



A STUDY OF CHALLENGES FACED BY PARENTS OF CHILD DIAGNOSED WITH AUTISM SPECTRUM DISORDER (ASD)

Dr. Vidhu Rajput*

*General Secretary, Voluntary Action Group for Differently Abled Persons (VAGDAP), (Registered under Societies registration Act of 1860, India) Since 2007

For Education Training and Empowerment of PwDs

Ex Research Officer Rehabilitation Council of India, Department of Empowerment of PwDs,
Ministry of Social Justice & Empowerment, GOI, New Delhi, India

Ex Lecturer NIEPID RC NOIDA, Department of Empowerment of PwDs , M/O Social Justice and
Empowerment ,GOI , New Delhi , India

Introduction

Autism spectrum disorders (ASD) are a diverse group of conditions. They are characterized by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviours, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations.

The abilities and needs of autistic people vary and can evolve over time. While some people with autism can live independently, others have severe disabilities and require life-long care and support. Autism often has an impact on education and employment opportunities. In addition, the demands on families providing care and support can be significant. Societal attitudes and the level of support provided by local and national authorities are important factors determining the quality of life of people with autism.

Characteristics of autism may be detected in early childhood, but autism is often not diagnosed until much later. People with autism often have co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder as well as challenging behaviours such as difficulty sleeping and self-injury. The level of intellectual functioning among autistic people varies widely, extending from profound impairment to superior levels.

Autism spectrum disorder (ASD) is a range of neurodevelopmental disorders that are characterized by the following core deficits: impairments in social interaction and communication, and restricted, repetitive behaviours (DSM-5, American Psychiatric

Association, 2013). ASD affects people worldwide, irrespective of race, ethnicity or socioeconomic status (Sharpe & Baker, 2011; Durkin et al., 2010). Studies and empirical evidence also show ASD is related to many potential comorbidities such as epilepsy, attention problems, gastro-intestinal problems, oppositional behaviour, anxiety and depression, sleeping disorder and feeding disorders (Hodgetts, Zwaigenbaum & Nicholas, 2015; Kogan et al., 2008; Vohra, Madhavan, & Sambamoorthi, 2017

Autism is a neurological developmental disability characterized mainly by impaired social interaction and communication and the presence of repetitive behaviours or restricted interests. Children with autism may also have their sensory sensitivity affected i.e, they may be under or over sensitive to certain senses (eg. loud noises, certain fabrics etc). Autism is known as a spectrum disorder because its symptoms and characteristics appear in a variety of combinations that affect children in different ways. Males are diagnosed four times more often than females. Some children may have severe

challenges and would need help while others may be able to manage their tasks independently, with less help. Earlier, each condition (autistic disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger 2 syndrome) was diagnosed separately but now, these conditions are grouped together and are called as autism spectrum disorder.

Autistic spectrum disorder (ASD) is seen in all races, cultures, and societies. ASDs are also known as pervasive developmental disorders (PDDs). In Diagnostic and Statistical Manual-Text Revised (DSM-IV-TR), PDDs included autism, Asperger's, PDD-not otherwise specified (PDD-NOS), disintegrative disorder, and Rett's disorder. But in the new classification of Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), autism, PDD-NOS, Asperger's, and disintegrative disorder are all named as autism spectrum disorders (ASDs). Children with ASD have fundamental impairment of communication and social interactions. They also have restricted pattern of interests and stereotyped movements. They might also have developmental delays and intellectual disabilities, in addition to difficulties in processing social and emotional information and expressing their emotion. In sum, the disorder results in developmental and functional deficits.

Epidemiology

It is estimated that worldwide about one in 100 children has autism. This estimate represents an average figure, and reported prevalence varies substantially across studies. Some well-controlled studies have, however, reported figures that are substantially higher. The prevalence of autism in many low- and middle-income countries is unknown.

Dr. N. K Arora, Exec Dir- INCLIN who had undertaken the first ever survey says "the survey identified about 1 to 1.5 percent of children with ASD between two to nine ages in India." As the first ever survey, it also shows that ASD is increasing desperately in India as it reports that more than ten million kids suffer from autism in the country. The survey reports the prevalence rate of 1 in 66. There is lack of national studies in this field and so in India, the rate of Autism fluctuates between 1 in 500 and 1 in 150.

As to the population prevalence of ASD, estimated figures vary depending on the country of study, the period studied, and the estimation method used. Recent estimates range from 1 per 160, 1 per 100, to 2 per 100 (Baird et al., 2006; Baio et al., 2018; Cidav, Marcus & Mandell, 2012; Hughes, 2009; Knapp, Romeo & Beecham, 2009). Most recent estimates for the US as collected by the Autism and Developmental Disabilities Monitoring Network (Centers for Disease Control and Prevention, U.S. Department of Health and Human Services), for instance, yielded overall ASD prevalence estimates varying from 13.1 to 29.3 per 1,000 children aged 8 years with an average prevalence estimate of 16.8 per 1,000 children aged 8 years (Baio et al., 2018). Based on the prevalence estimates of several studies across multiple countries, Lyall et al. (2017) estimated the population prevalence to be around 1.5% in developed countries around the world. As possible reasons for the discrepancy in estimated prevalence figures, studies point out, among other things, that for several countries (e.g., Belgium, Scotland, most of the Arabic countries, etc.) there are no reliable and/or only limited statistics available regarding the prevalence of ASD and that diagnosis in ASD can be difficult or complicated due to no or ineffective screening, and the interactions that occur between development and ASD symptoms. Studies on the prevalence of ASD also show that there is an increasing trend in the percentage of the population that is diagnosed with ASD (Lyall et al., 2017; Jacob, Scott, Falkmer & Falkmer, 2015; Sharpe & Baker, 2007), with more recent studies showing higher estimates of prevalence rates compared to older studies. However, it is unclear whether this increase is due to an actual increase in prevalence of ASD, more broadly defined diagnostic criteria, better public and medical awareness, improved possibilities of diagnosing children at a young age, or a combination of all these factors (Jacob et al., 2015; Kogan et al., 2008; Leslie & Martin, 2007). Studies also showed that a considerable share of the people with ASD have intellectual disabilities. Estimates of individuals with ASD having intellectual disabilities reported by recent studies vary between 30%-50% (Baio et al., 2018; Beuscher et al., 2014; Atladottir et al., 2007; Baird et al., 2006). For instance, recent estimates for the US show that

31% of children with ASD were classified in the range of intellectual disability, i.e. IQ < 70) (Baio et al., 2018; Centers for Disease Control and Prevention). In a study of the costs of ASD in the US and the UK, based on findings of previous studies, Beuscher et al. (2014) reported a 40-60% split (i.e., 40% of individuals with ASD having intellectual disabilities).

Causes

Available scientific evidence suggests that there are probably many factors that make a child more likely to have autism, including environmental and genetic factors. Available epidemiological data conclude that there is no evidence of a causal association between measles, mumps and rubella vaccine, and autism. Previous studies suggesting a causal link were found to be filled with methodological flaws.

There is also no evidence to suggest that any other childhood vaccine may increase the risk of autism. Evidence reviews of the potential association between the preservative thiomersal and aluminium adjuvants contained in inactivated vaccines and the risk of autism strongly concluded that vaccines do not increase the risk of autism.

Assessment and care

Diagnostic Criteria and Core Characteristics of Autism

Autism was included in the Diagnostic and Statistical Manual (DSM) in its third edition in 1980 as —infantile autism. Since then, DSM has delineated autism diagnoses, and in DSMIVTR, different diagnostic criteria were described for —Autistic Disorder, —Asperger ‘s Disorder, and —PDD-NOS (Sadock & Sadock, 2007). All these different diagnoses were combined under an umbrella term Autism spectrum disorders, in its recently revised diagnostic criteria as described in the Diagnostic and the Statistical Manual of Mental Disorders, fifth Edition (APA, 2014). Several changes have been made in the DSM 5 contributing to the refinement of the definition of autism. The most significant changes in the recent definition is that the areas of impairment have been reduced from three to two, combining communication and socialization together. An individual qualifies for a diagnoses of autism spectrum if he/she has a Persistent deficit in social communication and social interaction across multiple contexts, either currently or in history by

- a. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions;
- b. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication;
- c. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

To qualify for a diagnosis, he/she must also have Restricted, repetitive patterns of behaviour, interests, or activities, as manifested either currently or in the past by:

- a. Stereotyped or repetitive motor movements, use of objects, or speech;
- b. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior;
- c. Highly restricted, fixated interests that are abnormal in intensity or focus;
- d. Hypo- or hyperactivity to sensory input or unusual interests in sensory aspects of the environment

Diagnostic and statistical manual also states that the Symptoms must be present in the early developmental period, but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life, and that the symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

Diagnoses of Autism spectrum disorders is not given if these disturbances are better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Autism is a condition that shows impairment in three areas of development. They are a —heterogeneous set of disorders with impairments in three areas referred to as the “Triad of impairment” (Wing, 2002).

A broad range of interventions, from early childhood and across the life span, can optimize the development, health, well-being and quality of life of autistic people. Timely access to early evidence-based psychosocial interventions can improve the ability of autistic children to communicate effectively and interact socially. The monitoring of child development as part of routine maternal and child health care is recommended.

It is important that, once autism has been diagnosed, children, adolescents and adults with autism and their care takers are offered relevant information, services, referrals, and practical support, in accordance with their individual and evolving needs and preferences.

The health-care needs of people with autism are complex and require a range of integrated services, that include health promotion, care and rehabilitation. Collaboration between the health sector and other sectors, particularly education, employment and social care, is important.

Interventions for people with autism and other developmental disabilities need to be designed and delivered with the participation of people living with these conditions. Care needs to be accompanied by actions at community and societal levels for greater accessibility, inclusivity and support.

Human rights

All people, including people with autism, have the right to the enjoyment of the highest attainable standard of physical and mental health.

And yet, autistic people are often subject to stigma and discrimination, including unjust deprivation of health care, education and opportunities to engage and participate in their communities.

People with autism have the same health problems as the general population. However, they may, in addition, have specific health-care needs related to autism or other co-occurring conditions. They may be more vulnerable to developing chronic noncommunicable conditions because of behavioural risk factors such as physical inactivity and poor dietary preferences, and are at greater risk of violence, injury and abuse.

People with autism require accessible health services for general health-care needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness. Nevertheless, autistic people have higher rates of unmet health-care needs compared with the general population. They are also more vulnerable during humanitarian emergencies. A common barrier is created by health-care providers' inadequate knowledge and understanding of autism.

WHO resolution on autism spectrum disorders

In May 2014, the Sixty-seventh World Health Assembly adopted a resolution entitled *Comprehensive and coordinated efforts for the management of autism spectrum disorders*, which was supported by more than 60 countries.

The resolution urges WHO to collaborate with Member States and partner agencies to strengthen national capacities to address ASD and other developmental disabilities.

WHO response

WHO and partners recognize the need to strengthen countries' abilities to promote the optimal health and well-being of all people with autism.

WHO's efforts focus on:

- increasing the commitment of governments to taking action to improve the quality of life of people with autism;
- providing guidance on policies and action plans that address autism within the broader framework of health, mental and brain health and disabilities;
- contributing to strengthening the ability of the health workforce to provide appropriate and effective care and promote optimal standards of health and well-being for people with autism; and
- promoting inclusive and enabling environments for people with autism and other developmental disabilities and providing support to their caregivers.

WHO *Comprehensive mental health action plan 2013–2030* and World Health Assembly Resolution WHA73.10 for “global actions on epilepsy and other neurological disorders” calls on countries to address the current significant gaps in early detection, care, treatment and rehabilitation for mental and neurodevelopmental conditions, which include autism. It also calls for counties to address the social, economic, educational and inclusion needs of people living with mental and neurological disorders, and their families, and to improve surveillance and relevant research.

Autism and Family

Raising a child with an autism spectrum disorder (ASD) can be an overwhelming experience for parents and families. The pervasive and severe deficits often present in children with ASD are associated with a plethora of difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. In addition to significant financial strain and time pressures, high rates of divorce and lower overall family well-being highlight the burden that having a child with an ASD can place on families.

These parent and family effects reciprocally and negatively impact the diagnosed child and can even serve to diminish the positive effects of intervention.

However, most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy.

It cannot be assumed that even significant improvements in the diagnosed child will ameliorate the parent and family distress already present, especially as the time and expense of intervention can add further family disruption.

There is a lack of systematic reviews focused exclusively on the prevalence of Autism spectrum disorders in India. With the incidence of Autism spectrum disorders on the rise, it becomes important to understand how these disorders affect the affects the child and the family, including reciprocal associations between parent emotions and child behaviour.

While examining such challenges is helpful in increasing our understanding of parenting stressors, examining the interplay of both parental and child factors as they contribute to the parent-child relationship (in terms of parental emotions and child behavior problems) will provide a greater understanding of the types of support and potential interventions needed by families of children with ASD.

Parental stress and ASD

All parents hope for a perfect child, but some children are born with serious developmental disorders. ASD one of several disorders that interrupt normal development in childhood and cause impairment in physical, learning, language, or behavior areas. They may affect a single area of development (specific developmental disorders) or several (pervasive developmental disorders). These conditions

begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. These disorders may be mild and easily manageable with behavioural and educational interventions, or they may be more severe and affected children may require more support. Of the group of developmental disorders originating in childhood that involve serious impairment in different areas, Autism is the third most common developmental disorder.

Several factors have been shown to work in concert to increase stress in parents of children with ASD. First and foremost, the realization that there is no cure for the disorder may serve to increase parenting stress. Aspects of the child's behavior, specifically socially inappropriate and aggressive behaviours typically associated with ASD, have been found to be associated with increases in parenting stress, as well as being confronted by antipathy for their child's behaviors due to a lack of understanding of ASD. Additionally, raising a child with ASD typically involves allocating extra time to meet the needs of the child. Multiple changes occur in the parental role to accommodate the challenges of raising a child with ASD.

Parents of children with autism spectrum disorders (ASDs) thus have been shown to experience increases in stress, depression, and anxiety, which are also associated with child behaviour problems related to ASDs.

Stress of Parents of Children with Autism

Stress is an inevitable part of the human experience. It is an individual and subject product of the interaction between an individual and their environment, and it affects each individual uniquely. According to Lazarus⁴ (1993), stress includes four components: the external event (i.e., the stressor), cognitive appraisal of the event, coping mechanisms, and the consequential effects on the body and mind (i.e., the stress reaction). In the transactional model of stress and coping, events are perceived as stressful based on both the meaning an individual attributes to the event and the individual's perceived coping resource. If the individual's coping mechanisms do not meet the demands placed on the individual, the stress experienced will impact their mental health quality of life

Hans Selye (1974) described stress as a response of the body to certain demand that is made on it and he further stated that this response was nonspecific. Baum et al. (1981) have defined stress as a "process in which environmental events or forces, called, stressors, threatens an organism's existence and wellbeing". Schafer (1998, pg. 6) defined stress as "arousal of mind and body in response to demands made on them".

Truxillo et al. (2016, pg. 440) defined stress as "the body's reaction to a change that requires a physical, mental or emotional adjustment or response". This definition has further elaborated the response as being physical, mental or emotional in nature.

Everyone experiences stress and anxiety at times, and generally it is short lived. For the people having autism child, stress and anxiety is instead a normal way of life as the disorder is a lifetime and generally stable with persistent impairments in language, social skills, and daily life activities. The difficulties present in rearing the autism child put strong pressure on parenting skills as the disorder is stay alive from the early ages. These difficulties produce stress if the parents' perceptions of the demands of their parental role exceed their coping resources, without being able to restore equilibrium through the usual methods and strategies.

Autism spectrum disorder (ASD) is a neurodevelopment disorder characterized by Pervasive impairments in social communication and patterns of restricted and repetitive behaviors. Individuals with ASD may exhibit impairments in joint attention, social skills, language use, have highly restricted interests, challenging behaviors (e.g., tantrums, aggression, etc.), or stereotyped Both early identification of ASD and beginning early intensive behavioural interventions (EIBI) before the age of 3 are critical for children, as they are associated with improved long-term individual and family outcomes Access to EIBI can improve children's communication, adaptive behavior, and other important skills, which may lessen lifetime costs associated with treating an individual with ASD. Parents of children with ASD consistently report higher levels of stress compared to parents of children with other developmental delays and typically developing children. Several factors influence parental stress levels at different stages of their child's life, from initially obtaining a diagnosis to

seeking appropriate intervention and educational services and paying for said services. Thus the Costs of intervention services are one of many factors that may impact the levels of stress a parent of a child with ASD experiences throughout their child's life.

Some disabilities are quite evident at the time of birth, such as a malformed limb. Certain others are detected a few days after birth, such as severe lack of vision, acute hearing loss or deafness. But some other conditions, like mental retardation, partial loss of sight or ! partial loss of hearing, may not be detected for quite some months or even years after birth. The child thus loses the precious early years when development in all areas is extremely important .

Parental Anxiety Stress and anxiety may seem similar, but they're not the same. The difference refers that stress is a response to daily pressures or a threatening situation, while anxiety is a reaction to the stress. Anxiety, which has no clear cause, tends to last longer and be more difficult to treat. Anxiety is arguably an emotion that predates the evolution of man. Its ubiquity in humans, and its presence in a range of anxiety disorders, makes it an important clinical focus. Every one experiences anxiety in different forms, while this is visible in some, it can be inferred in others from their physiological and psychological responses. Anxiety also varies in frequency and intensity in different persons, even in response to the same stimulus. It is a generalized state of apprehension or foreboding and also called as social phobia, have such an intense fear of social situations that they may avoid them altogether or endure them only with great distress. There is much to be anxious about such as health, social relationships, examinations, careers and conditions of the environment are but a few sources of possible concerns. It is normal, and even adaptive. Anxiety is an appropriate response to threats, but it can be abnormal when its level is out of proportion to a threat. In extreme forms, anxiety can impair our daily functioning. Like stress, anxiety is also a subjective feeling. We are all used to feeling anxious from time to time. When we are about to take exams, or facing a job interview, or awaiting results of some important medical tests, we feel worried about what might happen. We are tense and anxious about how we will be affected. But exactly what does anxiety mean? Anxiety is a word we use to describe our feelings when we are frightened. So, if something frightens us we get anxious. For example, if you are walking down a street and suddenly a ferocious dog runs up to you, barking madly or snarling and baring its teeth, you will almost certainly feel anxious because you are frightened that the dog will attack you. The negative emotional state with feelings of nervousness, worry and apprehension associated with activation or arousal of the body.

Anxiety is a word used to denote a general state of nervousness, fear, apprehension, and worrying. As a matter of fact every one undergoes anxiety whenever he faces some challenge or some task that entails on ones worth and self esteem, in such circumstances anxiety is real and productive as it pushes the person toward accomplishment of that goal in reasonable timeframe.

Anxiety is fairly different from fear. Fear is a response to perceived immediate threat, while anxiety is a response to an expected or future threat. It is a feeling of worry and uneasiness. The symptoms of anxiety are muscular tension, restlessness, fatigue and problems in concentration. Anxiety is a common experience. But if it is experienced regularly, then it might lead to anxiety disorder. Anxiety of Parents of children with Autism Parents are the primary caregivers of an infected/disabled individual. They are the considered to be the first teachers in the said individual's life. The parent-child relationship is considered to be one of the most significant relationships in an individual's life. It is the unique bond between a caregiver and his or her child. The way parents and child interact with one another physically, emotionally and socially, pave the way for parent-child relationship. As long as both of them are feeling congenial by each person's thoughts, feelings, and behaviors, the quality of relationships will be good.

When parent-child relationship is impacted by one or other way, then it develops stress and anxiety on the one who affected much out of others thoughts, feelings, and behaviors. Especially the children disability such as autism will impose anxiety on the parents as the health needs of the children are long-lasting one. Moreover, future of the autism child also aggravates the anxiety of the parents. Parental anxiety is thus a widespread problem that has changed the landscape of raising children The parents of children with autism reported that their life is full of hard work, exhaustion, fear, hope, desire, anger, isolation, intimidation, commitment, acceptance and love.

Some parents have experienced abandonment and isolation, while some acknowledged the support provided by services. They were exhausted of pushing for everything their child needs.

As per the previous studies, most of the parents have the fear over the future of their children after their demise. This fear seems to pervade their lives, especially the parents of children with profound autism. Most parents too doubt about availing the needed services to their children with autism because of the scarcity of resources and staff members in particular. Some parents were more positive than the others depending on the level of autism of their children. They were positive with the hope that their children might be able to live independent lives. Others were doubtful about it.

Having children naturally changes the family function. Parental role could be a source of stress for many parents. Parenting a child with autistic disorder is expected to cause an enduring stress and is a demanding responsibility for the parents. Several studies have reported higher level of stress among mothers of children with autism. In comparison to parents of normal children, parents of autistic children show an inclination to report higher family stress, and they experience severe physical and psychological problems. The enduring stress eventually shows in the form of various psychological problems such as depression, anxiety, lack of satisfaction in life, and sleep disorders. These problems not only lead to parents having an anxious and sad life, but also decrease the effect of early educational and therapeutic interventions for autistic children. These parents need to be evaluated for psychological problems, and they need to have a strong social support network. Perceived social support network can increase the feeling of satisfaction and competence as a parent.

The fathers of children with autism are suppressing their feelings most of the time at the cost of anger. One study confirmed that any child disabilities have a greater impact upon the mother than the father. The association between gender and stress levels was examined. This study revealed that mothers reported higher stress levels than fathers. Another study has found similar result . In addition, it is parents of children with ASD have significantly higher divorce rates than families of children without disabilities. In a study it is indicated that due to having children with autism stressful life events are very common like divorce, separation, moving home, the death of a family member, economic, job, or legal problems that decreases family functioning . In some cases, having an autistic child may place added strain on marriages and partnerships.

Aside from the emotional and financial stressors associated with having a child with a neurodevelopmental disorder, it can be difficult for parents or caregivers to always be on the same page when it comes to making decisions about accommodations and support.

This may include a difference of opinion regarding which type of medical support, therapies, schooling, and long-term care is best for their child.

While some researchers have speculated that parents of autistic children have higher rates of divorce, empirical evidence among the broader population is lacking.

Emotional impact

When a child receives an autism diagnosis, some caregivers may not be able to get appropriate support for their child due to their location, availability of services, or financial situation.

In Buerkens' experience, oftentimes families feel guilty for having a range of emotions regarding their child's autism diagnosis, including fear, anxiety, and frustration. They might not know how best to support their child, or whom they can trust regarding support.

Research from 2009 shows that mothers of autistic children, who tend to be a child's primary caregiver and decision maker, experienced more stress and fatigue than mothers of children without ASD.

In addition, other research from 2009 indicated that mothers of autistic teens were more likely to have higher levels of cortisol, the stress hormone.

While one 2014 study noted that mothers of autistic children were more likely to experience post-traumatic stress disorder (PTSD), the research was limited to white professionals and not indicative of the general population.

Sibling Impact

the impact of children with ASD on siblings is mixed . Some studies found positive and some of related studies indicated negative impact in children with autism. Another study also indicated mixed (positive and negative) results.

The most of brothers and sisters of children with ASDs interfered in total life cycle like vocational, marital, and family planning .Another study confirmed that siblings are reporting the negative impact of having a brother/sister with autism is feelings of embarrassment or shame. In this it is also reported that in siblings ages 8-15, 84% reported aggression produced by their brother/ sister with autism when they are trying to interact with them during playing .

The siblings of persons with autism have greater genetic vulnerability for cognitive, social, linguistic and learning difficulties than the general population. Having a brother or sister with an ASD does alter normative life cycle events. It has been reported that the siblings of children with autism have high levels of loneliness and problems with peers .A study found loneliness to be related to a lack of social support from friends . But one study found that no adverse effects of having a sibling with autism . Siblings of children with ASD are facing at an increased risk of adjustment problems .

Further, this is of greater concern in low and middle income countries like India, where no state support is currently available to cater to a large number of individuals with autism and their siblings. There is also an unspoken cultural expectation that the typical sibling will care for the autistic sibling once the parents are old and eventually when they are no more.

The focus on siblings in such programs is very rare, as siblings are often neglected in such family centred approaches. Even though studies have established that siblings may have increased care responsibilities, receive less attention from their family and may experience low self-esteem and social isolation. Involving siblings is a great way to enable children with specialized needs to experience a dynamic and supportive environment. As they build their communication, it helps the siblings to build a deeper relationship with each other.

Many a time siblings of children with special needs end up feeling left out because of all the focus and energy being given to the latter.

This manner of involving them can be one of the ways to enable them to overcome that feeling. As established from the existing literature, they may also experience guilt and resentment and may face unique challenges including negative reactions from others.

The sibling support programs are rarely conducted. It is not uncommon for siblings to be in late their late adulthood, and not know another sibling who may have similar life . There is growing literature outlining why and how to support siblings but more initiatives and services are needed to provide this support (Cooke & Semmens, 2010). Research has established that the typically developing siblings will show resistance to attending such programs, and therefore it is especially important that they find the intervention not just informative, but also enjoyable. A sibling support model developed by Don Meyer, called Sibshops has received significant research support for typically developing siblings of children with developmental conditions including Autism (Meyer & Vadasy, 1994). If we support typically developing sibs as they grow up, we increase the chances that they will make a choice in their adulthood to remain lovingly involved with their brothers and sisters with disabilities (including autism) and continue to share an intimate relationship.

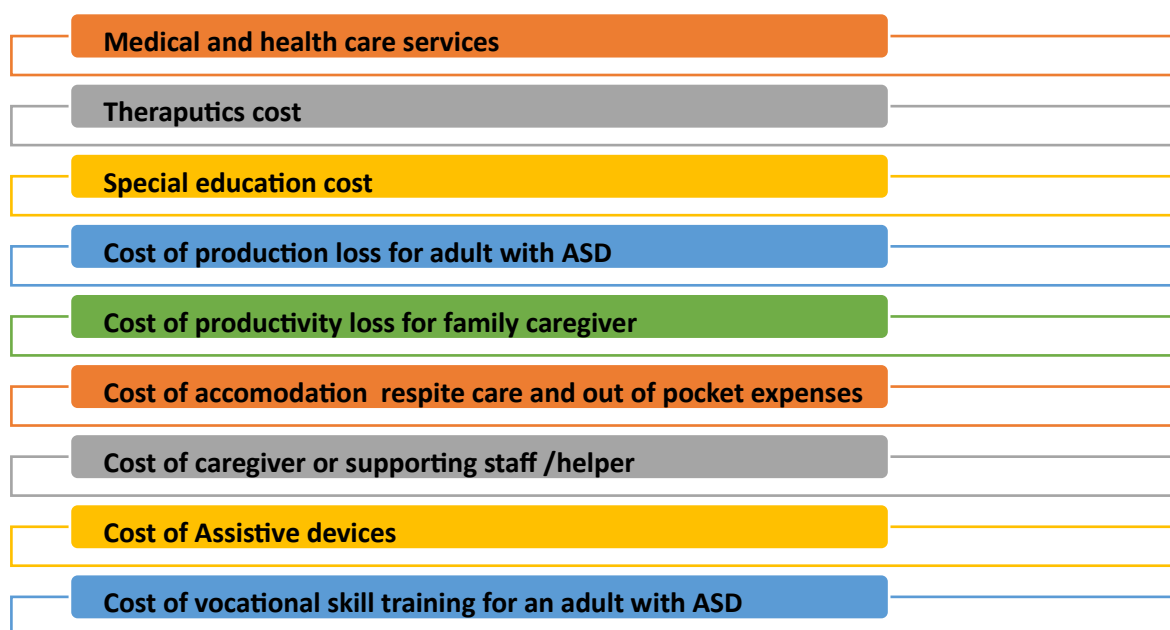
Economic Impact

Children with parent-reported ASD had higher levels of health care office visits and prescription drug use compared with children without ASD ($P < .05$). A greater proportion of children in the ASD group used special educational services (76% vs. 7% in the control group, $P < .05$). After adjusting for child demographic characteristics and non-ASD-associated illnesses, ASD was associated with \$3020 (95% confidence interval [CI]: \$1017-\$4259) higher health care costs and \$14,061 (95% CI: \$4390-\$24,302) higher aggregate non-health care costs, including \$8610 (95% CI: \$6595-\$10,421) higher school costs. In adjusted analyses, parents who reported that their child had ASD did not have

significantly higher out-of-pocket costs or spend more time on caregiving activities compared with control parents.

Families with ASD children from urban and rural areas had higher per-capita household expenditures by 60.8% and 74.7%, respectively, compared with provincial statistics for 2007. Behavioral therapy accounted for the largest proportion of health expenses (54.3%) for ASD children. In 19.9% of urban and 38.2% of rural families, health care costs exceeded the total annual household income. Most families (89.3% of urban families; 88.1% of rural families) in that province reported higher health care expenditures than the provincial household average .

Six important areas identified of the expenditure are following:



General finding is that individuals with ASD and families with children with ASD have higher costs. Education costs appear to be a major cost component for parents with children with ASD.

The aggregate cost of supporting people with ASDs in the UK is £27.5 billion annually. Of this, 59% is accounted for by services, 36% by lost employment for the individual with an ASD, their families and other carers, and the remainder by family expenses.

The economic burden of families with Autism Spectrum Disorders (ASD) children that are far beyond the needs of typical children causes physical and mental stress for their parents.

The impact of children with Autism affect negatively on the family's life style and their socioeconomic status . In a study it showed that childhood autism is associated with a large loss of annual household income and another study also confirmed that caring for children with ASD is a costly matter .

In case of autism child weekly out of pocket costs approximately to \$120 that was directly related to the education and care of their child with autism and finally impact on economic status of family . The low-income caregivers suffer an uneven burden because of monthly out of pocket expenses. It showed that the economic burden associated with ASD . Another problem that the parents of children with autism face is the financial problem. They are concerned about the considerable costs required to take care of their children. Likelihood of financial problems was positively associated with use of medical interventions, having unreimbursed medical or therapy expenses, and having relatively lower income. Use of speech and language therapy was negatively associated with likelihood of financial problems. Many survey respondents forfeited future financial security and even experienced bankruptcy to provide needed therapy for a child with autism

Autism Spectrum Disorders (ASD) consist of a variety of childhood-onset and lifelong neurodevelopment disorders with an long-lasting effect on multiple domains of functioning, characterized by persistent deficits in social communication and social interaction and restricted and repetitive behaviour, interest and activities.

The effects of having a child with ASD on parents and families are, like the disorder itself, multifaceted and pervasive. Meeting the high care demands of affected children requires much time, effort and patience.

Caring for children with ASD is challenging task due to the severity and chronicity of ASD, their extensive developmental and physical co- morbidities, and the difficulties of availing the integrated and intensive health services needed by persons with ASD.

The huge impact of having a child with ASD is apparent in both the severity and breadth of parent domains that seem to be influenced and as a result maintaining a child with a disability has been recognised as a major source of burden and distress in family care giving.

Western studies demonstrate that the additional childcare demands associated with a child's disability can create significant parental stress as well as disruption in family relationships.

A study showed that Families of children with ASD face significant economic burden. In this study also revealed that mothers of children with ASD earn an average of 35 % (\$7189) less than the mothers of children with another health limitation and 56% (\$14 755) less than the mothers of children with no health limitation.

A study showed that there were associated with decreased odds of living in a higher income household. Childhood autism is linked with a large loss of annual household income. 21% of children in families with at least one disabled member are living in poverty, a significantly higher proportion than the 16% of children in families with no disabled member "There is some concern that expenses associated with disabled children are underestimated. Estimates might include things the parents or carers can quantify such as travel costs for hospital visits, or adaptations to the home. But wrapped up in this are more intangible factors that affect living standards, such as limits to parents' work capacity, or the impact on the rest of the family.

For families of children with disabilities, life can seem impossibly complicated. For example, finding specialist childcare so that parents can work may be a costly and insurmountable hurdle.

"Families with disabled children required considerably more to achieve the same living standards as families without."

"Mental disability had a greater financial impact than physical disability."

Autism spectrum disorders not only affects the child but the family too and also has direct and indirect cost implications on the nation as resources have to be utilized in providing health care, support for education, and rehabilitative services for these children.

The financial impact of medical support, psychotherapy, and specialized education for autistic children can take a toll on the mental well-being of parents and caregivers, costing thousands of U.S. dollars per year.

In fact, the lifetime social cost for autistic people is estimated at \$3.6 million (in 2019 dollars).

Keep in mind that social cost refers to the cost to the state or country. It doesn't take into account what families may pay to treat or manage the disorder. These costs depend on various factors, including:

- whether you have insurance and what the insurance plan covers
- how severe symptoms are
- whether your child has any co-occurring conditions

Still, these personal costs can be quite high. Some parents may have the added expense of child care, while others may choose to forego one household income and have one parent stay at home to tend to their autistic child's well-being.

Social Impact

The symptoms of autism consist of communication, socialization, behavioural and interest impairments, as well as minimal social skills. The families of children with autism and their families are facing various types of challenges. The challenge starts early and it lasts a lifetime. It is associated with other problems such as personal, professional, marital, and financial. These problems occur across a wider social context. Autism is not only effect on parents but also the entire family is involved including; the marital system, the parental system, the sibling system, and the extended family system . It is due to parents not sending their child out into any family program, the community to play or for social participation.

Through increased engagement in social participation within inclusive contexts (both environmental and social), families are able to both model and facilitate occupational engagement for their children with ASD in support of building and maintaining their current and future mental health and well-being.

Students with ASD their functioning in a school environment can be complicated through their limited understanding of social situations. Children with autism usually have rigid and limited play patterns are unable to share their desires and capacities for play, make a friendship, and develop a peer-group Autism inclusion is the practice of fully including autistic people in typical community experiences by designing those experiences for everyone.

Living with a person with an ASD affects the entire family—parents, siblings, and in some families, grandparents, aunts, uncles, and cousins. Meeting the complex needs of a person with an ASD can put families under a great deal of stress—emotional, financial, and sometimes even physical.

Recommendation

Autism is a complex disorder that has wide range of symptoms. From various studies it is acknowledged that families with children face various type of challenges. The results of this study found about that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.

There is no 'cure' for autism. There are still no drugs that can 'cure' autism. ..

➤ *From a family and societal perspective, support that allows family members to work may more effectively assist families with children with ASD by lessening the financial burden and improving well-being of all family members.*

financial costs are not sufficiently funded by public resources or health insurance programs this might negatively affect the access to certain services for ASD-individuals (or their families) with limited personal financial resources.

A clear overview of the total cost of ASD and all its individual components can help policy makers make informed decisions about public resource allocation and the organization of public services for

individuals with ASD. Thirdly, costs related to ASD are not limited to service and healthcare costs. A comprehensive overview of indirect costs, such as informal care and parental lost productivity, might assist policy makers in finding ways to help families through family support systems.

To reduce the impact on siblings they need to get involved in sports, clubs, or other community activities where they can develop relationships with peers and just have fun. Doing so allows them the time and space to be their own person and establish a sense of individuality not defined by their sibling with autism (OAR, 2014).

Stress is a normal part of life, but families with autistic children often have a lot of stress. For stress management, try making time for family activities, doing positive thinking and relaxation exercises, getting organised and more For Communication and behaviour management parents can provide structure such as visual supports. Encouraging choice making skills in 'free time' for an Autistic Child.



- Secondly, in responding to this challenge of a larger number of people being diagnosed with ASD, those responsible for developing and implementing policies and deciding on resource allocations need to have good knowledge of the consequences of their decisions.

To reduce anxiety by an autistic child one can, look for

- *NEW FORMS OF COMMUNICATION*
- *CREATING A SENSORY DIET PLAN*
- *DEEP TOUCH PRESSURE.MECHANISM*
- *KNOW YOUR CHILD'S SIGNS OF DISTRESS*
- *CREATE A SAFE SENSORY SPACE.*
- *CREATE A SENSORY TOOLBOX*
- *FIND TECHNOLOGY THAT CAN ASSIST IN COMMUNICATION*
- *TRY SELF SOOTHING STRATEGIES*

Although stress is a normal part of family life, too much stress can have a negative effect. Managing stress is good for the emotional and mental health and wellbeing of everyone in your family.

➤ To reduce parental stress and other impact on family and functioning interventions for children with autism is needed. Different type of supports like respite care, parent training by professionals, treatment and self-help groups can contribute to positive impact on the family.

Positive thinking and self-talk increase positive feelings. And feeling positive increases your ability to cope with stressful situations. Writing a diary expressing problem areas and probable solutions help in organising the thoughts and procedures .

One can practise some breathing exercises and muscle relaxation techniques. Alternate nostril breathing such as Anulom Vilom is noted for its physical and mental health benefits, including: improved patience, focus, and control. relief from stress and anxiety. improvements to brain, respiratory, and cardiovascular health. The goal of pranayama is to strengthen the connection between your body and mind. According to research, pranayama can promote relaxation and mindfulness. It's also proven to support multiple aspects of physical health, including lung function, blood pressure, and brain function . Stress is often related to the feeling that things are out of your control. Getting organised is a very effective way to get things – including your stress levels – under control.

An effective routine can help reduce stress, which can lead to better mental health, more time to relax and less anxiety. Routines like sleep schedule and bedtime habits affect mental sharpness, emotional well-being and energy. Routines help your family get through tasks more efficiently and free up time for more enjoyable things. One can adjust these routines for children with additional needs.

When one has an autistic child, one forget to make time for oneself. One can reduce the stress levels in family by making sure that all family members have time to do things that make them feel good. Celebrating a festival making of Rangoli together and colouring of Diyas kind of activities help in celebrating a joy together.

Family traditions and rituals can give you a sense of belonging and togetherness. This can strengthen family relationships, which will help mothers get through stressful times. One might have to modify traditions to suit the needs of autistic child.

When a child gets an autism diagnosis, family and friends can be a great source of practical support. The child and extended family member can spend some time together which gives some time to Mother or time to get other things done.

To reduce parental stress and other impact on family and functioning interventions for children with autism is needed. Different type of supports like respite care, parent training by professionals, treatment and self-help groups can contribute to positive impact on the family.

In 2001 a meta-analysis was done on the impact of respite care for children with developmental delay concluded that ensuring respite care is helpful for reduction in parental stress and an increase in coping abilities but no study has not been yet shown that respite care is appropriate for children with ASD.

Appropriate teacher training is an indicator for effective behaviour management in students with ASD. Social work professionals may focus on client strengths which prevents the social work professional from judging or blaming the client. Thus, help to clients become more aware of their successes and strengths. Social work professionals are also able to identify family influences on the individual client. In case family members are feeling very stressed every day, it might help to **talk to a health professional**. One could start by seeing GP, who can help you make a plan for managing stress. This might include referring family members to another health professional for some specialist support. Children and adults with Autism and their families have the right to choose the services and support that work best for them, as well as the right to choose providers of those services.

There is a lack of systematic reviews focused exclusively on the prevalence of Autism Spectrum Disorders in India. With the incidence of Autism Spectrum Disorders on the rise, it becomes important to understand how these disorders affect the child and the family, including reciprocal associations between parent emotions and child behaviour.

we can say that Autism not only affect a person but also the people associated with them that include the family members and the care takers, most interventions for ASD are evaluated only in terms of child outcomes, ignoring parent and family factors that may have an influence on both the immediate and long-term effects of therapy.

In the case of children with autism spectrum disorder (ASD), the attention is focused on three essential aspects that can affect them and their family's quality of life: (a) receiving an early diagnosis and specialized early care, (b) having adequate educational and community resources and (c) having a social support

Autism often has an impact on education and employment opportunities. In addition, the demands on families providing care and support can be significant. Societal attitudes and the level of support provided by local and national authorities are important factors determining the quality of life of people with autism and their families.

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