. Cognitive mediation plays a significant role in such stressful situations and can be conceptualised in terms of two interacting processes: appraisal and coping (31). Appraisal may determine whether a situation/encounter is personally stressful or not, thus altering one's cognitive appraisal can reduce stress. The impact of events still perceived as stressful can be minimised through effective coping skills.

In India, some of the most commonly used coping strategies in times of distress is religious belief, destiny, karma theory, and theory of reincarnation. Dalal and Pande (32) investigated cultural beliefs and attitudes of a rural Indian community towards physical disability. The results revealed fatalistic attitudes and external dependence in families with disabled children. Bhan, Mehta and Chhaproo (33) found that irrespective of the economic status of families with a child with disability, intervening factors like mother's personality, optimism, and religious support were found to alleviate the degree of stress. Positive attitude, social support and faith in God, helped mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving.

Interventions focused on parents' coping skills have reported positive results. These interventions use ideas from stress and coping theories to inform parent training in problem solving and decision-making, communication skills, skills in accessing and utilising social networks, and coping strategies such as positive self-statements, self-praise and relaxation. Some successful strategies include gaining perspective, finding meaning in an event, acceptance, positive reinterpretation, and humour (34). Training has often been carried out in groups rather than and individual programme. Intervention group mothers showed a great

deal of improvements in communication skills, coping skills, satisfaction with family support and intimate support (35). Sibling support groups have been found to benefit siblings of a child with autism in offering support, but ideally follow-up sessions should be organised (36).

In their article Gupta and Singhal (37), report studies recognising families that have been successful in developing positive perceptions regarding raising a child with disability. It has been reported that families with a child with disability can and in fact do have positive perceptions which leads to a better quality of life for the family, and scope for maximising the child's potential. Positive perceptions play a central role in the coping process and assist us in dealing with the traumatic and stressful events (38). Not only do they benefit the parents and the siblings in coping with the child, the disability, and the difficulties associated with it; but it also helps the family unit as a whole.

### **PARENT-PROFESSIONAL COLLABORATION**

Collaboration between families and schools additionally supports the powerful role of parents in their children's education and therefore, provides good interventions for the children (39). This approach considers the child and family characteristics that are important in designing interventions and providing suggestions when problems arise. Conjoint behavioural consultation has been used to improve social skills of children who are socially withdrawn. Results have demonstrated greater improvements in children's social skills, following a collaborative approach rather than when only the teacher is involved (40).

Parents of children with disabilities are not only included in direct intervention of services through parent education, but they are also considered valued members of their children's special education team (41). Parents have been particularly empowered through Individualised Education Programme (IEP) meetings and IEP documents, whereby, they can be active participants in the assessment, development, and evaluation of their children's school programmes (39). This approach encourages the amount of coordination between children, their families, agencies, and schools.

### **PARENTS AS THERAPISTS**

It is now frequently acknowledged, that parents are the single most important resource for any child and must be an integral part of the service-delivery and planning process. Given

the fact that children spend the early years of life under nearly constant parental supervision, parents can serve as primary educators by directly teaching their children throughout the day in a variety of natural settings. There is a shift in the focus of intervention services from child-centered to family-centered (42).

Tunali and Power (43), studied how mothers coped with the stresses of raising an autistic child. The results indicate, that mothers of autistic children placed less emphasis on career success and were likely to believe that mothers of young children should not work outside of home. Unlike professionals and service providers, parents can give round-the-clock intervention that the children absolutely need (44).

A large body of literature on parent training involves including parents as therapists in their children's intervention programmes. Training parents as therapists increases the amount of support for children who require intensive, individualised intervention (14). It also provides a cost-effective model of service delivery and contributes to the children's rate of progress. Research has demonstrated that parents can be effective implementers of behavioural, social, and communication programmes with their children with autism. Researchers have studied the effects of including parents as direct service providers in their children's intervention process as a means of increasing the quantity and availability of intervention (44; 41) and as a means of providing support not only to the individual but also the family (5).

Parent education includes training the parents in specific procedures to work directly with their children, to teach them specific skills, reduce problem behaviours, pivotal response training (5), improve non-verbal communication skills (22), verbal communication skills (41) and increase appropriate play skills. A part of this programme also includes teaching parents to advocate for their children (41) and to provide information and support to other parents (45).

Parent education can be beneficial not only for the children but also for the parents (44). For example, parents can learn techniques to work with their children with autism, to help them overcome their socially avoidant behaviours. Parents with children with autism have reported having lower parenting competence, suggesting that they may feel uncertain about whether they are good parents. Usually, they doubt their competence because their child does not respond as expected. There appears to be increased self-blame as a coping strategy, greater

caretaker burden, family burden and more disrupted planning, reported by the mothers of children with autism (29). Since, the parents with children with autism are commonly plagued with the feelings of incompetence, parents often choose isolation over the frustrations of taking their child out in public, thus thwarting their chances of developing any support systems. This positive behavior change has potentially high reinforcement for parents.

Though in general, parent education has been shown to be an effective intervention strategy, in some situations and with some families, it has not been shown to be effective. Specific groups of parents have been identified as being less likely than others to benefit from a parent education programme alone, due to various factors. Single parents, low-income families, and parents experiencing depression, divorce or with poor social support, may be less likely than others, to benefit from such programmes without additional support (46).

#### **DESIGNING INTERVENTION STRATEGIES WITHIN ECO-BEHAVIOURAL FRAMEWORK**

Apart from the type and severity of the specific stressors caused by having a child with autism, coping with the general stress of a developmental disorder requires significant, long-term adaptation within the family, and these changes affect both the individual family members and the family unit as a whole. For a significant number of individuals, the entire burden of providing emotional, social and economic support falls on the family members, especially the parents. There is a greater burden on caretakers and a higher probability of disruptive routines within the family of a child with autism, than in the families of children with other disorders (29).

Studies indicate that the associated stress effects of having a child with autism, impact on most aspects of families' lives, including: housekeeping, finances, emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends and neighbours, the opportunities for the personal development of each family member and time spent in family recreation and leisure activities (2).

Parent-professional collaboration approach, views the child and the family in the broader environmental context. Parents may look to professionals such as physicians, therapists,

and others, who have the expertise in working with the children with disabilities to determine what they feel are the best services for their children. However, since each child is a member of a broader family system, it is important to consider the socio-cultural context when assessing the needs of individuals and their families and in developing effective intervention programmes. Thus, the support providers must consider the individual needs of each family, in order to provide effective support for families of children with disabilities.

Many variables influence families' experience of having a child with disability, and it is important to consider the individual needs of each family, when determining what support is required. Cultural values, financial needs, available resources, severity of the disability, level of social support, family structure, and geographic location are all variables to consider in designing and implementing effective intervention programmes. All, or any of these variables can enhance or limit the effectiveness of a programme and highlight the need for individualisation. For example, a low-income, single parent family would have different needs, sources of stress and/or available resources than an affluent, both parent family. Thus the level and type of support should fit the needs of the individual family. Ecological approaches can be used to provide a framework for considering a child as a member of a larger contextual system.

Ecological approach has been represented by embedded concentric circles, where the individual is represented at the core of the arrangement with each successive level, representing a larger ecological context e.g. family, school, community (47). Using formal and informal supports, services are then tailored to the needs of the family (21). A team of individuals, including the family, relatives, neighbours, and appropriate agency personnel, assist in the development of a plan directed at providing the supports, necessary to meet the needs of the family and the child. A resource coordinator facilitates the team process. Typically, this approach is used for families whose children are at a risk for removal from their homes or schools, for a variety of reasons, including substance abuse, parenting issues, and emotional or behavioural issues.

Eco-behavioural approaches have received increasing attention in the literature, as a framework to provide education and training services to individuals with challenging behaviours. To address challenging behaviors and improve lifestyle outcomes that serve to increase the overall quality of individual's life, positive behavioural support (PBS) has been

found to be successful (21). Three professional activities that could improve services to children with severe behaviour problems:

- (a) developing and implementing family-centered, home based positive behavioral support services,
- (b) expanding the analysis and intervention to focus on family routines,
- (c) teaching professionals to build collaborative partnerships (48).

PBS employs procedures derived from the behaviour analytic literature, is grounded in person-centered values, and focuses on making meaningful changes to enhance a person's quality of life (49). Behavioural interventions employed, are non-aversive and are driven by functional assessments of behaviours. Functional assessments of behaviour involve employing methods to determine the motivating variables that maintain a specific challenging behaviour. Once the functional assessments are complete, hypothesis statements regarding the function of the challenging behaviour(s) are formed. These hypothesis statements then provide the foundation by which to select ecological, antecedent, and/or consequence strategies to address the challenging behaviour.

Also inherent in a philosophy of PBS, is an emphasis on building new adaptive behavioural repertoires that address a broad range of skills that will generalise across a wide variety of people, settings, and situations. Thus, the quality of a person's life is more directly considered. At the core of PBS is the philosophy of treating individuals with dignity and respect. This approach too, requires no expert in the development of a support plan. The team collaboratively develops and ensures appropriate implementation of all aspects of the plan. Since the process is ongoing, programmes are monitored closely to ensure that they are meeting the needs of the family and child. Typically, applied to individuals with severe developmental disabilities and/or challenging behaviour, this approach has recently been extended to other strata of population including entire school systems. A variety of studies employing PBS strategies or aspects of PBS have demonstrated positive behavioural and quality of life outcomes, for individuals with autism (50).

Another ecological approach which is the Eco-cultural theory, provides a foundation for designing programmes for families with children who have disabilities. This theory emphasises

the contextual variables, including child characteristics, family values, and culture, that should be considered when assessing a family's needs and developing a support plan for that family. This theory considers a family's value systems, niche, accommodation, and perception in determining the type of treatment or support that would be most beneficial for a family (51).

The family niche involves the ways that the family's material environment (e.g. income, housing) changes over time, and accommodation refers to how a family reacts or adapts (e.g. adopting a new parenting style) to the forces in its members' lives (52). This approach considers the family members to be active participants in an active process of change. It describes the interaction among the environment, the family, and the family values. Perceptions and values are also considered as agents in the interactive process. For instance, families may perceive the severity of their child's disability differently. While one may perceive to be the most salient hurdle to overcome, another family may not consider it as the most challenging obstacle. To determine the family's value system, ecological theory looks at how families construct their daily routines (53). Ecocultural theory suggests that family values are embedded in daily routines and that families maintain their routines, in order to adapt to the continuously changing environment.

Daily routines include ordinary events that occur regularly and that family members do together, such as preparing meals, cleaning up, waking up and getting dressed. During these routines, parents interact with their children and therefore, provide their children with predictable events and natural learning opportunities. Through daily routines, children learn how they are expected to behave, and they learn the values embedded in their family system. Symon, (14) explains that a family placing high value on meal preparation and dining, might expect a child to assist in meal preparation and sitting together for meals. Whereas, another family may perceive meal times as a function of survival rather than a time of social exchange and may allow the child to eat while watching television. In general routines are based on family values, cultures and subcultures. They are means of organising the family system into meaningful events. Families rearing a child who has a disability, accommodate in certain ways by organising the environment around them into daily routines. It is important that the family accommodations made in regard to their child's disability be sustainable. If the cost of accommodating to a valued routine exceeds the benefit, the accommodation will not be sustained.

The process of raising a child with autism, presents unique challenges to families. Getting a diagnosis of autism and accepting a lifelong responsibility of bringing up a child with autism is a traumatic experience for the parents. Raising a child with autism is an all-encompassing task, that is often exhausting and isolating. As the families learn about the limitations of pediatricians, autism specialists, school systems and state intervention, many of them begin to perceive the social system as unjust and unfair, for the first time in their lives. As a result, parents quickly discover that if they do not advocate for their child with autism, that child will not receive suitable education or treatment. It is important to note how families deal with issues of grief, loss, marriage strain, stigma and shame. Several of these aspects are relevant to the issue of providing psychosocial support to the families of children with autism. The development of these approaches is a response to the call for a shift from provider-based, or expert driven services to a collaborative approach with a formal focus on family context and quality of life concerns.

### **THE INDIAN SCENARIO**

Autistic spectrum disorder represents a continuum of cognitive and neurobehavioral disorders including autism. The prevalence of autistic spectrum disorder is estimated to be 1 - 6 per 1000 (54). At India's current population, this means there are an estimated 2 million autistic persons in the country (15), assuming that there are no significant variations in this rate, worldwide. However, no empirical studies have been done in India to establish these figures as yet. While the disorder is not rare, a majority of children with autism, even in urban India, have not been diagnosed and do not receive the services they need. This problem occurs in many countries, but is especially true in India, where there is a tremendous lack of awareness and misunderstanding about autism among the medical professionals, who may either misdiagnose or under diagnose the condition.

Daley (55) reflects on the fact that the lack of research in the Indian context may reflect the fact, that some researchers have assumed that autism is rare in non-Western countries (56), or 'an illness of modern civilization' (57). In addition to recognition, the meaning attributed to a particular symptom is likely to vary. For example, a study of psychiatric disorders among children in South India found that parents did not initially report concerns about their children (it had never occurred to most parents that their children's troublesome ways were anything other than an accepted part of family life), until a researcher came along (58).

Apart from these initial difficulties of obtaining timely and accurate diagnosis, there is also the issue of availability of services to meet the needs of persons with autism. Cohen and Volkmar (59) poignantly note, 'where there is no cure, there are a hundred treatments'. Although there is no pharmacological cure for the disorder and only a few medications that appear to be effective in relieving symptoms, in her study Daley (55), found that 75% of the sample had taken medication in the past, and 42% were taking medication at the time of the interview and that children had been prescribed over 50 different medications for their 'autism'. Other treatments used by urban Indian families included pranic healing, reflexology, astrologists, acupuncture, speech therapy, vitamin therapy, tutoring, Siddha, behavior therapy, and yoga, and over half the sample had used either, or both Ayurvedic and homeopathic treatment.

Currently, the needs of children with autism in India, are not being met in either the regular or special education systems. Children with autism are frequently refused admission in these special schools because officials protest that they are not equipped to handle these children. It is important to keep in mind, that until 2003, no formal training for autism specific techniques was available in India. Since then, Rehabilitation Council of India (RCI) has established 4 training centres across India, who will annually train approximately sixty to eighty professionals adequately skilled in working with children with autism. Although, this is a drop in the ocean, it is a significant beginning.

India being a developing country, the situation is even more dismal in the rural areas. With a significant part of the population lying below the poverty line, the focus for the families is understandably on meeting the needs for daily sustenance. With low awareness levels and high levels of stigmatisation, there is an increased need for public education programmes. The media needs to be more involved in this process, as television access has very effectively succeeded to cross the geographical and educational boundaries. People with autism have a normal life span and many will require supervision after their parents' death. There is thus an urgent need to begin planning vocational centers and residential homes for these children in preparation for the time when they become adults.

Even within this framework, most of the work being done in autism focuses on the child and facilitates the improvement in the child. However, not much is done in the Indian context

focusing on a parent's difficulties and struggles and how a parent can cope with them most effectively. Even less is known about the levels of parental involvement in the whole process. An individual with autism and their families, need positive support from the system and need to know that they are respected as individuals and as human beings. In a country like India, where the awareness about autism is still emerging, and the availability of services is in rather short supply, the role of the service provider would best be described as multifaceted - an information giver, a leader, a supporter, and a guide, and sometimes an advocate against a system which often seems to work against the individuals with autism. There is a great need to develop effective service providers, willing to deal with the individual, the family and society in general and as a whole.

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