AWARENESS AND ATTITUDE OF PARENTS OF CHILDREN WITH AUTISM (CWA)

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CERTIFICATE

This is to certify that this dissertation entitled **“*Awareness and attitude of parents of Children with Autism (CWA)*”** is a bonafide work in part fulfillment for the degree of Master of Sciences (Speech Language Pathology) of the student (Registration No. 10SLP026). This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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DECLARATION

This dissertation entitled "***Awareness and attitude of parents of Children with Autism (CWA)"*** is the result of my own study under the guidance of Dr. Y.V. Geetha , Professor in Department of Speech Sciences, All India Institute of Speech and Hearing, Mysore, and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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* * *

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CHAPTER-I

INTRODUCTION

Autism is defined by the Autism Society of America (ASA) as: “Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. The symptoms change over the life of the child, and into adulthood, with some symptoms falling away and others emerging, but they are found in all cultures.”

Childhood disorders that Kanner and Asperger (1944) described over sixty years ago are called pervasive developmental disorders (PDDs) or autism spectrum disorders (ASDs). The term ASDs is used to describe conditions including autism, Asperger syndrome, pervasive developmental disorder/not otherwise specified (PDD/NOS), childhood disintegrative disorder, Rett syndrome, and fragile X syndrome. In particular, Autism is a pervasive developmental disorder that varies on a spectrum of mild to profound impairment marked by disinterest in typical social interaction; severely impaired communication skills; and repetitive, stereotypical movements, combined with narrowly circumscribed, obsessive interests. The condition affects virtually every domain of a child’s development (Hegde & Maul, 2006). Guiding the parents of children with autism (CWA) in understanding the nature of disorders on the spectrum is the first step in empowering them to deal with the condition.

Communication problems are often one of the first indicators of possible autism (Owens, Metz, & Haas, 2007). This affects the child’s ability to make sense of, and use, all forms of language and communication. A brief list of language and communication problems that a parent can observe in their child with autism includes:

- Starts talking later than other children or does not speak at all
- Does not respond to his or her name
- Does not babble point or make gestures that can easily be interpreted as communication
- Repeats what is said (echolalia)
- Speaks with an unusual tone or rhythm (such as a singsong voice)

Approximately 50 percent of children with PDD/ASD are nonverbal (Prizant, 1983). Without oral language, these children may attempt to express themselves in inappropriate ways, resulting in severe behavioural problems requiring intervention.

Current epidemiological studies carried out worldwide indicate that at least one child in every 150 new-borns has an autistic spectrum disorder. This makes autism the third most common developmental disorder, affecting upwards of fifty lakhs of people in India, more common than Down’s syndrome, spina bifida, or cancer in paediatric populations.

Awareness of autism has grown tremendously since it was first described by Leo Kanner in1943. Despite many gains that have been made in more accurately understanding and describing the causes, course and treatment of the disorder, many myths and misconceptions about autism still prevail. In many countries of the world, most of the public as well as many professionals are still unaware of how it affects people, and how to best work with individuals with autism. The majority of children with autism in India have not received a diagnosis or any intervention.

From among all the many professionals who come into contact with children, paediatricians are in the unique position to provide an early diagnosis of autism, since they are frequently the first point of professional contact for a parent. Despite their busy schedule, paediatricians are also in the best position to provide more than just a diagnosis of autism, and paediatricians in India have increasingly expressed interest in how to best direct parents about what to do next.

ASDs are mysterious and have attributes that can be strange, awe inspiring, and unexplainable, and thus there are many myths among parents about autism that abound. People think that everyone who as ASD has a special, extraordinary talent, they are mental retarded, there is no cure, have no emotions, live in their own life, do not want to socialize, do not like to be touched or hugged and these children cannot learn.

None of these points are accurate. Children with ASD can learn, communicate, interact, and can indeed break out of their ‘world’ (Aspy & Grossman, 2007).

Parents require being educated about the team approach to dealing with autism. Different professionals involved in autism assessment and intervention are:

- The developmental or child psychologist
- Child psychiatrists
- Behavioural paediatricians
- Speech and language pathologists (SLPs)
- Educational specialists
- Occupational therapists
- The parents themselves

The SLPs have a specific role to play in the assessment and management of children with ASD. Children with autism have language problems that affect comprehension and expression. Children with autism are known to have problems in the area of pragmatics. The SLP is a critical part of any diagnostic team for autism. The SLPs are initially involved in the process of differential diagnosis and assessing the strengths and weakness of a child in terms of communication and language. Following this the SLP is involved in facilitating language and communication in the child as well as equipping the parents in dealing with the communication challenges the child with autism presents, in terms of preventive and early identification.

Prevention programs are often subcategorized as primary, secondary and tertiary. Although there are currently no primary prevention programs for autism, secondary and tertiary prevention of autism is possible (Whitman, 2004). Secondary prevention programs, although not curative, are designed to prevent the full development of the disorder. An early diagnosis of autism allows secondary prevention programs to be put in place sooner, thus increasing the probability of their success. Tertiary prevention programs occur once the disorder is fully manifested and are directed more at symptom prevention, symptom reduction and behaviour management.

Participation of parents of children with autism is common place in most comprehensive intervention programs, yet, there is limited research relating to the best practices in this area (Steiner, Koegel, & Ence, 2011). While the nature of parent involvement can vary widely across programs, families, and children, the most common form of parental participation is a ‘Parent education model’, in which parents are taught techniques to work with their child so that intervention can continue in the absence of the professional (Steiner, et al., 2011).

The Parent education model, aims at educating parents of CWA with communication disorders. This involves basically providing counselling and guidance services to improve motivation, being about positive attitude changes in managing the CWA.

An attitude is a hypothetical construct that represents an individual's degree of like or dislike for something. An attitude is generally positive or negative views of a person, place, thing, or event and is often referred to as the attitude object. People can also be conflicted or ambivalent toward an object, meaning that they simultaneously possess both positive and negative attitudes toward the item in question.

Attitudes are judgments. They develop on the ABC model (affect, behaviour, and cognition). The *affective* response is an emotional response that expresses an individual's degree of preference for an entity. The *behavioural* intention is a verbal indication or typical behavioural tendency of an individual. The *cognitive* response is a cognitive evaluation of the entity that constitutes an individual's beliefs about the object. Most attitudes are the result of either direct experience or observational learning from the environment.

The parents of CWA represent a vast and important reservoir of information on the benefits and intervention process. Collecting parent ratings is considered useful in many interventions tried on their CWA. Therefore they play a key role in intervention. Increasingly parents are educated to understand the child’s problems. So their expectations are more from the clinicians. The parents play an important role in intervention by coming together around a common purpose of helping children.

The information in the recent research considers parent view during intervention process rather than to make it clinician oriented. Today it has been realized that involving parents in the care and teaching of the child with disability is absolutely crucial. The question is therefore no longer whether parents should be involved but how and when they should be involved (Balasundaram, 1995).

There are many studies focusing on measuring the awareness and attitude with respect to many of the disorders like stuttering and other speech-language disorders and by different target populations such as SLPs, teachers, public, parents or the client themselves. This knowledge will help in ascertaining the overall influence of such factors in the management of the problems in general by increasing awareness and positive attitude changes wherever required.

Need for the study:

Children with autism have been found to have deficits in various domains. But, the most common characteristics of autism that both children and adults may show in any combination, level or degree of severity are problems in socialization with people, in communicating and restricted, repetitive, or ritualistic behaviours, interests, and activities. These behaviours get negative reactions from the people around. Literature has shown that there is very little awareness on autism by parent and professionals as well.

The study is of current need simply due to the increasing number and variety of children with autism. The method may be used clinically to tap the specific deficit areas and the findings may offer direction to the intervention strategies. Moreover, studies of this kind on children with autism are scanty, especially in the context of India.

Parents must work together with the teachers to plan the development of the child in a stepwise manner and to remain alert for signs from the child that he or she may be ready to go to the next stage. The steps should be divided into easy and small parts as they cannot achieve the goal at a time. They may need help in every step of education and training. When development takes place by slow motion or when it is distorted by severe handicap, the parents must find the strength to undergo any hardship for the development of this child.

The infant and preschool child cannot do without the support of parents as their care givers. It is to the benefit of both parent and child, to equip parents with the skills to provide such support. The vast majority of parents in developing countries are not involved in service delivery because they have not been inducted into programmes where they are an integral part of services. Their experiences are not mobilised and channelled into services they can perform.

Perhaps one reason for this, particularly in India, is the aura round the term "doctor" or "professional". These experts are supposed to know all the answers. Another reason, mostly in families who are poor and uneducated or marginalised in some way, is the lack of education and information on disability. This coupled with the attitude that "doctor knows best", prevents parents from involving themselves. Parents can in fact play the role of advocate, help in special education centres, organize parent groups, and become active partners in NGOs working for disabled persons. This has been demonstrated in many countries and one of our successful community workers is a parent.

In developing countries, the opportunities for parent involvement is not structured and hence not a vital, pulsating movement which can perform near miracles. Tapping parental resources will provide a wealth of committed and dedicated individuals who can work shoulder-to-shoulder with the 'experts'. For those of us who make do with insufficient equipment, material and professional supports, 'parent power' in service delivery for persons with disability is the obvious answer.

So this type of study is of greater need which will tell awareness, attitude and acceptance of parents with regard to various factors such as: SES, urban and rural background, gender etc.

Aim of the study:

The present study is aimed to investigate the awareness and attitudes of parents of CWA towards the problem.

Objectives:

The specific objectives of the present study are:

1. To see to what extent the parents of CWA are aware of the nature, characteristic features of autism.
2. To find out the nature of attitude of parents of CWA with respect to the problem and management issues.
3. To compare and see if the attitude and awareness of parents of CWA differ with respect to SES, gender and age of the child.
4.

Clinical implication

Information obtained regarding the awareness and attitudes of parents of CWA can be used during counselling and management of CWA.

CHAPTER-II

REVIEW OF LITERATURE

This chapter explores evidence on attitudes and awareness to Autism in India, and their implications on quality of life. Attitudes of society, families and people with disabilities (PWD) themselves contribute to converting impairments into disabilities. Research in India has consistently found substantial social marginalization of people with disabilities (PWD). The attitudes of specific societies are critical in assessing both the intensity of disability (i.e., how disabling a given type or level of impairment becomes for the individual with disability) and in assessing areas where collective action is likely to fail the disabled community, and hence public action be desirable. In addition to the attitudes of the general society, the attitudes of persons with disabilities and their families are important, in some ways even more important. At the same time, the different sets of attitudes clearly interact, so that negative views about PWD in the broader community are likely to be internalized in many cases by people with disabilities and their household members.

Much of the literature on disability in India has pointed to the importance of the concept of karma in attitudes to disability, with disability perceived either as punishment for misdeeds in the past lives of the PWD, or the wrongdoings of their parents. As two Indian authors have put it, “At a profoundly serious and spiritual level, disability represents divine justice”. At a more mundane level, people with disabilities are traditionally perceived as somehow inauspicious. Much qualitative research has found considerable social marginalization of people with disabilities in India, though most also acknowledge that the social status of the PWD’s family has an impact on their potential acceptance in society. In Hindu mythology, the portrayal of people with disabilities is overwhelmingly negative, but also exhibits a strong gender bias in terms of the perceived capacities of disabled men and women.

In Bollywood films in which PWD feature, several common images of disabled men and women emerge. However, it is important also to note films that have sought to enhance the sensitivity of society towards the needs, rights, sensibilities and potential of people with disabilities - Sparsh , Black, Koshish (both old and new), Jagriti, Dosti, Main Aisa hi hun, and Koi Mil Gaya to name a few. Lagaan is an excellent example of a mainstream film that has highlighted the process of inclusion of a Dalit disabled person. In the absence of opportunities for interaction between people with disabilities and society at large, such films have played an important role in highlighting aspects of the lives of people with disabilities that are not clearly understood and in dispelling myths and biases that society holds about them. Films such as those noted have also demonstrated the attempt of non-disabled people to understand people with disabilities. At a different level, there are initial but interesting initiatives in the NGO sector on the issues of media and people with disabilities.

More broadly, much research remains to be done on assessing, and developing strategies to improve, the attitudes of public officials and service providers to PWD. Changing societal attitudes to people with disabilities, even among people with disabilities themselves at times, presents many challenges. However, a basic starting point is facts. Changing attitudes to disability is likely area where it is particularly important for governments to work with people with disabilities, NGO/DPOs, and communities.

Existing studies reveal that very often the parents have a negative attitude towards their CWD. The parents are plagued with feelings of pessimism, hostility, and shame (Rangaswami, 1995). Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are the usual parental reactions. Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt whereas others go through periods of disbelief, depression, and self-blame. The siblings also experience feelings of guilt, shame, and embarrassment (Frude, 1992).

In India, disability is still viewed in terms of a "tragedy" with a "better dead than disabled" approach, the idea being that it is not possible for disabled people to be happy or enjoy a good quality of life. Cultural beliefs about disability play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation (Sen, 1988). Studies report that parental expectations from their disabled child were mostly negative and unrealistic. Dalal and Pande, (1999) investigated cultural beliefs and attitudes of a rural Indian community towards physical disability. The results revealed fatalistic attitudes and external dependence in families with CWD. In India, there is a very strong belief in the metaphysical causation. Also, most of the respondents felt that the disabled member in their family could not do anything and just needed help and sympathy.

Studies reveal that this negative attitude adversely affects the parents. Family members of CWA are often perceived to experience harmful psychological effects. These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction (De Myer, 1979). Parents are found with unstable emotionality, constant grief, psychological ill health, and unsatisfactory social health. Studies have found them to be at a higher risk for marital discord and social isolation. The commonest psychiatric disorder that was found is dysthymia followed by generalized anxiety disorder and moderate depression (Chandorkar, 2000). It is also found that the parents of CWA perceive more problems in themselves and their family.

It has been well documented that the parents of children with disabilities (CWD) experience chronic stress. The recent research evidence has evaluated the types, degree and determinants of the stress faced by the families in caring for their disabled members (Crnic, 1995). The literature is uniform in reporting that families do experience high levels of stress. It is also noted that having a child with disabilities affects not only the parents, but also siblings and the relationships among the family members (Harris, et al., 1994).

The nature of stress has been shown to span over several aspects of family life such as daily care demands, emotional distress (e.g., maternal depression), interpersonal difficulties (e.g., parental discord), financial problems and adverse social consequences (e.g., social isolation). Stress experienced by the families is influenced by child specific variables like age, sex and severity of the problem; socio-demographic variables such as social class, family income and domicile; and family coping resources and strategies like acceptance of the child's diagnosis and perception of stigma associated with the disorder (Beresford, 1994). Additional stress is also created due to marital conflicts associated with rearing the handicapped child, extra financial burdens to obtain the necessary services, and fatigue and loss of leisure time due to care-taking responsibilities (Mc Andrew, 1979).

Added to these is the extent of behavior problems exhibited by children and adults with disabilities. Not only do child characteristics influence parental stress levels, but negative reactions from others can also serve as a source of stress for the families (Singer, et al 1993). Parenting a child with a disability increases stress in the areas of everyday management of disruptive behavior heavy care-giving responsibilities, and concerns about the future of the child when the parents are no longer able to care for him or her.

The majority of literature has highlighted the stresses and the subsequent negative consequences in caring for a CWD. The primary focus in this literature seems to be on stress, strain, grieving, and other negative issues. In fact, researchers have even proposed that when a child is diagnosed as having a severe disability, the parents may experience similar cognitive processes to those individuals who have experienced a traumatic event (Turnbull, 1986). Although many researchers have found that the families of CWD report more stress than do other families, recent research shows that there is no clear evidence that they also report fewer positive feelings or perceptions. In fact, data are suggestive of no differences or even reports of more positive perceptions in families of CWDs.

An enormous amount of research has been done to explore the stressors associated with caring for a CWD and the deleterious effects these stressors have on parents' well- being. There is research evidence that the family attitude contributes to the prognosis. Family stresses 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 (Seifer, 1992). Environmental risk factors such as lack of services and negative attitudes can also have an adverse influence on the prognosis of the child with disability.

Coping that generates positive perceptions

Coping basically involves creating, reinstating, or reinforcing meaning in the midst of stress. This aspect has long been implicated in the appraisal of stress (Lazarus, 1999) where it helps determine the personal significance of a stressful situation in relation to the individual's beliefs, goals, values, or commitments. This appraised or situational meaning shapes the emotions that the person experiences in the stressful encounter. This is in contrast with the global meaning which refers to a more abstract, generalized meaning related to people's fundamental assumptions, beliefs, and expectations about the world and the self in the world (Park, 1997).

Because stress by definition is something that an individual cannot contend with through his or her usual means of coping, a traumatic event may actually force an individual to choose a different strategy for resolving a crisis. Dabrowski's (as cited in Hague, 1995) psychological model of positive disintegration suggests that once psychological development reaches equilibrium, any further development occurs very gradually. Before rapid development and significant change can occur, disintegration of that equilibrium must take place. Moreover, he suggests that only a life crisis or a major challenge results in that disintegration.

There is evidence in the recent research that has shown that stress need not be an inevitable consequence in a family with a CWD. Mullins (1987) presented themes arising from a content analysis of 60 books written by parents of children with a variety of disabilities. He identified significant demands and emotional stress, but the majority of the authors also felt that their lives had increased meaning and enrichment as a result of their experience with their children. In a similar analysis of fathers' published accounts, Hornby (1992) noted stressful experiences and negative feelings but also strong positive feelings and claims of personal growth. Furthermore, it has been found that relatives who have been studied less intensively by researchers, such as siblings and grandparents, anecdotally reported positive views about their relative with a disability.

The functional role that positive emotions serve in the context of stressful events was considered by Lazarus, Kanner, and Folkman (1980). They hypothesized that under stressful conditions, when negative emotions are predominant, positive emotions may provide a psychological break or respite, support continued coping efforts, and replenish resources that have been depleted by the stress. Positive perceptions could be viewed as a factor ameliorating the impact of a child's disability on family members. Essentially, positive perceptions are different outcomes to stress and other negative experiences but they occur in concert with the negative or stressful experiences. Positive affect might help to bolster psychological and physical resources during stress, act as a buffer against the adverse physiological consequences of stress and help to protect against clinical depression (Folkman, et al., 2000).

Existing individual and family focused theories suggest that positive perceptions play a central role in the coping process. It has been proposed that positive perceptions may assist us to cope better with the traumatic and stressful events (Taylor, 1983). Cognitive adaptation model of responses to threatening events posits that we attempt to adapt to threatening events by searching for meaning, trying to gain mastery, and enhancing the self. A key mechanism by which this adaptation is achieved is termed as cognitive illusions (Brown, 1993). When these illusions are challenged, different perceptions will be generated in order to maintain meaning, mastery, and/or the self-system. Setting achievable goals and engaging in problem-focused coping in order to achieve them leads to feeling of control and mastery.

Problem-focused coping refers to efforts directed at solving or managing the problem that is causing distress. It includes strategies for gathering information, making decisions, planning, and resolving conflicts. It also includes efforts directed at acquiring resources (e.g., skills, tools and knowledge) to help deal with the underlying problem, and instrumental, situation-specific, task oriented actions (Lazarus,1984). In a stressful situation, it is possible to identify goals and experience efficacy, mastery, and control even in situations that appear uncontrollable and even worsening. However, this often requires relinquishing previous goals that are no longer tenable and turning to new, realistic goals (Carver, 1998).

Recent focus has also been on the factors that differentiate families who adapt successfully to the birth of a child with disabilities. It is important to study the impact of a disability on the coping effectiveness of the family unit and extend the concept of positive perceptions as a coping mechanism at the level of the family. The focus here is on family as an interacting system. Meichenbaum and Fitzpatrick (1993) affirm that recovery from a traumatic event is predicated on the ability of an individual or a family to adapt in a manner that restores faith in the goodness and inherent value of self and of life. This is accomplished through the construction of narratives, or stories, by the individual or family unit that enables them to interpret the stressful life event in a positive way.

McCubbin and Patterson (1983) discovered that some families might adapt well to raising a child with developmental disabilities; a state called "bonadaptation". Patterson's family adjustment and adaptation response model (Patterson, 1988, 1989) is focused on the processes by which families restore the balance between demands and capabilities and minimize their experience of stress. Thus, parents might attend to the positive and emphasize growth and development of the self and the family unit while minimizing limitations of the child and problems caused for the family. A further concept is that of a family schema. A positive outlook may also be a part of such a schema: the shared beliefs, meanings, and values that a family develops in order to coordinate their interaction patterns and consequently, cope or adapt to their situation.

This notion of family schema has also been discussed in the resiliency model of family stress adjustment and adaptation (McCubbin, 1993). Family schemas within this model are hypothesized to help maintain family stability. They are also the filters through which all experiences, including the appraisal of potential stressors, are evaluated. Having positively focused schemas assists families to maintain a more general positive view of events and, thereby, cope or adapt to challenges. Dunn (1996) 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 influences the ways in which a family functions.

There is research evidence that the families benefit when instead of totally depending on external agencies for rehabilitation, parents take charge of the situation and educate and train themselves. Basu and Deb (1996) observed significant improvement in the behavior, study habits and pro-social behavior of children with Attention Deficit Hyperactivity Disorder (ADHD) as a result of training parents of children with ADHD. Similarly, in their study Bhan, Mehta and Chhaproo (1998) found that irrespective of the economic status of families of a child with cerebral palsy, 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.

Poyadue (1993) maintains that there is a stage of adaptation that is beyond acceptance that might be called "appreciation" or the "all right" stage. Parents at this stage may be a resource to families facing difficulties. One effective way of doing this could be through parent support groups. In their study, Singer, et al., (1999) found that parents involved in a parent-to-parent support group reported an increase in their positive perceptions of their child with a disability. In effect, one of the key factors of success was a positive outlook on the part of supporting parents. It is imperative that the families adopt a constructive approach of sharing to promote self-confidence and urge for self-reliance to the maximum. In another study, Russell, John and Lakshmanan (1999) examined the efficacy of interactive group psycho-education on measures of parental attitude toward intellectual disability. Results indicated a significant clinical improvement in the attitude of parents, their orientation towards child rearing, knowledge of intellectual disability and the attitude towards management of intellectual disability.

Positive perceptions: an adaptive coping strategy

It has been shown that positive emotions promote creativity and flexibility in the process of thinking and problem solving (Isen, 1987). Positive affect also facilitates the processing of important, relevant information even if that information is negative and may potentially damage self- esteem (Trope, 1998). Another route through which feeling positive may offset the deleterious physiological effects of stress is through the neuroendocrine system.

The possibility that positive feelings may prevent adverse physiological effects of stress is reinforced by findings that positive and negative affects are associated with different neural structures (Cacioppo, 1999). Studies indicate that the women's positive affect, as a result of meaning-based coping in response to traumatic events, may have made them more physiologically resilient in the face of subsequent stress and may have protected them from the maladaptive neural, endocrine, and immune responses to chronic stress that can lead to diseases (McEwen, 1998).

A number of studies have examined positive outcomes of stressful events. Even though the events themselves may not have had favorable resolutions, outcomes include the perception of benefit from the stressful encounters, the acquisition of new coping skills and resources (Schaefer, et al.,1992), the perception of growth related to their stress (Nolen-Hoeksema, et al.,1999), and the spiritual or religious transformation that results from the stressful experiences.

Scorgie, et al., (1999) did a qualitative analysis of the mechanisms that led parents to achieve positive transformations in their perceptions of their child with a disability. This analysis revealed that parents arrived at a more positive state through three processes:

1) The need to form new identities,

2) Attempts to derive meaning from the situation, and

3) The development of a sense of personal control

Many parents find meaning through acquiring new roles like parent group leaders, conference speakers, or members of advisory councils for schools, hospitals or agencies representing people with disabilities.

Some other parents have focused on acquiring new traits like becoming more compassionate and less self-focused, learning that they could achieve rather than remain powerless, developing endurance or greater personal strength in the midst of their feelings of weakness, progressing from depression to being able to view life as worthwhile and of value, and facing life with new boldness rather than capitulating to fear. Though not being able to 'grin' and be 'happy' overall in life, they were however, able to cultivate a sense of humor and increase the 'happy times' in life (Scorgie, et al., 2000). Some parents have also reported loss of friendships as a result of having a CWD but also cited other parents of children with disabilities, personnel from agencies serving people with disabilities, and caring health professionals as primary members of their new friendship networks. They intimated that they might not have had relationships with such a depth if they had not had a child CWD.

One of the acquired traits rated highest by the parents was the ability to speak out on behalf of their children. Though for some it is a long and difficult learning process, it stemmed largely from their desire to protect and support their CWD. This was often done to fight against the discrimination and difficulties associated with accessing equal services. Parents have reported the exhilaration of knowing that through advocacy they have "made a difference" in someone else's life. While there have been reports of disintegration of marriage with the diagnosis of a disability, some parents have also reported that their marriage had emerged stronger as a result of parenting a child with disabilities, citing that the need to find solutions to complex situations and work together as a team required them to improve their communication skills and reinforce their marriage (Isen, 2000).

Research has also been done to understand the themes of positive perceptions. Behr, Murphy, and Summers, (1992) used exploratory factor analysis to study more than 1200 families and identified positive factors:

1) A source of happiness and love,
2) A contribution to family strength,
3) A stimulus for personal growth and development,
4) A source of pride and contribution,
5) A path to learning and contribution,
6) A key to understanding life's purpose,
7) A guide to understanding future issues, and

8) A stimulus for career growth

In a review of published research on positive perceptions of families with children with development disabilities, Hastings and Taunt, (2002) compared themes, items and factors in various research studies and found some key themes about the nature and structure of parents' positive perceptions and experiences of their child with a disability and the caregiving experience. These can be summarized as:

1) Pleasure/satisfaction in providing care for the child,
2) Child as a source of joy/happiness,
3) Sense of accomplishment in having done one's best for the child,
4) Sharing love with the child,
5) Child providing a challenge or opportunity to learn and develop,
6) Strengthened family and/or marriage,
7) Giving a new or increased sense of purpose in life,
8) Development of new skills, abilities, or new career opportunities,
9) Becoming a better person (more compassionate, less selfish, more tolerant),
10) Increased personal strength or confidence,
11) Expanded social and community networks,
12) Increased spirituality,

13) Changed perspective on life (e.g., clarified what is important in life, more aware of the future), and

14) Making the most of each day and living life at a slower pace.

Attitudes and perceptions of parents of CWA

Since 1967 the Autism Research Institute has been collecting parent ratings of the usefulness of the many interventions tried on their autistic children.The questionnaires designed to collect information from parents help them to check the benefits and adverse effects of the large variety of drugs on intervention.

An impaired ability to initiate, negotiate, and maintain adaptive social interactions with same-age peers and adult (i.e., social deficits) is the hallmark criterion of autism spectrum disorders (ASD). Parent–child informant discrepancies may also relate to parental adjustment and functioning. In parents of chronically ill children, higher ratings by parents of child’s problems (relative to children’s own ratings of their problems) relate to more parenting stress (Canning, et al., 1993), suggesting that such discrepancies are relevant to parental perceptions in disparate populations. Parent–child conflict has, in turn, been shown to predict decreased parental self-efficacy (Cinamon, et al., 2007) and increased parental stress after controlling for depressive symptoms (De Los Reyes & Kazdin, 2006).Personal factors such as gender and disability, knowledge factors such as having a close family member or a close friend with a disability were associated with more positive attitudes, supporting several earlier findings.

Beresford, Rabiee and Sloper (2007) studied the outcomes for parents with disabled children in which parents also wanted to feel confident about the services they were using and to know that professionals were working in partnership with them.In this study, parents of children (aged between 2 and 18 years) with complex health needs, degenerative conditions, autistic spectrum disorders, or children who did not use speech to communicate, were invited to participate in the project via invitations distributed by social services, health and voluntary sector professionals. Ninety mothers and eighteen fathers across three local authorities participated. All parents were interviewed: these interviews covered desired outcomes for their child and themselves. In addition, thirty-two of the parents attended focus groups with other parents of children with the same condition and of a similar age. These groups were facilitated using various exercises to help parents think about their lives now and what changes they would want to make to their lives. The discussions also explored barriers to achieving those desired outcomes and the role of services in achieving them.

Prasad and Shanbal (2011) done a study on the need for the education of parents of children with autism with communication disorders from a Speech-Language Pathologist’s (SLPs) perspective which enable the professionals (SLPs) to understand the strengths and lacunae of knowledge persisting in parents of children with ASD (CWASD). The aim of the present study was to examine the need for a parent education program (PEP) for the parents of children with ASD with reference to the communication disorders in CWASD. The study has served its aim of examining the need for a parent education program due to the following two reasons. Firstly, the positive attitude and enthusiastic response of all the participant parents to the prospect of receiving an educational program to help them better understand the challenges faced by their children. This indicates that parents would rather understand ASD through the interactive help from a professional, than read about the same through other available sources such as books and the internet. Secondly, comparison of the pre and post-training scores indicates that the relative performance of participant parents improved on the post-training questionnaire, thus showing a better understanding of ASD following the parent education program. The understanding of ASD is significant since this will better equip the parents in dealing with the condition, provide necessary and appropriate choices for intervention, educational and vocational placement in future.

Assessment tools for CWA

In these tools, parent view is considered important in assessment and intervention purpose which considered an increasing awareness toward their child disability.

Lord, Rutter, DiLavore and Risi (1989) developed Autism Diagnostic Observation Schedule (ADOS) which is the "gold standard" for assessing and diagnosing autism and pervasive developmental disorder (PDD) across ages, developmental levels, and language skills. The Autism Diagnostic Observation Schedule-Generic (ADOS-G) (2000) is a semi-structured, standardized assessment of social interaction, communication, play, and imaginative use of materials for individuals suspected of having autism spectrum disorders. The examiner observes the clients' behaviour and assigns identified segments to predetermined observational categories.

Rutter, Le Couteur and Lord (1994) developed a comprehensive interview which provides an assessment of individuals suspected of having autism or other autism spectrum disorders. The Autism Diagnostic Interview, Revised (ADI-R) has proven highly useful for formal diagnosis as well as treatment and educational planning. The ADI and the ADI-R focus on getting maximal information from the parent about the three key areas defining autism:

1) Reciprocal social interaction
2) Communication and language, and
3) Repetitive, stereotyped behaviours

The ADI-R is administered via an interview with a parent or caregiver who is familiar with the developmental history and current behaviour of the individual being evaluated. The interviewer records and codes all responses.

The Parent Interview for Autism–Clinical Version (PIA–CV) was another tool developed by Stone, et al.,(2003) to measure autism symptom severity across a wide range of behavioural domains. Two studies were conducted to examine the psychometric properties of the PIA–CV for a sample of children under 3 years old. Results of study revealed adequate internal consistency for nine of the 11 PIA–CV dimensions, as well as significant group differences on social-communication domains between 2 years old CWA and a developmentally matched sample. The second examined the association between changes in PIA–CV scores and changes in autism symptomatology from age 2 to age 4. Results revealed that changes on PIA–CV dimensions assessing social and communication skills were associated with clinically significant behavioural and diagnostic improvements. These findings support the utility of the PIA–CV for obtaining ecologically valid information from parents and for measuring behavioural change in young child. The PIA is a respondent-based interview that requires parents to make judgments about the frequency of occurrence of specific behaviours. PIA items are administered verbally, so that parents' questions can be clarified.

The information in this research is meant to consider parent view during intervention process rather to make it clinician oriented. Today it has been realized that involving parents in the care and teaching of the child with disability is absolutely crucial. The question is therefore no longer whether parents should be involved but how and when they should be involved (Balasundaram, 1995).

A large scale, two phase study to estimate prevalence, and raise awareness, about Autism Spectrum Disorders in India was done by Mukerji (2009). This project represents a large-scale attempt to estimate the prevalence of ASD in India. In parallel, a structured program to raise autism awareness in the country was be carried out. This was the first major epidemiological study of autism coupled with a structured autism awareness drive in three major cities of India which is still going on. No preliminary results found.

There are many studies focusing on measuring the awareness and attitude with respect to many of the disorders like stuttering and other speech-language disorders and for different target populations such as SLPs, teachers, public, parents or the client themselves. This knowledge will help in ascertaining the overall influence of such factors in the management of the problems in general by increasing awareness and positive attitude changes wherever required.

According to McAdoo and De Myer (1978), the autistic child is a consistent and chronic source of stress on the family. De Myer's (1979) clinical experiences reveal that the failure of a family's CWA has a debilitating impact on the structure and cohesion of the family altogether. Furthermore, these failures impede the development of the parent himself/herself to the point where their relations with their CWA may be questioned. DeMyer (1979) found that one-third of the mothers of autistic children suffered from depressive symptoms. In addition, he documented that one-third of siblings expressed feelings of neglect because most of the attention was given to their sibling with autism. Furthermore, parents with older CWA report difficulties concerning the uncertain changes in behaviour and the unstable mental condition, or perhaps worsening conditions of their CWA. As the complications of their CWA grows, De Myer (1979) stated that parents feel like perpetual caretakers, constantly worrying about the state of their CWA while expressing their inability to financially take care of them through the uses of public services, psychological resources, and institutions that have the experience to deal with autism. Through the use of a 285-item questionnaire given to 29 families, Holroyd et al., (1975) studied the levels of stress in families with CWA. Their study found that families with non-institutionalized CWA suffered from profound stress as their age increases.

Marcus's (1977) clinical experience with parents of CWA shows that parents were detrimentally affected by their children's disabilities with persistent fear, worry, and apprehension as the parent's general mindset. One of the most central issues for parents, according to Marcus (1977) was their inability to cope with their linguistic, auditory, and perceptual handicaps. Furthermore, parents with CWA have an extreme inability to cope with their autistic child's human relatedness and putting themselves in tremendous stress while the CWA gives them nothing in return. Throughout his experience in dealing with parents of CWA, he concluded that there is an urgent need for research concerning factors that may add to more progressive coping strategies, access to social activities as well as development of appropriate expectations because a parent's developmental expectations may exceed that of their autistic child's ability to perform.

Leighton (1969) reported different experiences in dealing with parents who have a CWA. Her clinical experiences included parents with difficult and perhaps even compromising circumstances that require immediate consultation which include:

1) Issues of high parental expectations for their child
2) Guilt associated with keeping a CWA, perhaps even blame-shifting concerns
3) Appropriate placement for their children
4) Family assistance and practical solutions
5) Reducing their emotional stress

The impact on family life is a significant developmental issue concerning CWA because of their incredible sensitivity to physical and emotional attachment.

Gilland Liamputtong (2011) studied the experience of stigma amongst mothers of children with Asperger's Syndrome (AS). They found that mothers perceived themselves to be stigmatized, specifically in the school and community environments. Participants also compared their own experiences of stigma with other families with physically disabled children. Several strategies were established by these mothers in order to allow them to deal with this stigma better.

Improving attitudes to people with disabilities is a key priority of the National Disability Authority (NDA). NDA committed to regular surveying to benchmark attitudes in relation to disability, and to date has carried out two such national surveys (2001 & 2006).Some of the key findings of this literature review include the following:

A) Attitudes to disability around the world

- While negative attitudes to disability persist, there is also evidence that attitudes to disability are improving in Ireland and worldwide.
- A clear relationship between attitudes and personal experience of disability was found in both the 2001 and 2006 national surveys in the Republic of Ireland as well as in many other studies worldwide.
- Negative attitudes towards intimate relationships for PWDs indicate that PWDs are still not fully integrated within society.
- PWDs who voluntarily meet with other people with disabilities collectively may hold the most positive attitudes of all towards disability.
- The negative attitudes of PWDs towards disability and other people with disabilities is an area that requires attention as such attitudes can slow progress towards equality.

B) Changing attitudes

- Understanding social constructions of disability and impairment can help to explain why people with disabilities have been marginalised and discriminated against and can draw attention to what needs to be done to eliminate negative attitudes.
- Attitudes are complex so interventions must also be wide-ranging.
- It is important to understand what each intervention can bring to change behaviour and attitudes and how interventions interlink.

- Contact with people with disabilities under particular conditions can reduce prejudice.
- Affective ties including forming close friendships appear to be very effective in reducing prejudice.
- Disability Awareness Training is required for all but how it is carried out is important. The impact of disability awareness training should be evaluated.
- In the absence of personal experience and contact, the media may play a larger role in determining attitudes and knowledge than otherwise and, in these circumstances, the need for an enlightened, responsible and non-discriminatory media culture becomes more important.
- Understanding and promoting the values underpinning basic human rights or the basic human conditions required for development - equality, autonomy, dignity and solidarity/social justice - is essential if governments and individuals are to commit themselves to ensuring that each and every person can access the conditions required to live as self-determining individuals.

The need to investigate attitudes

At the 2006 NDA Research Conference in Dublin, Bert Massie, Chairperson of the UK Disability Rights Commission, said: "Attitudes to disability are the major barrier to disabled peoples' full participation. From pity, awkwardness and fear, to low expectations about what PWDs can contribute, stereotypical and negative attitudes hold people back" (Massie, 2006). "People with disabilities regularly identify societal attitudes as the most potent and negative stressor in their lives..."(Voh, 1993).

As long as negative attitudes persist, the full rightful acceptance of PWDs is unlikely (Nowicki, 2006). Recognizing that PWDs are still exposed to and oppressed by prejudice and discrimination may be the first step in reducing prejudice (Genesi, 2007).

In *'Everybody Belongs'*, Shapiro (2000) discusses how negative myths and stereotypes continue to create ingrained prejudices toward PWDs. These prejudices are reflected in negative attitudes and behaviour, which can impede the participation of people with disabilities in social, educational and vocational contexts (White, 2006).

The study by Rosenthal, et al., (2006) demonstrates that how negative social attitudes block the integration of PWDs into society. They also demonstrate the constrictive effects of negative societal attitudes in preventing individuals with disabilities from "mainstreaming into society". Deal (2006) also cites studies that demonstrate that attitudes towards PWDs are predominantly negative and are linked to behaviours such as social rejection and maintenance of higher levels of social distance toward PWDs.

The negative attitudes resulting in discrimination in the workplace continues to be a significant problem for PWDs (Brostrand, 2006). In spite of the 1990 ADA legislation in the USA, discrimination at work, rooted in negative attitudes, continues to adversely affect employment outcomes (Brostrand, 2006).

Societal attitudes influence social policy and legislation and there is support for the societal attitudes theory that public attitudes dictate, to a considerable extent social policy (Hewes, et al., 1998). Negative public attitudes can be a formidable barrier to the success of particular policies because the public significantly influences how much importance is given to an issue. This situation is not helped by the fact that "disabled people are under-represented in the public sector, particularly in strategic and management positions. They are under-represented where decisions about policy and service provision are taken" (Massie, 2006).

While many researchers highlight the fact that negative attitudes to disability persist including Brostrand (2006), as well as those mentioned earlier, there is also evidence that attitudes to disability are improving.

Studies related to attitudes towards disability around the world

In England, Deal (2006) in his doctoral research found that people with and without disabilities had similar attitudes to disability. These attitudes fell within the positive threshold of the scale, reflecting a positive attitude towards disability. More negative attitudes were found in both groups when a subtle prejudice subscale was used. PWDs who voluntarily met with other PWDs collectively held the most positive attitudes of all towards disability.

In the 2004 Canadian Attitudes Survey (Office of Disability Issues, Canada), there was broad agreement among people with and without disabilities that progress had been made towards including people with disabilities in Canadian society. However, respondents considered that PWDs still faced numerous barriers, first and foremost being the negative attitudes and prejudices of other people and society.

In the UK 2002 Attitudes Towards Disability Study, *Disabled for Life* (Grewal, et al., 2002), commissioned by the Department for Work and Pensions (DPG), the majority of the 2064 respondents, of whom 47% had a disability, thought that the position of PWDs had improved in the prior two decades but that strong attitudinal and structural barriers remained. The study showed a continuum of attitudes towards disability from inclusive attitudes, characterized by a positive view of the lives of PWDs and a broad definition of disability to exclusionary attitudes that focused on differences negatively.

Diversity in Disability (Molloy, et al., 2003), a follow-on qualitative study from the 2002 UK Survey, *Disabled for Life*, also commissioned by the DPG, involved 103 people with disabilities. *Participants* in the study believed that progress had been made in society and that opportunities for PWDs had substantially increased. They described a range of life experiences and attitudes. They considered that negative attitudes to disability can lead to low self-esteem, restricted opportunities for PWDs to fully participate in key areas of life and ongoing adverse effects on the physical and mental health of PWDs.

Attitudes are directly influenced through questioning, personal experience and positive or negative reinforcement Attitudes are indirectly influenced through social learning and observation or by learning through association (Fossey, 1993; Sdorow, 1990 cited by Eby, et al., 1998).

The role of direct experience may be particularly important in attitude formation. Positive effects of contact have been demonstrated in many domains including attitudes towards the elderly, psychiatric patients and children with disability (Hewstone, 2003). Attitudes formed through direct experience may be better predictors of later behavior than attitudes formed through indirect experience. The superior predictive power of attitudes formed through direct experience is not necessarily a function of the amount of information about the attitude object available to the individual (Fazio, et al., 1978 cited by Eby. et al., 1998). Direct experience may affect the attitude formation process by altering the way in which available information is processed.

Hewstone (2003) attempted to answer how direct contact between groups work in changing attitudes and diminishing or banishing prejudices. He proposed four major potential mechanisms:

1) Learning about the other group, the "out group"
2) behavior-driven attitude change e.g. forming more positive attitudes after cooperating in a learning task
3) "In-group" reappraisal and
4) Generating affective ties

It is generating affective ties, including the formation of close friendships that seems to be most effective in reducing prejudice.

Research has shown that the effects of attitude change depend on a host of individual and situational factors. A range of factors produces attitude change by different processes in different situations. There are multiple specific processes that can determine the extent and direction of attitude change (Petty, et al., 1998). Based on the research evidence, they consider it useful to divide the processes responsible for modifying attitudes into those that emphasize effortful thinking about the main merits of the attitude object from those that do not. Such a framework allows understanding and prediction of the variables which will affect attitudes, by what processes in what situations and the consequences of these attitudes (Petty, et al., 1998). Attitudes that are changed as a result of considerable mental effort tend to be stronger than those changed with little thought and are more predictive of behavior. Such attitudes are also more persistent and resistant to counter-persuasion than attitudes that are changed by processes involving little mental effort in assessing the main merits of the attitude object (Petty et al, 1998). Petty et al consider it useful to regard attitudes as falling along a continuum ranging from none to strong attitudes (Fazio, 1986).

When studying interventions to tackle negative attitudes and their consequences, the motives that generate attitude change and resistance are important. Wood (2000) reviewed the literature, focusing on the 2-year period from 1996 to 1998 and found three central motives involved in attitude change. These involved 1) concerns with the self and with others, 2) the rewards/punishments they can provide, and 3) a valid understanding of reality.

Emotional distress in parents of CWA

Raising a child with an autism spectrum disorder (ASD) has often been associated with higher levels of parenting stress and psychological distress, and a number of studies have examined the role of psychological processes as mediators of the impact of child's problem behavior on parent mental health. Weiss, et al., (2012) examined the relations among the child's problem behavior, parent mental health, psychological acceptance, and parent empowerment. Participants included 228 parents of children diagnosed with ASD, 6–21 years of age. As expected, psychological acceptance and empowerment were negatively related to the severity of parent mental health problems. When acceptance and empowerment were compared with each other through test of multiple mediations, only psychological acceptance emerged as a significant partial mediator of the path between child's problem behavior and parent mental health problems. As child's problem behavior increased, parents' psychological acceptance decreased, resulting in an increase in parent mental health problems.

Sivberg's (2002) study focused on the coping strategies of parents of children with autistic spectrum disorders (ASD) and the relation between these strategies and parenting styles. Coping strategies were measured using the Sense of Coherence Scale (SOC) and the Purpose in Life Test (PIL-R). Parental attitudes toward loving care, stress, worry, and guilt feelings were assessed using the Family Impact Questionnaire. Two groups of participants were included: parents of children with ASD (EG) (n = 66) and a matched control group (CG) (n = 66). SOC showed a stress-reducing effect in both the EG and CG. PIL-R explained 50% of the variance in SOC for the EG and 33% for the CG. The only significant gender difference in the EG was on SOC indicating a higher sense of coherence among the fathers and probably an indicator of a stronger burnout effect of the mothers.

Mathew et al., (2012) investigated discrepancies between parent and self-reported social functioning among youth with autism spectrum disorders (ASD). Three distinct samples showed discrepancies indicating that parents viewed their children as performing one standard deviation below standardization mean, while youth viewed themselves as comparably-skilled relative to peers. Discrepancies predicted lower parental self-efficacy, and lower youth reported hostile attributions to peers, marginally-lower depression, and decreased post-treatment social anxiety. Discrepancies predicted outcomes better than parent or youth report alone. Informant discrepancies may provide valuable additional information regarding child psychopathology, parental perceptions of parenting stress, and youth treatment response. Findings support a model where abnormal self-perceptions in ASD stem from inflated imputation of subjective experiences to others, and provide direction for improving interventions for youth and parents.

Awareness on disability

Koch (2011) had done qualitative study to explore the experiences of teachers who have a dual role, one of being both parent and teacher of a child or children with disabilities. Data were collected in a qualitative methodology (phenomenology) through semi-structured, one-on-one interviews with participants about their experiences of being both a parent and a teacher of children with disabilities. Questions focused on (1) how the teachers experienced their roles, (2) how they addressed role conflict, (3) their experiences in communication with parents of children with disabilities and their general education colleagues, and (4) their thoughts and experiences regarding their pedagogy. An analysis of the findings revealed that special education teachers who are parents believe that their parenting experience has had a positive influence on their teaching practices and pedagogy. Those parent-teachers, who have children with a disability, report they are better able to empathize with the parents of their students, have a better understanding of what it means to be a student with a disability and can bring a broader knowledge of disability and disability intervention to the classroom. Suggestions for pre-service and in-service teacher's professional development are offered, the most important being disability awareness and understanding of the parent's experience.

Awareness about ASD

York, et al., (1999) examined the awareness and knowledge of fragile-X syndrome, Down's syndrome and autism amongst staff in special and mainstream education. One hundred and two special school staff and 40 mainstream school staff completed questionnaires. Most staff offered a variety of features 'typical' of Down's syndrome and autism. In contrast, staff knew less about fragile-X syndrome. Specific knowledge about the learning styles of these children was very poor, but was associated with having taught an affected child. Mainstream and special school staff offered similar levels of knowledge for all three conditions. Staff did not demonstrate a sufficiently specialized knowledge of fragile-X syndrome to ensure that the special educational needs of these children were being met fully.

Loynes (2001) presented a report compiled for the All Party Parliamentary Group on Autism where they concluded that whilst there is the need for more financial outlay for people with autism, it has been demonstrated that preventative work to avoid crises for individual with autism and their families can save money in the long term, and enable people with autism to achieve their full potential.

Daley’s (2004) study provides data on the process of initial symptom recognition which help in initial diagnosis of a pervasive developmental disorder in India. The period of time between initial recognition of a symptom and initial diagnosis warrants examination because it can serve as a window into broader cultural factors and allow for more immediate treatment. Research on this process among parents of CWA to date has been useful, but has been limited to families in Western countries, whereas autism occurs all over the world. The current study provides data on the process of initial symptom recognition, help-seeking, and initial diagnosis of a pervasive developmental disorder among 95 families of CWA in India. The findings suggest that the specific symptoms that parents initially recognize may be associated with the speed with which they receive a diagnosis, and that the saliency of symptoms may be culturally shaped. Environmental, cultural, and socioeconomic factors may also have an impact on whether a parent receives a diagnosis. Implications for professional awareness and increased accuracy of diagnosis are also suggested.

O'Connell and Jean (2011) present a resource guide for general educators to use to increase their knowledge and awareness of the students with autism. The general consensus amongst many general educators is that they are under-prepared to work with students with disabilities, particularly those with autism spectrum disorders. This can be due to a lack of awareness programs available at school sites, but also a lack of disability awareness courses at the teacher preparation level at universities and/or colleges. This project presents a resource guide for general educators to use to increase their knowledge and awareness of the students with autism in a small district school. The development of this resource included the distribution of a questionnaire among staff at an elementary school to inquire their current knowledge about autism and what information would further increase their awareness about students with autism. Based on findings from this questionnaire, the resource guide was created and then professionals within the school district were asked to review the document and provide feedback. The final product includes, but is not limited to: basic components of autism, behaviors and interventions, sensory interventions, as well other supports and services needed to successfully include a student with an autism spectrum disorder into a general education classroom. The resource guide is composed in an A-Z format, with each letter representing information related to different characteristics of autism or strategies to support students with autism in their school environments. In the resource, educators are also presented with recommendations on how to implement the resource within the general education environment with other educators and potentially elementary-aged students who are typically developing. Ultimately, the goal for this resource is to increase awareness and facilitate dialogue between general educators and special educators as an initial step towards the creation of inclusive opportunities for students with autism.

Rahbar, Ibrahim and Assassi (2011) studied the knowledge and attitude of general practitioners regarding autism in Karachi. The general practitioners (GPs) have an important role in early diagnosis of autism. There have been no studies evaluating the knowledge of GPs regarding autism in Pakistan. They aimed to fill that gap by assessing knowledge and attitude of GPs in Karachi regarding autism. They conducted a crosssectional survey of 348 GPs; only 148 (44.6%) had heard of ‘‘autism.’’ Results show that GPs less than 30 years of age and those who obtained their medical degree in the last 5 years were more likely to report knowledge about autism. In addition, among those reporting knowledge about autism, many held misconceptions regarding the signs and symptoms and etiology.

Attitudes towards disability

Quality of life is a complex constructs one that has gained attention with increasing frequency in the field of disabilities. One aspect of quality of life for all persons is spirituality and religion. Often PWDs are not participating in religious and spiritual activities to the degree that persons without disabilities participate. The purpose of Jones (2010), investigation was to describe the ways in which families that have sons or daughters with disabilities participate in their faith communities (e.g., churches, synagogues, temples) and explore the factors that may influence their participation. The study used a mixed-methods approach in two phases: (a) a survey to determine demographic information, the type and frequency of the parent and child participation in faith communities, features available to support inclusion in the faith community, available programs and their helpfulness, and open-ended questions regarding inclusive practices; and (b) interviews of a sample of the respondents to contextualize the findings and provide detailed experiences of parents. The results indicate that those in the sample were primarily of the Christian faith, they were frequent attendees at their places of worship, and their faith was important to them. Most individuals with disabilities were involved in regular activities with their peers; however, a fifth of the individuals did not participate in any activities. Families who felt supported were more likely to be frequent attendees, children in large faith communities were more likely to be in segregated programs and parents of children with mild disabilities and of children with moderate to severe cognitive disabilities were more likely to report their faith community.

Other disorders

Roeher (1979) studied the attitudes of parents towards mental retardation: implications for medical practice. In this study the cooperation of professionals was sought in the way in which they counsel parents with children with mental retardation. Problems have arisen from existing societal attitudes and prejudices which have had the effect of misguiding those who provide information and advice, such as the family physician. Scientific studies of attitudes have led to some understanding of attitude formation and change, offering some approaches to easing the problem.

Govender (2002) studied the attitudes of parents in rural areas of Zululand towards mental retardation. The majority of parents in rural areas of Zululand were found to have a positive attitude towards their children with MR. Although a small proportion of parents had a negative attitude, no parents were found to have a strongly negative attitude.

Attitudes of parents of children with ASD

A lot has been written about the stressors in the lives of parents of children with disabilities. Studies have been done to understand the types, causes and the effects of these stresses. Most often, only the negative aspects of this situation are highlighted. The work is primarily addressed towards understanding and measuring the negative attitude and adverse consequences of having CWDs. Gupta and Singhal (2004) studied on positive perceptions in parents of children with disabilities. They examined the existing research done on this aspect and taken a step forward and focused on the cognitive processes as a result of experiencing a traumatic event. The authors move away from the negative outcomes and highlight the process of developing positive perceptions in these parents. The focus is on the process of coping that generates positive perceptions and the ways that these positive perceptions are used as an effective coping strategy.

Park, Chitiyol and Choi (2010) examined pre-service teachers' attitudes towards CWA in the USA. The research has contributed to better understanding of the disorder, shifting of conceptualizations as well as changing of professionals' and families' perceptions and attitudes towards the disorder. Together, these changes have helped to promote better outcomes among children with autism. This study was designed to examine pre-service teachers' attitudes towards CWA. Results indicated that pre-service teachers had positive attitudes towards CWA. The pre-service teachers' attitudes were found to be influenced by their gender, academic major and different types of exposure to CWA.

Morton and Campbell (2011) examined the effects of information source on peers' cognitive and behavioral attitudes toward an unfamiliar child with autism. Children (N = 296; M age = 10.21 years) received information about an unfamiliar child with autism from one of the following sources: (a) videotape, (b) teacher, (c) hypothetical mother, (d) hypothetical father, or (e) hypothetical "doctor." Interactive effects between source, and sex and grade were found for cognitive and behavioral attitudes. Fifth-graders reported more favorable cognitive and behavioral attitudes when information was provided by extra-familial sources (i.e., "doctor") versus parent sources. Mother yielded more persuasive effects on behavioral attitudes for third-graders versus fifth-graders. Attitudes toward autism differ depending on who provides information about the disability. Persuasion theory appears useful to guide evaluation of educational interventions to improve attitudes towards autism.

Many studies have been conducted to observe the effect of contact on attitudes toward people with mental illnesses, but few studies have observed the effect of contact on attitudes toward individuals on the autism spectrum specifically.

From the above studies we can conclude that parents play an important role in assessment as well as intervention part, so we should also consider parent view while assessing and managing CWA. Now a days parent are very much concern about their child development whether they are educated or not. It also helps family to develop a positive outlook in the serving point of intervention. Although, the research in this area is limited as yet, most often the intervention is done at the level of the child and addressing the disability per se. Therapists might want to concentrate on this aspect and facilitate families' coping processes by encouraging and supporting positive outlook on self and life which can further help in therapy. This can be executed through the course of family therapy, marital therapy, or individual counseling.

CHAPTER III

METHOD

The present investigation sought to investigate the awareness and attitudes of parents of Children with Autism (CWA).

Participants

The participants consisted of 85 parents (both fathers and mothers) of CWA within the age range 20 to 50 years. The majority of the sample consisted of parents with children attending speech therapy which caters mainly, for children from urban areas. The rest of the sample were parents of CWA who attended therapy at AIISH, Mysore. Fifteen of these parents were fathers and seventy were mothers(Table 1).

Table 1: Distribution of participants for the study

Gender	N	%
Females	70	82.4
Males	15	17.6
Total Sample	85	100

There was higher proportion of females than males in the sample. The respondents were predominantly Hindi speaking (which reflected the dominant national language of the area in which the study was conducted). It can thus be assumed that the sample reflects to a large extent attitudes typically held by members of the north Indian population. All respondents were surveyed on a voluntary basis.

Inclusion criteria:

The participants should be parents of children diagnosed as ASD by a professional including speech language pathologist and clinical psychologist, pediatrician or a child psychiatrist irrespective of the type of Autism at least 6 months prior to the data collection.

Exclusion criteria:

Children should not have any other associated abnormalities such as hearing loss, language problem, fluency disorder, voice disorder, motor speech disorder. The children had attended speech and language intervention for more than 6 month.

Materials:

1. A questionnaire developed in English covering various aspects of awareness and attitudes of parents with respect to ASDs based on literature review was used as the material for data collection for the study. This was pilot tested taking input from a couple of SLPs working with CWA and five parents before finalizing the same. Questionnaire consisted of demographic information and statements related to the awareness and attitudes about Autism, demographic data and involved the rating scale (ordinal) on Social interaction, Communication and language; and other characteristic features of Autism. The questionnaire was prepared which consisted of four domain related to ASD (Appendix A). Each question was formulated to address questions related to awareness and attitudes of parents regarding the below four categories of:

    1) Awareness on knowledge, cause and characteristics

2) Awareness on management
3) Attitude at home environment
4) Attitude of other people towards CWA

This questionnaire was modified after the pilot study and input from the qualified SLPs. The questionnaire comprising forty eight statements of close ended questions served as the measuring instrument. The responses were obtained from the participants using interviewing method. Respondents had to indicate to tick mark on yes or no if they agree or did not agree respectively with the each statement. The higher the scores, the more positive the participants' attitude and vice versa.

2. *Socio Economic Status (SES) Scale-2011* developed and standardized by Venkatesan (2011) was used to obtain the overall SES score.

Procedure:

The questionnaires were administered to the parents of CWA individually with the instructions (by reading the question or rephrasing it) by the investigator if they had any problem in understanding question. Parents were asked to fill out the questionnaire.

Parents were first informed of the study by the professional. Parent’s consent to participate in the study was obtained. Parents who decided to participate were given time to complete the questionnaire without discussing with the others. Instructions and questions were read out and explained individually to the parents and response was obtained.

Scoring:

Data collected was scored and coded by the researcher. All coding was rechecked by the researcher. Information on scoring is reported in Chapter 4.

Data analysis

Frequencies and percentages of responses were tabulated for the total sample and suitable statistical analyses were carried out to answer the research questions.

CHAPTER V

RESULTS AND DISCUSSION

The aim of the study was to investigate the awareness and attitudes of parents of CWA towards the problem. A questionnaire was prepared for the purpose incorporating items related to awareness and attitudes of parents in terms of causes, characteristic features, diagnosis and management. Eighty five parents of CWS in the age range of 20-50 years, were administered the questionnaire, irrespective of gender, language and severity of their children's autism. The parents were classified under fathers and mothers as shown in Figure 1.

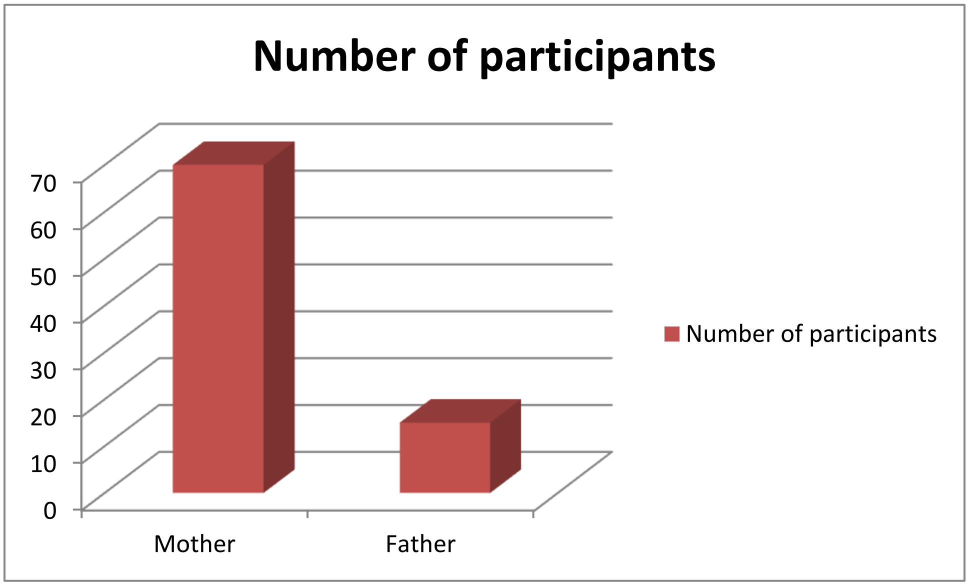

Figure 1: Number of fathers and mothers

Totally 85parents took part in the study. From the above table we can see that majority of the participants were mothers (88%) as mothers are the ones who are much concerned about their children and always accompany them for therapy. But some of the fathers were also available to participate in the study since they were accompanying the child for therapy regularly in spite of their busy schedule.

The data collected in the form of questionnaire has been analyzed and the results are discussed below under three broad headings:

1) Parents' awareness of the nature, characteristic features and management of autism.
2) The attitude of parents of CWA and other peoples' attitude with respect to the problem and management issues
3) The attitude and awareness of parents of CWA with respect to SES, gender and age.

1) Awareness of parents

The questionnaire used in the study consisted of forty one questions on awareness which included Part-A with thirty two questions related to knowledge, causes & characteristics in which last four questions is converted into nine questions for better analysis and Part-B with nine questions related to awareness, regarding management.

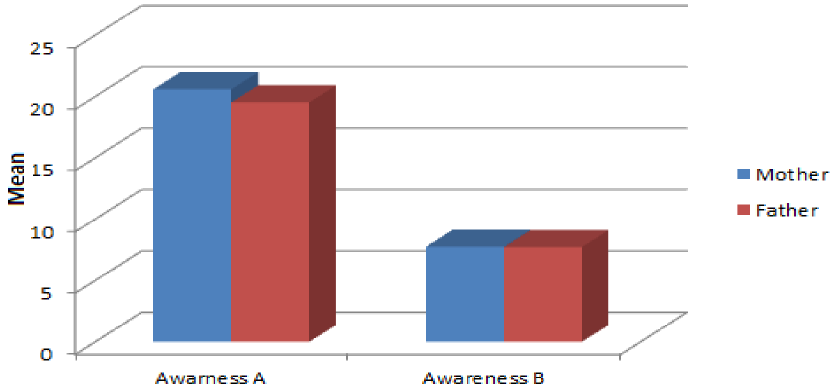

Figure 2: Mean scores of awareness between Mothers and Fathers

It is evident from the Figure 2 that the mean scores of mothers in Awareness -Part A are slightly higher than that of the fathers, although not very significant. That is, they are more aware with respect to some of the aspects about autism compared to the fathers. Also, awareness regarding Part-A items are much higher compared to Part-B in which both the fathers and mothers obtained low mean scores. This suggests that they are less aware about the management issues compared to the causes and characteristics. This is because characteristic features of CWA can be perceived easily and it is visible to all parents of CWA and other people but Awareness-B which is related to management and causes are more related to parent knowledge about CWA and how much they are concerned about their child. Regarding awareness many professionals are also not aware about the management of CWA and have misconceptions about it. Still research is going on the management of Autism in western countries but as compare to India the studies are scanty.

There are many studies which are in agreement with the above findings. Mullins (1987) did content analysis of 60 books written by parents of children with a variety of disabilities. He noted that with increased experience with their children they become more aware of their behaviour. Koch (2011) did a study which explored the experiences of teachers who have a dual role, of being both parent and teacher of a child or children with disabilities. He noted that teachers who were parents of children with disabilities had better understanding of what it means to be a student with a disability and can bring a broader knowledge of disability and disability intervention to the classroom. To check for the significance of association between the responses of parents, Mann-Whitney U Test was done. Table 1 show that there is no significant association.

*Table 2***:** Mann Whitney U test for comparison between Mother and Father

Parameters	**Awareness-A**	**Awareness-B**
Z	-.927	-.426
Asymp. Sig. (2-tailed)	.354	.670

From the above analysis it can be seen that there is no significant difference (p>.05) between the awareness of mothers and fathers with respect to knowledge, cause and characteristics and question related to awareness regarding management issues. Both parents have similar levels of awareness about CWA. This is because parents share their feelings for their CWA at home and have same amount of awareness between them regarding knowledge of causes, characteristic and management.

Daley's (2004) noted that if we recognize initial symptoms it can help in initial diagnosis of a pervasive developmental disorder. Rahbar, et al., (2011) observed that in Karachi although the General Practitioners (GP) has knowledge about autism, many held misconceptions regarding the signs and symptoms and etiology. Since the overall scores did not reveal a significant difference on awareness, subsequently the scores of individual questions related to characteristic, causes and management was compared using chi square test and significant difference was found (p<0.05) for some of the questions related to Part-A on characteristic features of CWA i.e., they have more behavior problem, lack eye contact and have communication problems. Minimum score in Part-A was 12 (37%) and maximum was 28 (87%) from total of 32 which shows that majority of the parents are better aware of the child’s problems. On Part-B significant difference was found on question related to progress with the treatment, speech therapy can help CWA, early intervention facilitate outcome and parent role is very much important in management. Most of the parents (90%) answered “yes” towards the above questions. Minimum score in Part-B was 5 (50%) and maximum was 9 (100%) from total of 9 which means that 50% parents are aware on Part-B, regarding management part.

2) Attitude of parents and other people

The questionnaire used with respect to attitude of parents towards children with autism consisted of twenty questions, which included Part-A ten questions related to attitude of parents regarding their CWA in general and Part-B ten questions related to their feelings about attitudes of other people towards CWA.

Table 3: Mean scores of attitude between Mother and Father

Informant		**Attitude-A**	**Attitude-B**
Mother	N	70	70
	Mean	6.89	5.91
	Median	7.00	6.00
	Std. Deviation	1.629	1.855
Father	N	15	15
	Mean	6.40	6.07
	Median	6.00	6.00
	Std. Deviation	1.920	2.017
Total	N	85	85
	Mean	6.80	5.94
	Median	7.00	6.00
	Std. Deviation	1.682	1.873

As we can see from the above table the mean scores of mothers and fathers in both Part-A and Part-B are not very different. We can conclude that both the parents have more positive attitudes. The minimum score the parent showed in Part-A and Part-B was 3 (30%) and maximum was 10 (100%) from total of 10 but more than 60% of parents showed positive attitude towards CWA. This is supported by functional role that positive emotions serve in the context of stressful events was considered by Lazarus, Kanner, and Folkman (1980). They hypothesized that under stressful conditions, when negative emotions are predominant, positive emotions may provide a psychological break or respite, support continued coping efforts, and replenish resources that have been depleted by the stress. Positive attitudes are shown by parents who are close to the child and this positive perception may assist parents to cope better with the traumatic and stressful events (Taylor, 1983). Table 2 also shows that fathers' mean scores are slightly better than those of mothers in Attitude-B because mothers' and fathers' perception towards other people's attitude towards their CWA are different. However, it appeared insignificant

Mann-Whitney U Test was done to compare within parents attitude towards CWA.

Table 4: Association between response of parents and attitude

	A	**B**
Z	-.937	-.315
Asymp. Sig. (2-tailed)	.349	.753

From the above analysis we can see that there is no significant difference (p>.05) found between the attitudes of mothers and fathers and also regarding attitudes of other people towards CWA. Hornby (1992) noted that stressful experiences and negative feelings but also strong positive feelings and claims of personal growth in his study. Furthermore, it has been found that relatives who have been studied less intensively by researchers, such as siblings and grandparents, anecdotally reported positive views about their relative with a disability.

Perceptions differ widely and are generally unrelated to the type of disability, although there are some indications that perceptions of severely disabled children tend to be more negative than those of children with less severe disabilities. However, in the present study such comparisons were not made.

The overall attitude of parents towards CWA is around 70% whereas that of other people as perceived by parents is a little less than 60%. This is expected because most of the parents feel guilty and embarrassed about their child with disability and anticipate negative perceptions from the others even when they do not exist.

The overall scores of mothers and fathers did not reveal a significant difference on attitude Hence, the scores of individual questions related to attitude was compared across each parent and their demographic data by using chi square test and significant difference is found ($p<0.05$) related to attitudes at school and attitudes of other people. The results are similar to that of Choi, et al., (2010), who examined pre-service teachers' attitudes towards CWA in the USA indicating that pre-service teachers had positive attitudes towards CWA. Some studies also revealed negative attitudes of society and parents towards CWA. According to Rangaswami, (1995) the parents often have a negative attitude towards their CWD and are plagued with feelings of pessimism, hostility, and shame.

3) Attitude and awareness of parents of CWA

3.1) Socio Economic Status (SES): Cultural beliefs and one’s background about disability play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation (Sen, 1988). Socioeconomic status of the family is an important variable which determines the attitudes of people about disability in their close circles. Table 4 provides details about the same in the current study.

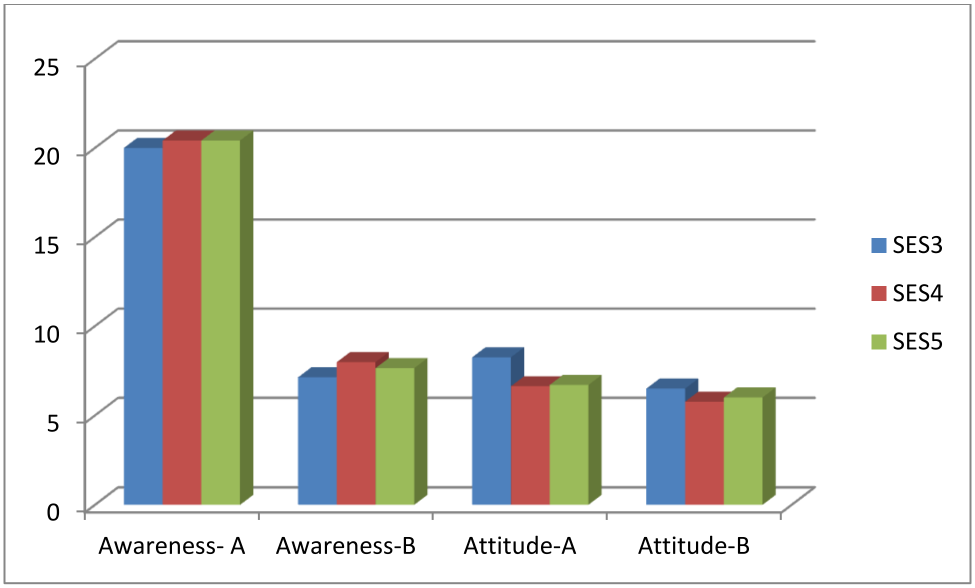

Figure 3: Mean value of awareness and attitude with respect to SES

Table 5: Mann Whitney - U Test was done to test the association between SES and responses for attitude towards CWA.

	Awareness -A	**Awareness-B**	**Attitude-A**	**Attitude-B**
Chi-Square	.259	5.788	6.099	1.168
df	2	2	2	2
Asymp. Sig.	.879	.055	.047	.558

From the above table it is clear that parents belonging to higher SES i.e., level 4 and 5 have better awareness and attitudes compared to the lower ones, which is in agreement with previous studies on Autism. This is to be expected as those in the higher SES will be better educated and have better access to information. However, the numbers of participants in the lower SES groups are very less in the present study which is the limitation of this study as the parents are mostly from the urban areas. There are 85 parents in this study but one of the parents lies in SES 2. For statistical analysis that parent has been removed from the data.

There is significant difference between the SES groups in parental attitude towards CWA at home. From Mann Whitney test, it was noticed that SES 3 is different from other 2 groups at 5% level. It means parent showed more positive attitude and awareness (SES 4-51% and SES 5-39%). As SES increases the attitude and awareness also increase, which is because of better financial support and reduced stress on parents to cope up with the CWA. Family stresses associated with limited financial support leading to lack of appropriate services, are risk factors contributing to poor prognosis (Seifer, 1992), which can in turn influence on the prognosis of the child with disability. Study related to other disorder that are not in agreement with this study is by Bhan, et al., (1998) who found that irrespective of the economic status of families of a child with cerebral palsy, intervening factors like mother's personality, optimism, and religious support were found to alleviate the degree of stress. The negative attitudes resulting in discrimination in the workplace irrespective of SES continues to be a significant problem for PWDs (Brostrand, 2006). There is one study related to the attitudes of parents in rural areas of Zululand towards mental retardation done by Govender (2002) which found that small proportion of parents had a negative attitude, although no parents were found to have a strongly negative attitude.

3.1) Gender of the child:

There are many studies reporting that autism is more common in male child than female child (Newschaffer, et., al 2007). In this study there were 64 male and 21 female CWA which means 3:1 ratio and support the conclusion of other studies. The age range is from 2.8 years to 17 years. The table given below shows the attitude and awareness of parents of male and female CWA.

Table 6: Mean score of the parent awareness and attitude (A & B) with respect to gender of their CWA

Gender		**Awareness-A**	**Awareness-B**	**Attitude-A**	**Attitude-B**
Female	***N***	21	21	21	21
	Mean	19.52	7.95	6.71	6.19
Male	***N***	64	64	64	64
	Mean	20.70	7.70	6.83	5.86
Total	***N***	85	85	85	85
	Mean	20.41	7.76	6.80	5.94

As shown parental attitudes and awareness was not related to the gender of their CWA. To compare if gender of the child with autism is important contributor to the awareness and attitude, Mann Whitney U test was done. Table 9 gives details of the same.

Table 7: Mann Whitney U test for gender of the CWA with the awareness and attitude

	Awareness -A	**Awareness-B**	**Attitude-A**	**Attitude-B**
Z	-1.726	-.851	-.280	-.485
Asymp. Sig. (2-tailed)	.084	.395	.780	.628

As shown there is no significant difference between the genders of CWA with respect to parental attitude and awareness. This is in agreement with study by Jones, (2010).

3.2) Age of the child:

Table 8: Age and frequency of CWA

Age	**Frequency**
<3	1
3-5	28
5-7	24
7-9	13
>9	19
Total	**85**

However, two groups were considered with respect to age, < 8 years and > 8 years) to see if the age of children is important in determining the awareness and attitude of parents.

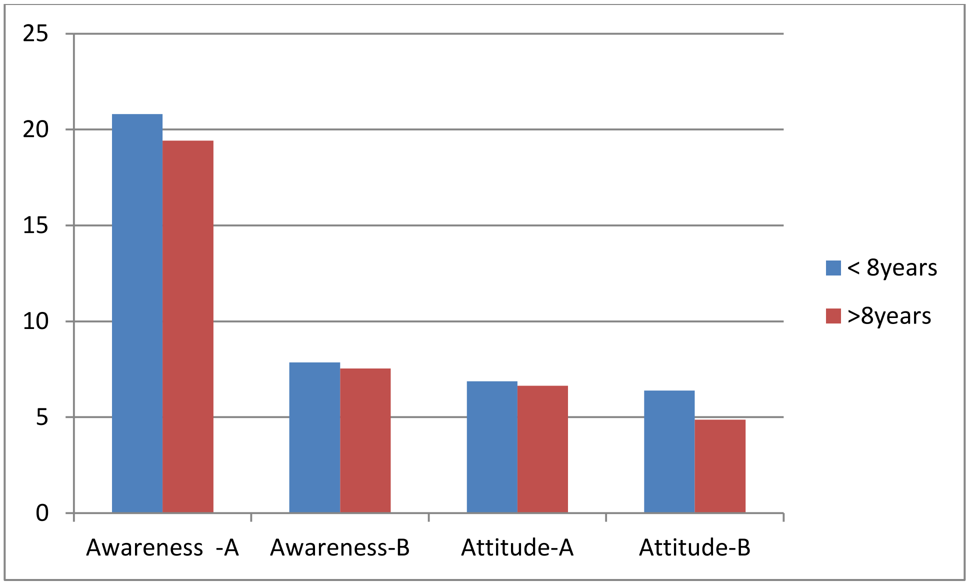

Figure 4: Mean scores of the parent's awareness with respect to age of the child

Most CWA were below 8 years (58) in the study whereas only 28 were above 8 years. The mean of the two groups of age of the child i.e., above 8 years and below 8 years showed that there is no difference in mean score of Awareness A and B with respect to age of the child.

Table 9: Mann-Whitney U Test for the parent's awareness and attitude with respect to age of the child

Z	**Awareness -A**	**Awareness-B**	**Attitude-A**	**Attitude-B**
	-2.091	-1.302	-.241	-3.531
Asymp. Sig. (2-tailed)	.037	.193	.810	.000

Mann-Whitney U Test showed significant difference ($p<0.05$) on questions related to Awareness-A and Attitude-B at 5% level. The reason for this increased awareness and attitude is that as the child becomes older, (>8 years), the perception of attitude of other people becomes positive by parent probably because of better acceptance and they get more aware of children characteristics and knowledge about their coping behaviour.

Holroyd, et al., (1975) studied the levels of stress in families with CWA. Their study found that families with non-institutionalized CWA suffered from profound stress and their attitude changes as their age increases.

From this study finding it can be concluded that parents in India are more aware about CWA related to causes, knowledge and characteristics of CWA but are less aware about management issues. In terms of attitude the parents have positive attitude towards CWA but still feel sometime depressed and frustrated about their child. It is also seen that SES of parents with CWA are important in determining how they accept their CWA. Findings also reveal that if the age of the child is more, the parent becomes more aware and shows positive attitude towards CWA. But no difference is found with respect to change in attitude toward the gender of the child, same attitude and awareness is shown by mother and father.

CHAPTER V

SUMMARY AND CONCLUSIONS

The awareness regarding the disability and positive attitudes in managing the individual with a disability by the parent or caregiver is a very crucial aspect in the overall fruitfulness of the rehabilitation program. The present study is aimed to investigate the awareness and attitudes of parents of CWA towards the problem. The participants consisted of 85 parents, within the age range 20 to 50 years (both fathers and mothers) of children diagnosed as ASD by a professional, irrespective of the type of autism at least 6 months prior to the data collection. A questionnaire developed in English covering various aspects of awareness and attitudes of parents with respect to ASDs based on literature review was used as the material for data collection for the study. This was pilot tested taking input from a couple of SLPs working with CWA and five parents before finalizing the same. Questionnaire consisted of demographic information and statements related to the awareness and attitudes about Autism. The questionnaire involved the rating scale (ordinal) on Social interaction, Communication and language; and other characteristic features of Autism. The questionnaire consisted of four domains related to ASD (see Appendix). Each question was formulated to address questions related to awareness and attitudes of parents regarding the awareness on knowledge, cause and characteristics, awareness on management, parental attitude and attitude of other people towards CWA.

The data obtained from the 85 parents was analyzed using SPSS 16 software to answer the research objectives. The results revealed the following observations:

1) There was no significant difference in the awareness of mothers compared to the fathers regarding autism indicating that they both had better exposure to their child with autism and more involved in their management. However, their awareness was around 70%regarding the causes and characteristics and little less than 60% regarding the management aspects.
2) Parents having higher income i.e., >Rs.20, 000 per month were better aware about autism as expected as they were also better educated.
3) The parents of older children were more aware of causes, and characteristic of CWA as they had longer years of exposure to the problem.
4) Mothers had more positive attitudes than fathers as they were more involved in the management of the child and had exposure to other children with similar problems.
5) The CWA get same attitude from parents and other people irrespective of the gender.
6) Parents of CWA who had attended therapy for more than 6 months duration, had more positive attitudes
7) Parent belonging to higher SES were more concerned about the intervention of their child

It has been well documented that the parents of children with disabilities (CWD) experience chronic stress. The recent research evidence has evaluated the types, degree and determinants of the stress faced by the families in caring for their disabled members (Crnic, 1995). The literature is uniform in reporting that families do experience high levels of stress. But some of the psychological model explains that as the parents are experienced the attitude towards CWA changes from negative to positive by Dabrowski's (as cited in Hague, 1995). Some of the related studies on educating parent were done by Basu and Deb (1996), they observed that if parent are trained of children with behaviour problem (ADHD) significant improvement in the behaviour can be seen, Lakshmanan (1999) examined the efficacy of interactive group psycho-education. Results indicated a significant clinical improvement in the attitude of parents. Recently study done by Prasad and Shanbal (2011) done for the need for educating parents of children with autism which enable the professionals (SLPs) to understand the strengths and lacunae of knowledge persisting in parents of children with ASD (CWASD).

As a conclusion it can be pointed out that parents with CWA are aware of the problem and show positive attitudes towards CWA. Parents' attitude towards autism and disability in general can have tremendous impact on the quality of the life of CWA and their family. The most commonly encountered attitudes seen are discomfort and rejection. Attitudes can be changed by the knowledge gained in recent years about autism, thanks particularly to the growing numbers of reports made available by individuals with autism, their families and advocates, which have helped the general population to understand this condition better.

Implications of the study: The study has important clinical implications. Information obtained regarding the awareness and attitudes of parents of CWA can be used during counseling and management of CWA. Appropriate counseling and guidance can be provided to the parents depending on how the parent scores in the questionnaire. The questionnaire provides detailed information regarding awareness (causes, knowledge, characteristic and management) and attitude (parents and other people) which can be helpful in counseling parent and also the guardian of CWA. It can also be used in creating awareness to the allied professionals and the public to bring about positive changes in their attitudes for improving the quality of life of CWA.

Limitations of the study: The sample size used for the study was small and mostly from urban areas and higher SES group and hence cannot be generalized to other population.

Recommendations for further study: The study may be replicated on a larger population controlling different variables as type and severity of autism, age, education, and occupation of parents. Further research may be carried out to study the awareness and attitude of teachers or other professionals towards CWA. Although the present study is limited in scope, it has provided a basis for much needed research in the area.

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APPENDIX
Questionnaire on Awareness and Attitude of Parents of CWA

Informant: Date: Contact Ph. No:

Parent details:

Father's/Mother's Name: Age/sex: Date:
Education: 1-Illiterate; 2- Primary-middle 3-10th -12th 4- UG 5- PG

Total family income/month (Rs):1- < 5000; 2- 5000 to 10000; 3-10000-15000; 4-15000-20000; 5-> 20000
Occupation: 1-Unskilled; 2-Semi-skilled; 3-Skilled; 4-Semi-professional; 5-Professional
Address-

Child details:

Name: Age/sex: Case No:

Diagnosis of the child's problem: Date of evaluation:
Schooling: 1- NA; 2-No school; 3-Normal school; 4-Special school
Class: 1-NA; 2-Preschool; 3-Primary; 4-Middle; 5-Higher (specify)
Language used by child: Mother Tongue- Other languages:
Therapy attended (if any): 1 -No; 2- Yes
If yes, total duration of therapy: 1-<1 month; 2-1 to 3 months; 3-3 to 6 months; 4->6 months
Are you satisfied with the therapy attended? 1- No; 2- Yes
How is the present condition of the child? 1- Regressed; 2- Static; 3- Improving; 4- Fluctuating

I. Awareness
A) Knowledge, cause & characteristics

Sl. No	Particulars	No	Yes
1.	Do you know what Autism is?		
2.	Is autism common in India?		
3.	Is autism on the rise?		
4.	Is autism more common in boys?		
5.	Does the onset of autism occur from birth?		
6.	Is the cause of autism known well?		
7.	Are all children with autism 'aloof and withdrawn'?		
8.	Do CWA play with their fingers/rock back and forth/ spin around?		
9.	Will CWA become normal without treatment?		
10.	Does Autism run in families?		
11.	Are CWA also mentally retarded?		

12.	Are CWA more sensitive to pain?		
13.	Do CWA follow commands or answer to your questions?		
14.	Do CWA love music?		
15.	Do CWA sniff/smell things more often?		
16.	Do CWA have more behaviour problems?		
17.	Do CWA lack eye contact?		
18.	Do CWA like playing with peer group?		
19.	Do CWA have communication problem?		

1. What do you think is the cause of Autism? (can choose more than one)
   1-Neurological; 2-Psychological; 3-Genetics; 4-Birth defects; 5-Medication; 6-Do not know
2. What other conditions commonly occur with autism?
   1- Mental retardation; 2-Hearing impairment; 3-Visual impairment; 4- None
3. What are some common characteristics of children with autism? (Specify)
   a) b)
   c) d)
4. Who diagnoses autism? (can choose more than one)
   1-Psychologist; 2-Speech-language pathologist; 3-ENT specialist; 4 – Others (specify)

B) Management

Sl. No	Particulars	No	Yes
1.	Is there any treatment for autism?		
2.	Is there a medication for autism?		
3.	Do CWA progress with treatment?		
4.	Does sensory integration help CWA?		
5.	Can speech therapy help CWA?		
6.	Will special diet or medication help CWA?		
7.	Do CWA require special education?		
8.	Will early intervention facilitate outcome?		
9.	Is parental role important in management?		

II. Attitude

A) Self

Sl. No	Particulars	No	Yes
1.	Do you allow your child to do work at home?		
2.	Do you care for the CWA more than you do for others at home?		
3.	Do you avoid your CWA?		
4.	Do you isolate your CWA?		
5.	Do you avoid interacting with your CWA when guest are		

	home?		
6.	Do you allow your CWA to mingle with other children?		
7.	Do you face lot of problem in taking routine care of your CWA?		
8.	Do you feel frustrated to be with your CWA?		
9.	Do you spend more money on your CWA?		
10.	Do you feel depressed because of your CWA?		

B) Attitudes of other people towards your CWA

Sl. No	**Particulars**	**No**	**Yes**
1.	Do people avoid letting their children play with your CWA		
2.	Do people think the CWA is mad?		
3.	Do School authorities refuse to admit the CWA in their school?		
4.	Do teachers refuse to interact with CWA?		
5.	Do you feel difficulty in taking your CWA in bus or to public places?		
6.	Do people laugh or make fun of your CWA?		
7.	Do people sympathize with you because of your CWA?		
8.	Do people offer to help you manage your CWA?		
9.	Do you feel it is better to isolate CWA than taking them to public places?		
10.	Do you feel you can change people' attitude toward CWA?		

Any other information:

Date:

Name