

# Parents and family impact of autism spectrum Disorders

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## ABSTRACT

The purpose of the present study was to examine the parents' burden caused by their autistic children.

The study was made by taking 18 fathers and 18 mothers of autistic children collected from the Center for Autism Therapy, Counselling, and Help (CATCH), Bhubaneswar.

In order to evaluate the burden levels of the parents', the Zarit Burden Interview Scale was used and the burden scores were collected through interview by applying the above scale.

The statistical analysis was performed by taking the scores as determine by the scale. The mean burden scores were indicated and also a "t" test to show the differences between mother and father groups was also made. Further an ANOVA was also made to indicate the effect of socio-economic status on the burden levels of parents'.

Form the result it was found that though there was some visible differences between the gender groups (father and mother) on burden levels it could not be substantiated significant at .05 levels. Similarly, in consideration of their means though the burden levels in low socio-economic status, middle socio-economic status, and high socio-economic status levels was different, but could not be statistically significant.

Hence, it was conclude that both the parents irrespective of their differences in sex and socio-

economic status had similar levels of burden while taking care of their children suffering from autism.

## I. INTRODUCTION

Autism Spectrum Disorders (ASDs) are now the second most prevalent developmental disability for children within the United States and a major problem in many other states too. (Newschaffer et al., 2007). The service needs for individuals with Autism Spectrum Disorders (ASDs) and the potential loss of productivity of persons with autism and their families have strong implications for society as annual financial costs are estimated to exceed \$35 billion (Ganz, 2006). Fortunately, research supports that early diagnosis and intervention can assist in fostering the mastery of many adaptive skills and behaviours in children with Autism Spectrum Disorders (ASDs) and ultimately result in these children learning to become productive citizens, which greatly benefits society as a whole (Carothers & Taylor, 2004). Parents and families play integral parts in children's development into productive citizens, as parents are responsible for providing their children with opportunities to learn and grow. However, the responsibilities associated with being a parent or family member of a child with an ASD does not come easily as the behavioural challenges and social communication deficits that characterize

ASD often are correlated with increased financial and emotional burden on the entire family (Jarbink et al, 2003). These emotional and financial burdens can inhibit parents and families from effectively helping their children with ASDs and could lead to significant stress and fractured family relationships. For these reasons, it is paramount that research investigates and addresses the possible stressors and challenges these families face so that appropriate interventions can be developed and children with ASDs have the best chance for developing into productive citizens. Over the past decade, there has been an increase in the number of children diagnosed with an Autism Spectrum Disorder (ASD). According to The Centre for Disease Control and Prevention (2012), approximately 24,000 children born this year will be diagnosed with an ASD and 1 in every 68 children is diagnosed with an ASD. The prevalence rate for males is significantly higher than females, with the number of males (1 in every 42 boys) being diagnosed almost 5 times higher than that of females (1 in 189 girls) (CDC, 2014).

In addition to prevalence of Autism Spectrum Disorders increasing, the recurrence risk, the chance that each sibling born after an autistic child will develop autism, also has also increased. Previously thought to be between 310%, a recent study found that the rate of recurrence within a family is now

18.7%. The presence of one or more older siblings with an ASD significantly predicts recurrence, and the rate of recurrence increases fivefold if the older affected sibling is male (Ozonoff et al., 2011). Researchers have noted that having a sibling diagnosed with an ASD is the greatest risk factor for developing an ASD; in fact, Fombonne (2009) found that having an affected sibling increased the risk 22-fold.

From a genetic perspective, one of the first and most widely cited twin studies reported a 92% concordance for monozygotic (MZ) twins and only a 10% concordance rate for dizygotic (DZ) twins (Bailey et al., 1995). A 2009 follow-up study also supported greater ASD concordance in ML (88%) versus DZ twins (31%) (Rosenberg et al., 2009). These findings have been further replicated in a series of twin studies demonstrating that in identical twins, if one child has an ASD, the other

is found to also have an ASD about 36-95% of the time. In fraternal twins, the other is afflicted between 0-31% of the time (Hallmeyer et al., 2011; Ronald et al., 2006; Rosenberg et al., 2009; Taniai et al., 2008).

#### Meaning of Parents

Parents are the earliest and closest mentors of their children; the views, values, and attitudes of parents have an enormous impact on their children's development. Parents are the caregiver of the offspring in their own species. In humans, parents are the caretaker of a child (where "child" refers to offspring, not necessarily age). A biological parent is a person whose gamete resulted in a child, a male through the sperm, and a female through the ovum. Therefore, Parents are first-degree relatives and have 50% genetic meet.

Also, parents can be elaborated as an ancestor removed one generation. With recent medical advances, it is possible to have more than two biological parents. —For examples, third biological parents include instances involving surrogacy or a third person who has provided DNA samples during an assisted reproductive procedure that has altered the recipient's genetic material.

#### Types of Parents

The most common types of parents are:

1. Biological parents
2. Mother
3. Father
4. Grandparents
5. Step-parents
6. Surrogacy parents
7. Adoptive parents

We briefly take up each point separately.

#### 1. Biological parents

Biological parents refers to, the persons from whom the individual inherits his or her genes.

#### 2. Mother

"Mother" means "a woman in relation to a child or children to whom she has given birth". On the other hand, A mother is a female who has a maternal connection with another individual, whether arising from conception, by giving birth to, or raising the individual in the role of a parent More than one female may have such connections with an individual. Because of the complexity and

differences of a mother's social, cultural, and religious definitions and roles. So, it is challenging to define a mother to suit a universally accepted definition.

### 3. Father

A father is a male parent of any type of offspring. It may be the person who shares in the raising of a child or who has provided the biological material, the sperm, which results in the birth of the child.

### 4. Grandparent

Grandparents are the parents of a person's own parent, whether that be a father or a mother. Every sexually reproducing creature who is not a genetic chimera has a maximum of four genetic grandparents, eight genetic great-grandparents, sixteen genetic great-great-grandparents and so on.

In cases where parents are unwilling or unable to provide adequate care for their children (e.g., death of the parents), grandparents often take on the role of primary caregivers. Particularly in traditional cultures, grandparents often have a direct and clear role in relation to the raising, care and nurture of children. Grandparents are second-degree relatives and share 25% genetic overlap.

### 5. Step-parents

A stepfamily or blended family is a family where at least one parent has children that are not genetically related to the other spouse or partner. Either one parent may have children from a previous relationship. Children in a stepfamily may live with one biological parent, or they may live with each biological parent for a period of time.

### 6. Surrogacy parents

Surrogacy is a method or agreement whereby a woman agrees to carry a pregnancy for another person or persons, who will become the newborn child's parent(s) after birth.

Intended parents may seek a surrogacy arrangement when either pregnancy is medically impossible, pregnancy risks present an unacceptable danger to the mother's health or is a same sex couple's preferred method of having children. Monetary compensation may or may not be involved in these arrangements. If the surrogate receives money for the surrogacy the arrangement is considered commercial surrogacy. If she receives no compensation beyond reimbursement of medical

and other reasonable expenses it is referred to as altruistic. The legality and costs of surrogacy vary widely between jurisdictions, sometimes resulting in interstate or international surrogacy arrangements.

### 7. Adoptive parents

Adoption is a process whereby a person assumes the parenting of another, usually a child, from that person's biological or legal parent or parents, and, in so doing, permanently transfers all rights and responsibilities, along with filiations, from the biological parent or parents

#### Role and Responsibilities of Parents

It is widely acknowledged that parents play a significant role in the cognitive, social and emotional development of their children. Through their role, parents provide children with socialization to cultural and societal norms and values meant to prepare them for the navigation of the communities in which they live and the needs of the society they will encounter in the future (Miller and Goodnow, 1995). Family, which serves as a first school for the child, appears to be an important source of rising expectations. Parents have an important positive or negative influence on the academic aspirations and achievements of children. An adolescent is strongly and positively identified with parental model but if that model is indifferent to or suspicious and critical of educational values and goals, the young person is likely to adapt him/ her to respective parent model. Therefore, family and parents significantly affect child's performance in many spheres of life.

Also, Molnar (1979) found that parents' education and home environment play a significant role in child's academic achievement. Shah and Lakhera (1986) reported that family climate and level of adjustment were highly correlated. Where on one hand, parental involvement leads to better social adjustment and academic achievement, on the other hand over aspirations and negative attitude of the parents lead to depression and stress among students. Parents usually set unrealistically high goals for their children and expect them to come up to their expectations. When children are unable to come up to the expected standards, they are accused of being lazy or dull which induces a sense of inferiority among adolescents and sometimes leads to drastic outpourings by them in

the form of mental disorders depressions, stress and even suicides.

How parents can help their child

D Be aware of your child's behaviours and emotions.

D Build trust with your child.

D Encourage the expression of feelings.

Teach and model good emotional responses.

Encourage them to tell you if they feel overwhelmed.

Encourage healthy and diverse friendships.

C) Encourage physical activity, good nutrition, and rest.

D Teach your child to solve problems.

Remind your child of his or her ability to get through tough times, particularly with the love and support of family and friends.

D Keep your child aware of anticipated family changes.

Use encouragement and natural consequences when poor decisions are made.

Help your child select appropriate extracurricular activities and limit overscheduling.

Make your child aware of the harmful effects of drugs and alcohol before experimentation begins.

Parents Burden Caused By Children with Autism

The United States has a population of approximately 53.9 million school aged children between 5-17 years of age; about 2.8 million are reported as having a disability (U.S. Disability Facts and Statistics of School Aged

Children, 2011). Disabilities can be listed as mild to severe and may affect the child's development intellectually (Down syndrome and developmental delay), emotionally (autism and bipolar disorder), and physically (arthritis and orthopaedic conditions (Nielsen et al., 2012). With no respect to race, age, gender or ethnic affiliation, increasing numbers of families face the possibility of raising a child with disabilities (CWD), since many of these children are now living longer and at home more than they did in the past.

Issues a parent faces in caring for a CWD continue to receive research and attention. Much of this research discusses how better health and social care have led to improved longevity within this population (Minnes & Woodford, 2005). This, combined with the growing numbers of CWD, suggests more people will be caregivers well into

their old age (Minnes & Woodford). Consequently, as more family members are affected by this situation for longer periods of time, there is an increased interest in the well-being of families raising these children. Concerns related to these families include: quality of life; parenting practices and stress; caregiving demands; family support and satisfaction; and cultural differences (Sosbey & Calder, 2006), suggesting these families may be burdened by the care a CWD requires compared to families raising typically developing children (TDC) (Wang, Michaels, & Day, 2010; Weiss, 2002). In fact, Oelofsen and Richardson (2006) discovered up to 84% of families raising a CWD experienced stress due to the child's care needs which may lead to parental caregiver burden.

For nearly all parents, having children and caring for them is an experience with triumphs, joys and also challenges and stresses (Resch et al., 2010). Although parents expect to provide care giving during the growth of a child, the caregiver role takes on a new significance when parents are raising a CWD (Raina et al., 2005), especially since recent practice supports caring for these children in the home. Related to this, Raina and colleagues discussed how duties and roles within the family unit may change when raising a CWD; caregivers are often faced with the possibility the CWD may require long-term care well beyond the typical child raising years, as these parents remain in the caregiver role longer and are continually required to sacrifice their own needs over the child's needs (Nguyen, 2009). They therefore, may experience caregiver burden because of increased stress raising a CWD (Abbeduto et al. 2004; Dumas, Wolfe, Fisman, & Culligan, 1991; Rodrigue, Morgan, & Geffken, 1990; Warfield, 2005), and because parenting these children is extremely complex with challenging caregiver duties and pressures (ManorBinyamini, 2011). In fact, many of these added stressors adversely affect caregivers' overall health (Oelofsen & Richardson, 2006), and can lead to depression (Hasting, Daley, Burns, & Beck, 2006), marital conflict (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Suarez & Baker, 1997), less effective parenting (Baker & Heller, 1996), and increased behaviour problems in their children (Baker et al. 2003).

In addition to the general challenge and pressure of raising a CWD, other factors are also linked to caregiver burden. For example, education is associated with the level of psychological stress (Al-Krenawi, Graham, &Gharaibeh, 2011; Cavallo, Feldman, Swaine, &Meshefedjian, 2008; Kumar, 2008). Specifically, educated mothers (those with post high school education) are more likely to seek help and provide appropriate and timely treatment for the child, which decreases the likelihood of medical crises (Kumar). However, parents who have low education levels (not completing high school) are much more dependent on medical staff and have little confidence in their ability to provide for their CWD (Cavallo et al.), and therefore, may experience more caregiver burden.

Parents also report increased caregiver burden when there are few resources available to help them find good healthcare and support for their child (McManus et al., 2011). In fact, parents of poor, minority, and uninsured children struggle to provide and coordinate their child's health care because many do not have easy access to or knowledge of resources available. Without proper access to resources, financial burdens arise, the child's health care needs continue to go unmet, and parents spend prolonged time searching for help (McManus et al.). However, caregivers learn to deal with burden by using coping mechanisms that lower stress and strain. Some of these mechanisms include support received from social and familial relationships, as well as from health care professionals (Cavallo et al., 2008). On the other hand, when a CWD receives professional health care, the needs of the child are generally the focus rather than on how parents are coping with the situation. Consequently, if the family as a unit is the focus of care and support, caregiver burden can be relieved, especially during those difficult experiences when a child may be hospitalized or receiving therapy (Al-Krenawi et al., 2009; Resch et al., 2010). Indeed, caregiver burden is experienced by parents raising a CWD. This added burden is linked to parents' well-being and can also lower the quality of care provided to the child.

#### The Autism Spectrum Disorders

As of 2013, the American Psychiatric Association revised the diagnostic criteria of the Autism Spectrum Disorders as reflected in the

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Unlike the previous edition of the DSM (the DSM IV-TR), this edition classifies Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified as one diagnosis. As a result of unifying the former four separate disorders as now one disorder, the symptoms are conceptualized as a continuum.

In addition to combining the disorders into a single continuum, the DSM-5 diagnostic criteria have been rearranged from three areas (social reciprocity, communicative intent, and restricted and repetitive behaviors) to two areas: social communication / interaction and restricted and repetitive behaviors. Additionally, in order to increase early detection and intervention, the symptoms must be present beginning in early childhood; however, symptoms may not be detected until the demands exceed a child's capacities (Hyman, 2013).

#### HISTORY

Eugen Bleuler (1857—1939), a Swiss psychiatrist, coined the terms schizophrenia and autism. He derived the latter from the Greek word *autos* (meaning "self"), to describe the active withdrawal of patients with schizophrenia to their own fantasy life in an effort to cope with intolerable external perceptions or experiences (Kuhn, 2004). The use of the term autism in its current sense started 30 years later when the Austrian paediatrician Hans Asperger adopted Bleuler's terminology of autistic psychopaths in a lecture he delivered at the Vienna University Hospital (Asperger, 1938). Asperger subsequently published his second PhD thesis in 1944 (first transcribed in 1943) (Asperger, 1944) where he described a group of children and adolescents with deficits in communication and social skills and also with a restricted, repetitive pattern of behaviours.

At the same time, in 1943 — separated by distance, the Second World War and apparently unaware of each other's work — Leo Kanner, at Johns Hopkins University Hospital in the US, described 11 children with striking behavioural



similarities to those depicted by Asperger in his classical paper

"Autistic disturbances of affective contact" (Kanner, 1943). Most of the characteristics described by Kanner such as "autistic aloofness" and "insistence on sameness" are still part of the criteria to diagnose autism in current classifications. Children described by Asperger differed from those of Kanner in that they had no significant delays in cognitive or language development.

Asperger's paper, published in German, remained largely unknown until Uta Frith translated it into English (Asperger, 1944), which made it widely available. These ideas were further disseminated by Lorna Wing (Wing, 1997) in the UK. As a result, there has been a gradual acknowledgement that autism constitutes a spectrum with a continuum from mild to severe symptoms and that

Asperger's disorder is part of that continuum.

It was a misfortune that the original meaning of Bleuler's term and its theoretical relationship with schizophrenia, combined with the psychoanalytic theories dominant in the mid twentieth century, amalgamated ASDs with psychotic disorders, classifying them under the rubric of childhood schizophrenia. The apparent withdrawal of ASD patients was misinterpreted as the same mechanism as that seen in schizophrenia, a defensive retreat from an intolerable external situation, the result of a pathogenic family (as it was then widely conceptualized). Unfortunately, some of these discredited ideas are still held by some. The relative importance of ASDs in relation to other health conditions continues to be underestimated by governments and international agencies. In Africa, for example, clinical work on ASDs did not start until three decades after Kanner and Asperger had published their work (Lotter, 1978;

Bakare & Munir, 2011).

#### DEFINITION

ICD-10 (World Health Organization, 1990) classifies autism under the pervasive developmental disorders, a group of conditions characterized by qualitative abnormalities in

reciprocal social interaction, idiosyncratic patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a feature of the sufferer's functioning in all situations. DSM IV (American Psychiatric Association, 2000) also uses the term pervasive developmental disorders, although its subdivision is different in the two classifications. Both taxonomies utilize a list of behaviours, require that a number of criteria be met to warrant a diagnosis and are periodically reviewed to incorporate new research data. In fact, both are currently undergoing a detailed review; DSM-5 is expected to be released in 2013 and ICD-II in 2015. Important changes to DSM-5 are expected while up to this point, ICD-II does not seem to be planning major modifications.

The changes proposed for DSM-5 have been polemical in scientific and lay circles. DSM-5 proposes to eliminate the division existent in DSM-IV between autism, Rett's disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorders not otherwise specified. According to the DSM-5 proposal, there will be a unique category of ASD, characterized by:

- Persistent deficits in social communication and social interaction across contexts not accounted for by general developmental delays
- Restricted, repetitive patterns of behaviour, interests, or activities
- Presence from early childhood (but may not become fully manifest until social demands exceed the child's limited capacities), and
- Limitation and impairment in everyday functioning.

DSM-5 will thus eliminate the diagnosis of Asperger's disorder while formalizing the "spectrum" concept espoused by Lorna Wing, who favoured considering Asperger's disorder a sub-category of a unified ASD construct (Wing et al, 2011).

Clinicians will find the classical symptoms grouped in these two areas (deficits in social communication and restricted, repetitive patterns of behaviour) with the addition of hyper or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment. Also, there will be a complementary classification of severity,

categorized as "requiring support", "requiring substantial support" and "requiring very substantial support".

A recent study by Frazier et al (2012) supports the validity of the proposed criteria. They report increased specificity compared with DSM-IV and suggest that a relaxed algorithm should be considered to improve identification and decrease cost, thus maximizing intervention resources. William et al (2012) tested the construct validity and reported the DSM-5 model was superior to DSM-IV, and the model fit in their sample was good, stable across age and gender and in those with clinical and sub-threshold autistic presentations.

#### EPIDEMIOLOGY

Autism was once considered a relatively rare condition. Recent epidemiological data have radically altered this perception. Based on large surveys in the US, the Centres for Disease Control and Prevention (CDC), estimates the prevalence of ASD as 1 in 88 children, occurring in all racial, ethnic and socioeconomic groups, although it is five times more common among boys (1 in 54) than girls (1 in 252). The CDC website also offers data from numerous studies in Asia, Europe and North America showing an average prevalence of ASDs of about 1%. A recent survey in South Korea, which screened children in the schools, reported a prevalence of 2.6% (3.7% among boys and 1.5% among girls) (Kim et al, 2011). Another study in England estimated a prevalence of ASD at almost 1% in adults (Brugha et al, 2011).

However, epidemiological studies are difficult to compare. They vary in the composition of the population surveyed, recruitment mechanisms, sample size, design, awareness, participation rates, diagnostic criteria, instruments used as well as whether impairment criteria are included (Fombonne, 2009). Nevertheless, using the same methodology over a period of eight years, the CDC's Autism and Developmental Disabilities Monitoring Network has found increasing rates of ASDs in the US.

Although studies do not rule out temporal or external demographic factors (such as being born to older parents; survival of premature or high risk low birth weight babies; earlier diagnosis of

young children with higher IQ who spontaneously make progress over time that would not have been diagnosed years ago; or only counting older children receiving special support), experts in the field explain this rising in prevalence by increased awareness and improvement in the recognition and detection of the disorder. This may explain why the prevalence of ASD is reported to be lower in China (6.4 in 10,000) (Li et al, 2011). While there is much research on ASD in Europe and North America, there is not a single epidemiological study of ASD in sub-Saharan Africa (Bakare & Munir, 2011), but a significant increase of ASD among children of Ugandan mothers (Gillberg et al, 1995) and of Somali women living in Sweden (Barnevik-Olsson et al, 2008) has been reported.

#### EARLY DETECTION

It is acknowledged that early detection constitutes a major advancement in that it enables prompt intervention that may improve prognosis in a significant proportion of children with ASD, but also because it clarifies the doubts and anguish of parents and allows adequate public planning for future school placements and community support.

It was known that there was a higher incidence of ASD among siblings of already identified cases; these observations have led to a more detailed examination of newborn siblings and follow up during their first years of life. Trying to identify early developmental signs that precede a diagnosis of ASD in siblings that eventually develop the disorder has been a fruitful area of investigation. This change, from a retrospective view of abnormal development to a prospective follow-up of children at risk, constitutes a remarkable scientific advance. It has been shown in these high-risk infants that there were no notable findings during the first six months in those later classified as ASD; however, in the following six months, social interaction problems started to unfold (Zwaigenbaum et al, 2005). By two years of age, toddlers in the spectrum had clear problems in social communication, play, language and cognition, as well as other sensory and motor difficulties (Zwaigenbaum et al, 2009). These findings confirm the notion that ASD can be identified earlier than usual in some cases and that for many children 24 months of age coincides with

a peak in new symptoms that would facilitate recognition. The same authors reported (in an oral presentation at the 2011 IMFAR-San Diego) that 25% of the 277 siblings followed up in their study were diagnosed with ASD at 36 months of age, but cautioned that in 46% of those there had been no diagnosis assigned in their evaluation at 24 months of age. Therefore, at least in this probably no representative sample, trajectories are quite different from what was considered retrospectively.

Relevant information to guide clinicians comes from the longitudinal research conducted by the First Words Project (Florida State University) that identified red flags for ASD, although they insist there is not a path gnomonic symptom that guarantees the presence of ASD. Not all children with ASD show all and every one of the symptoms all the time; and this should prevent clinicians from saying "this child does not have autism, because I saw him looking at the eyes of others" or similar. The First Words Project came up with nine red flags that helped to distinguish children with ASD from children with developmental disabilities and typically developing children, and four red flags that distinguished children with ASD and developmental disabilities from children with typically developing children (Wetherby et al, 2004).

Many questionnaires have been developed as possible screening tools for developmental assessment of children as well as for ASD screening. Information, sound practical advice and a description of the most useful ones can be found in the ASD website of the US Centres for Disease Control and Prevention. A variety of practice flowcharts are also available, largely produced by national societies, but the one produced by the American Academy of Paediatrics represents the current gold standard for screening ASD in developed countries (Johnson &Mayers, 2007).

### Screening instruments

Among the many instruments available, there are currently two that merit special mention since they are free, tackle different age groups (one younger children and the other older ones), have gone through cross-cultural adaptation and appropriate translation to many languages, and have been researched in various countries. These

are the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins et al, 2001) and the Childhood Autism Spectrum Disorders Test (CAST) (formerly known as Childhood Asperger Syndrome Test)n

The M-CHAT can be complemented with the M-CHAT Follow-Up Interview, also available at the M-CHAT website. It is recommended that MCHAT users also incorporate the M-CHAT Follow-up Interview into the screening, given recent findings demonstrating that use of the interview greatly reduces false positive cases, avoiding unnecessary referrals. The CAST is also available free for non-commercial purposes and in many languages at the website of the Autism Research Centre of the University of Cambridge.

The American Academy of Paediatrics recommends screening for ASD of 18 and 24 months old children using a staged procedure (Johnson & Meyers, 2007). However, there are practical and ethical difficulties to do so and it is questionable if this screening should be routinely implemented worldwide. First, the psychometric properties of these instruments are not perfect. Some,

like M-CHAT, identify a proportion of false positive cases that indeed do not have ASD. Health authorities may not consider this a problem since it detects children that require support for other conditions (e.g., developmental delays, speech problems). There are also false negatives: children having the condition who are not identified by the screening — there is no screening instrument with perfect sensitivity and specificity. Al- Qabandi et al (2011) challenge the belief that screening should be done because there is an effective treatment (e.g., early behavioural intervention) — although promising, treatments are not equally effective in all children with ASD and we are just beginning to understand who will be best served with what treatment but many questions remain. It is widely recognized that screening for a condition without having the resources or treatments (as it happens for ASDs in most regions of the world) may be unethical. In the same line, it is not clear whether young children with ASD are more easily recognized using universal screening instruments administered by professionals than, for example, through a culturally sensitive, community



campaign. Despite all these controversies it is accepted that increasing information, educating families, teachers and medical staff to recognize ASD is a step forward.

The mechanisms to detect ASD are likely to be different for each country and region, depending on culture and child rearing practices, but mainly depending on the availability of developmental surveillance (not isolated "checking" for a specific condition). Most children in the world do not have access to well-baby programs and to developmental surveillance. Access to health should include empowering communities and health systems to identify the most prevalent disabilities in a given community. In developed countries these include intellectual disability, cerebral palsy, deafness, blindness, and ASD. In other parts of the planet, the priorities for surveillance might be very different. In summary, we propose that context-friendly developmental surveillance should be conducted for all children with administration of screening instruments to those suspected of having ASDs.

#### ETIOLOGY AND RISK FACTORS

In the US, in the 1950s and early 1960s, autism was thought to be due to the defective upbringing of children by cold and rejecting parents, thereby leaving the child with no alternative but to seek comfort in solitude, as once claimed by Bruno Bettelheim. He compared autism to being a prisoner in a concentration camp (something he had experienced himself in Germany during

WWII) (Finn, 1997) in his book "The Empty Fortress: Infantile Autism and the Birth of the Self". In 1964, Bernard Rimland opened the way for the current understanding of autism by introducing the notion that it was a disorder of brain development with his seminal book "Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behaviour" (Rimland, 1964),  
Genetic factors

Evidence for the importance of genetic factors in the etiology of autism comes from many sources, including twin and family studies (Muhle et al, 2004). Autism is, for example, 50 to 200 times more prevalent in siblings of autistic

probands than in the general population. Among probands' relatives who do not have autism, there is also an increased prevalence of milder forms of developmental difficulties related to communication and social skills. Concordance rates for autism range from 36% to 96% in monozygotic twins but only 0% to 27% in dizygotic twins (Shaddock&Shaddock, 2008).

Although the heritability of autism has been estimated to be as high as 90% (Freitag, 2007), genetic factors are heterogeneous, complex and for the most part poorly understood. The precise mechanisms are being explored through whole genome screening, cytogenetic, and evaluation of candidate genes (Muhle et al, 2004). In studies of candidate genes, there are replicated

findings of increased risk for autism associated with variants in single genes on chromosomes 2, 3, 4, 6, 7, 10, 15, 17 and 22 (Freitag et al, 2010). Cytogenetic studies have implicated abnormalities at the 15q II-q 13 locus in individuals with autism (Muhle et al, 2004; Smalley, 1991). Genome-wide association studies have found slight effects on autism risk with genetic variants at the 5p14.1 and 5p15 loci (Ma et al, 2009; Weiss et al, 2009). Also, replicated copy number variations, found in genome-wide association studies to be more common in individuals with autism than in controls, are located on chromosome regions Iq21, 2p16.3, 3p25-26, 7q36.2, 15q11-13, 16p11.2 and 22q11.2 (Freitag et al, 2010). Future directions for genetic research in autism lie in identifying specific gene-environment interactions.

#### Neuroanatomic and neuroimaging findings

Neuroanatomic and neuroimaging findings, though not diagnostic, have consistently revealed increased cerebral volume that affects both gray and white matter, as well as enlarged ventricles. Neuroimaging findings also include abnormalities in brain chemistry, serotonin synthesis, and brain electrophysiology (Courchesne et al, 2004; Hazlett et al, 2005; Lainhart, 2006).

The autism "spectrum" is now understood to be neurodevelopmental, meaning that there are differences in the pattern of brain development. For example, early brain overgrowth has been documented in the first two years of life (Courchesne et al, 2001) and, in later development,

there are clear differences in the function and structure of the "empathy circuit" of the brain (amygdala, ventromedial prefrontal cortex, temporo-parietal junction, orbitofrontal cortex, anterior cingulate, and other related brain regions) (Lombardo et al, 2011). There are also differences in connectivity between frontal and parietal lobe functions that are thought to relate to cognitive style, in particular an over-reliance on processing details and a relative under-reliance on processing gist or holistic information (Belmonte et al, 2004).

#### Environmental factors

A number of environmental factors have been claimed, particularly in the Internet, as playing a role in aetiology of ASDs, including mercury, cadmium, nickel, trichloroethylene, vinyl chloride (Kinney et al, 2010). It is important to note that the previously suggested link between MMR vaccines and autism spectrum disorders (Wakefield et al, 1998) had been debunked by international agencies that included Centres for Disease Control and Prevention, Institute of Medicine of the US National Academy of Sciences, the UK National Health Service and the Cochrane Library. The Wakefield et al (1988) article published in Lancet that suggested the association between the MMR vaccine and autism has since been declared fraudulent and officially withdrawn (Goodlee et al, 2011).

Associations between different environmental factors contributing to vitamin D deficiency and increased risk of autism has also been proposed (Grant & Soles, 2009). This requires further studies.

#### Epigenetic factors

There are indications that, in addition to genetic and environmental factors, epigenetic factors also play some role through the fact that several genetic syndromes that are co-morbid with ASD show dysregulation of epigenetic marks that help regulate gene expression (Grafodatskaya et al, 2010). The epigenetic line of research also holds promise in offering an explanatory model to understand the putative increased incidence of autism suggested by epidemiological findings.

#### Risk factors

The NICE (2011) guideline "Autism: Recognition, Referral and Diagnosis of Children

and Young People on the Autism Spectrum", while stressing the low quality of evidence found, lists the risk factors for ASDs that are clinically and statistically important as:

- A sibling with autism
- A sibling with another ASD
- ' Parental history of schizophrenia-like psychosis
- Parental history of affective disorder
- Parental history of another mental or behavioural disorder
- Maternal age older than 40 years
- ' Paternal age between 40 and 49 (ASD)
- Paternal age older than 40 years (autism)
- ' Birth weight less than 2500 g
- Prematurity (under 35 weeks)
- ' Admission to a neonatal intensive care unit
- Presence of birth defects
- ' Male gender
- Threatened abortion at less than 20 weeks
- Residing in a capital city
- Residing in suburb of a capital city.

In relation to medical conditions associated with ASD, with the same proviso of low quality of the evidence, the NICE guideline lists the prevalence of ASDs in several medical conditions (prevalence of ASDs between parentheses):

- Intellectual disability (8%-27.9%)
- Fragile X syndrome (24%-60)
- Tuberosus sclerosis (36%-79%)
- ' Neonatal encephalopathy/epileptic encephalopathy/infantile spasms (4%-14%)
- Cerebral palsy (15%)
- Down syndrome (6%-15%)
- Muscular dystrophy (3%-37%)
- Neurofibromatosis (4%-8%).

Neonatal physical illnesses such as post-encephalitic infections and sepsis had been documented to precede the onset of symptoms of ASDs, especially in sub-Saharan Africa. Autoimmune factors have also been claimed as a possible etiological factor in ASDs. This would result, if finally demonstrated, from reactions between maternal antibodies and the fetus (Bakare & Munir, 2011).

In summary, although heritability of autism has been estimated as extremely high, the challenges faced in understanding the aetiology of autism lie in the observation that genetic factors are

heterogeneous, complex, and the interaction between genes and environment are poorly understood. There are on-going and ambitious individual and familial longitudinal studies that promise to give us useful data in this regard.

Future directions for genetic research in autism lie in identifying specific gene environment interactions. Research must overcome the challenges of elucidating the roles of genetic heterogeneity, epigenetic mechanisms and environmental modifiers. It is hoped that technological advances, combined with longitudinal projects, will help us understand in the near future the etiological complexities of these disorders and will advance specific ways to treat and to prevent them.

#### CLINICAL ASPECTS

##### Qualitative impairments in social interaction

Of the three core symptom domains that define autistic disorder, impairment in social interaction is central. This includes impairments in nonverbal behaviours used to regulate social interactions, failure to develop peer relationships appropriate to the child's developmental level, and lack of spontaneous seeking to share enjoyment, interests or achievements with others (e.g., by a lack of showing, bringing or pointing objects of interest to the attention of others). Children with impairments in these areas lack social or emotional reciprocity.

Responding to joint attention and initiating joint attention is very important in social learning and is associated with language and cognitive development. Impairment in joint attention is a very important early symptom that can be seen even in very young children with autism.

Research on the theory of mind has shown that children's ability to imitate others lies at the origin of understanding the perspective of others. Theory of mind enables one to have an idea of the mental state of others and, to some extent, predict their actions. This is also related to the ability to understand deception and other people's emotions (empathy). Theory of mind impairments negatively affects pretend play, empathy, and sharing, social and emotional reciprocity and peer relationships. Theory of mind impairments can be seen in all

individuals with ASD regardless of age and intelligence when mental-age-appropriate tests are used (Baron-Cohen, 2009). However, theories of mind deficits are not exclusive to ASD and can be seen in schizophrenia and in some personality disorders.

Another important concept is stimulus over selectivity: children with ASD exhibit overly selective attention. This is also not unique to ASD and can be seen in children with intellectual disabilities.

Stimulus over selectivity can be due to restricted attention or bias towards non global, local information. The latter has been described as the "weak central coherence theory" (Happe & Frith, 2006). The bias explanation allows individuals with ASD to have superior local information processing ability. Enhanced perceptual functioning theory (Mottron et al, 2006) posits that individuals with ASD have biased perception, which is more locally oriented; detail perception is enhanced and movement perception is reduced. BaronCohen and associates (2009) argue that sensory hypersensitivity leads to excellent attention to details and "hyper systemizing" leads to law-based pattern recognition, which can produce talent.

Children with ASD use nonverbal behaviours such as eye contact, gestures, body postures and facial expressions less often than typically developing children. One of the most important findings in recent years has been the observation that two-year-olds with autism fail to orient towards biological motion — human bodies in motion (Klin et al, 2009) — and they do not preferentially look to the eyes of approaching adults (Jones et al, 2008).

Children with ASD show several atypical behaviours, probably due to sensory hypersensitivity, that can be observed in visual, auditory and tactile modalities and can be specific to certain stimuli (Baron-Cohen et al, 2009). Visual hypersensitivity may lead to lateral vision — staring at objects with pupils at the corner of the eyes (Mottron et al, 2006). Lateral vision has been interpreted as an attempt to limit excessive information or to focus on optimal information. Auditory and tactile hypersensitivities can be very stressful. On the other hand, sensory

hypersensitivity may also lead to exceptional attention to detail.

Even high-functioning individuals with ASD may have problems in peer relations. While some of the subjects do not have any interest at all in relating to peers, others may have impairments in playing in different sides of a game (both seeking and hiding). Some children with ASD may want to have peer relations but they may have problems in interpreting other's actions and responding accordingly. Many subjects with ASD do not have insight into the nature of social relations, particularly in their part and role in relationships. Many individuals with ASD may fail to develop empathy. All of these difficulties lead to impairments in social relations.

Qualitative impairments in communication

This core symptom domain includes delay in, or total lack of development of spoken language, which is not accompanied by compensatory attempts; marked impairment in the ability to initiate or sustain conversations; stereotyped, repetitive or idiosyncratic language; and lack of varied, spontaneous imitative or make-believe play. Language delays, lack of language, and peculiarities in spoken language are common in ASDs and they are often the parents' initial concern.

The important distinction lies in the compensation attempts; children with other developmental and sensory disabilities usually use non-verbal means —such as gestures — for communication. In children with speech, functionality and social directedness of the speech is very important. Repetition of another person's words, echolalia is frequent in ASDs. The rate, volume and intonation of speech can be abnormally high, low, fast, slow, jerky, monotonous, etc. Individuals with ASDs may invent their own words or phrases and language can be repetitive, may repeat the same phrases even when they are inappropriate to the context. Even high functioning individuals with ASD can have problems initiating and sustaining a conversation. This includes lack of small-talk, not providing enough information, not asking for information and not building on other people's comments. When combined with restricted

interests, conversation with persons with ASD can be very difficult to sustain.

Play can be functional or imaginative. Functional play is when toys are used as intended, for example using a toy fork as a fork or pressing the buttons of a cause-and-effect toy. Problems in make-believe and imitative play are apparent in many children with ASD. Typically developing children play with several materials in a flexible and creative way. For example, in typical make-believe play children can use a puppet as a general and a wooden block as the car of the enemy soldier (imaginative play). Everything can be used in an imaginative way.

Repetitive, restricted, stereotyped patterns of behaviour, activities and interests

According to DSM-IV, this third core symptom domain includes preoccupation with stereotyped and restricted patterns, inflexible adherence to routines, stereotyped and repetitive motor mannerisms, and persistent preoccupation with parts of objects. It has been suggested that this domain is very broad and contains at least two subtypes of behaviours: (a) repetitive sensory motor behaviours (lower-order) and insistence on sameness — and possibly circumscribed interests — (higher-order). Repetitive sensory motor behaviours are more frequently seen in young children and are associated with lower non-verbal intelligence.

Many individuals show strong interests in some topics; they read extensively about them, collect items related to them, can talk on that subject for hours, and may proceed as young adults to join interest groups or societies dedicated to their interest. The difference between these normal behaviours and those of individuals with ASD can be explained in terms of narrowness of the focus, inflexibility, perseveration and lack of social quality. Individuals with ASD can focus on a very specific part of the object of their interest; for example, only the number of teeth in dinosaurs. They can have problems in switching to other topics even when other people are clearly not interested in what they are talking about. They keep focusing on the topic when they are supposed to do other tasks and may become distressed or even agitated when they are interrupted. They may show

less interest in sharing their hobby in social ways, like joining a club.

Inflexible adherence to specific, non-functional routines or rituals is also a typical symptom of ASDs. Difficulties with minor changes in personal routine and resistance to even small changes in the environment can cause significant problems in there and their families' daily lives.

Stereotyped and repetitive motor mannerisms and persistent preoccupation with parts of objects may be more evident in younger children and individuals with intellectual disability. These include hand and finger flicking, mannerisms, rocking, toe walking, sniffing and licking non-food objects, spinning, and unusual visual gaze, among others. Persistent preoccupation with parts of objects can be seen, for example spinning wheels, flickering the eyes of dolls, among others.

Stereotyped behaviours can be observed in several other conditions including Tourette's Disorder, Fragile X syndrome, Rhett's disorder, obsessive compulsive disorder, deafness, blindness, schizophrenia and a variety of intellectual disabilities without ASD. It seems that the frequency but not the pattern — which is related to the developmental level — of the behaviour is what is distinctive for ASDs (Bodfish et al, 2000).

## DIAGNOSIS

There is a wide agreement that, once the presence of ASD is suspected, the child should be referred for a multi-disciplinary assessment in which all members of the team should have some ASD training and at least one member should be trained in the assessment and diagnosis of ASD using standardized instruments. Also, it is recommended that the child should be ideally observed in several different settings, both structured and unstructured. It needs to be recognized, however, that the vast majority of child and adolescent mental health services worldwide do not have the state-of-the-art instruments used in specialized clinics in wealthy countries such as the Autism Diagnosis Observation Schedule, the Autism Diagnostic Interview, the Diagnostic Interview for Social and Communication Disorder or the Developmental, Dimensional and Diagnostic interview. This highlights the need for dissemination, training and development of multi-

cultural, multi-language, cheap, reality-oriented, user-friendly, instruments.

The NICE guideline is freely available and considers all the aspects of the ASD-specific diagnostic assessment, provides recommendations about its core elements, autism-specific diagnostic tools and how best to communicate to parents a diagnosis of autism for their child. In summary, the NICE guideline reiterates what has been established in other guidelines including a detailed enquiry into the specific concerns raised by family and teachers; medical history; home life, education and social care; and history and observation focusing on the developmental and behavioural features specified ICD-IO and DSM-IV. This core information is usually sufficient to establish a diagnosis of autism when diagnosis is straightforward. Beyond the diagnosis of ASD, a diagnostic assessment should also include a profile of strengths, needs, skills and impairments. The instruments needed for this will depend on the age of the patient and the developmental level, but should be instrumental in helping to identify:

' Intellectual ability and learning style

- Academic skills
- Speech language and communication skills
- Fine and gross motor skills
- Adaptive (including self-help) skills °  
Socialization skills
- Mental and emotional health including self-esteem, physical health and nutrition
- Sensory hyper- and hypo-sensitivities
- Behaviour likely to affect participation in life experiences, future support and management.

### Physical Examination

A comprehensive physical examination should also be undertaken. Findings from the physical examination may be useful to detect coexisting conditions or symptoms of disorders that may have a causative role or increase the suspicion of an ASD. Particular attention should be given to identifying skin stigmata of neurofibromatosis and tuberous sclerosis, as well as congenital abnormalities and dysmorphic features including micro and macrocephaly. The examination should also look for signs of physical injury, such as self-harm or maltreatment.

### Differential Diagnosis



Autistic disorder, when presenting in its full typical form, is not difficult to recognize by a professional with experience. However, clinicians should rule out medical, genetic, neurological or sensory dysfunctions or disorders. The situation is different for clinical pictures that do not fit the traditional descriptions of the disorder, which are becoming more frequent due to the widening of the construct into the autistic spectrum and this can lead to diagnostic disagreements.

### Infants and Toddlers

Differential diagnosis at this age should rule out disorders that interfere with normal development of language and social skills:

#### Hearing loss

It can be suspected if the child has lost his babbling, shows poor vocalizations or indifference to auditory stimuli. Routine exam in very young children who cannot be expected to cooperate include otoacoustic emissions and impedance audiometry. If they are normal, there is no need for further testing. If they are abnormal, the external ear should be examined and both tests should be repeated in two-three months. If the results are again abnormal, auditory evoked potentials should be studied.

#### Severe Psychosocial Deprivation

It is well known that severe emotional deprivation in childhood leads to serious psychological impairments including pseudo-autistic clinical pictures (Rutter et al, 1999). The autistic-like symptoms in these cases usually consist of a relative indifference to the environment, communications delay, restricted interests and repetitive behaviours. Unlike in autism, social reciprocity is not completely abnormal — although bonding may be affected — and deficits can be reversed quickly in the majority of cases if environment improves.

#### Intellectual Disability

It is often a difficult diagnosis to exclude in the early years of life because evaluation of cognitive functioning is more difficult. Some symptoms (e.g., facial dysmorphism, microcephaly) may suggest the existence of genetic or neurological problems known to cause intellectual disability may be suspected. It is also documented that severity of intellectual disability is positively

correlated with social interaction deficits (Wing & Gould, 1979). Therefore, attributing communication and socialization defects, self-injurious or stereotypic behaviours to autism or severe intellectual disability can be challenging. This can be provisionally solved if there is evidence of an abnormal development in social, discordant with the general level of intelligence (very difficult to clarify when mental age is below 18 months). It is important here to highlight that the association of AUDs and intellectual disability is very common and that many known causes of intellectual disability, such as chromosomal abnormalities often present with autistic symptoms (e.g., Fragile X syndrome, Prader-Willi syndrome).  
Rett's Disorder

DSM-IV includes this condition among the pervasive developmental disorders. However, DSM-5 proposes not to include Rett's disorder because although patients often have autistic symptoms they are apparent only for a brief period during early childhood, so inclusion in the autism spectrum is not appropriate for most individuals. Rett's disorder is an X-linked neurodevelopment disorder that affects girls almost exclusively. Typically, there is normal development until 6—18 months of age, then development stops and a regression appears (loss of speech and of purposeful hand use) with specific hand stereotypes and social withdrawal, which mimic an autistic picture. Besides, there is a deceleration in head growth leading to acquired microcephaly and seizures may appear. Research has led to identification of a gene (MECP2) on the X chromosome (explaining the higher frequency in girls, but some male cases have been reported) (Amir et al, 1999).

#### Receptive-Expressive Language Disorders.

Expressive language disorder is very common in children and usually consists in a simple delay in mastering phonology, lexicon and syntax that looks very selective in the context of a typical development of social skills, non verbal communication, cognitive skills and imagination. The situation is more challenging in a minority of non-autistic children of normal non-verbal intelligence who have severe receptive-expressive language impairment. This situation has been described as "semantic-pragmatic disorder" with

problems in the social communication aspects of conversational interchange, including echolalia. However, unusual preoccupations and rituals are much less common than in autism. It is of note that this disorder is not included in DSM-IV or ICD10.

#### Landau—Kleffner Syndrome

Acquired aphasia with epilepsy or Landau—Kleffner syndrome is characterized by a normal development until age three to four followed by a massive regression of receptive and later expressive language, typically in conjunction with the development of seizures or sleep electroencephalogram abnormalities. The regression may be associated with transient social withdrawal but a complete autistic picture is not observed. There is a sub-type of pervasive developmental disorder, childhood disintegrative disorder, where regression is evident, but the regression occurs earlier (18 to 24 months of age).

#### Selective Mutism and Separation Anxiety

Withdrawal, anxiety and communication problems are common. However, it can be easily distinguished from autism because of the existence of normal communication and social skills at home or in other familiar environments.

#### Older children

Differential diagnosis in typical autistic presentations is easier in older children, but it can be difficult in cases within the broader phenotype: cases in the "periphery" of the spectrum, especially in high functioning children or cases with a partial disorder. An accurate medical history, establishing the onset of symptoms before or after the age of three years, is often an important indicator.

Clinicians should consider childhood schizophrenia. The potential confusion between this rare condition and ASD may arise from poor expression of emotions and negativism. However, hallucinations and delusions are specific to schizophrenia. Furthermore, most children with early onset schizophrenia do not show the language delay or abnormalities and the social deficits that are typical of ASDs.

Other psychiatric conditions to be excluded are attention deficit hyperactivity disorder especially as both can coexist, and obsessive compulsive disorder because of the rituals and selected

interests, but the differential diagnosis can easily be made on the bases of the history and the global clinical presentation. It is of interest to highlight that some authors refer to a disorder not included in the current classifications: multiple complex developmental disorder (Towbin et al, 1993), which consists of impaired regulation of affective state, with primitive anxieties, impaired social reciprocity and thought disorders, but failing to meet criteria for ASDs.

#### PROGNOSIS AND ADULT OUTCOMES

ASDs are disorders that start in infancy; therefore, significant changes occur with development that will impact adult outcome. These changes should not be overlooked and require ongoing monitoring and individualized adaptation to optimize support programs. Baghdadli et al (2007) have stressed the high variability in short-term outcomes of preschoolers, emphasizing the importance of considering individual characteristics and adaptive strategies. They suggest that these differences may be due to certain initial characteristics like speaking skills and severity of autistic symptoms.

The more severe the co-morbid intellectual disability the poorer is the outcome. It is generally accepted that speech before the age of six and a higher IQ are associated with a better outcome (Billstedt et al, 2011). However, there is limited research data about the whole spectrum across the life cycle. Therefore, clinicians must be cautious when predicting the distant future of their patients. ASDs are lifetime disorders and cannot be cured. Nevertheless, disability depends not only on the characteristics of the individual but also on the environment that is offered to that person, adapted or not, to minimize the disabilities.

In this regard, uncertainty comes from three sources. First, little research has been done about the role played by the supports provided. Second, there is a younger and less severely affected group of individuals now diagnosed with ASDs in industrialized countries; their prognosis and response to treatment may be better than traditionally expected. Finally, there is limited epidemiological data on adults, particularly those with Asperger's disorder. Marriage and Wolverton (2009) showed that despite adequate academic

achievement, work, living and mental health status can be poor in this population. Lehndardt et al (2011) estimate that the lifetime rate of psychiatric consultations for this group can be as high as 78%.

Overall, it can be said that the vast majority of children with ASD will continue to show deviance and difficulties in social interactions throughout their lives. It should be assumed that they will need support and help in many areas. However, their quality of life can be improved when adequate programs are available in their communities. Community based programs should be adapted to each individual, taking into consideration areas of difficulty and strengths, as well as the resources that the community has to offer. People with autism will need structure, clarity and predictability throughout their lives.

Behaviour and adaptive skills tend to improve with age. Nordin and Gillberg (1998) found that measures of flexibility and cognitive shifting abilities tend to be predictors of good social outcome. Unfortunately, more research is needed on the adult population, so programs may be adequately tailored to meet their needs as well as supporting transition into adulthood.

Prognosis should be discussed with the family to avoid unrealistic expectations and focus all efforts on early intervention and fostering family involvement and knowledge, as well as community participation. It is important to underline that current efforts in treatments and creation of services (nonexistent in most countries), will shape the future functioning of the children diagnosed and treated now, as they grow and become adults.

## TREATMENTS

Treatment of ASDs depends on factors that make description of "the treatment" inadequate. Differences in age, degree of impairment, comorbid disorders, family and social situation, level of resources and community development, provision of education (or lack of it), health and welfare assistance, opportunities for sheltered employment and availability for inclusive living in the community in adult life will make a huge difference. If there are two words that would underline what should be done for ASDs, those two

concepts would be "to personalize" and "to contextualize".

Despite accepting these commonsense ideas, there is a tendency to search for a "cure" for ASD, as if there was a single cause, a unique mechanism and a single condition underlying the syndrome that, if identified, would lead to cure for all the ASDs. The Internet allows families and professionals to hear about many "treatments" some based on current knowledge but others based on sheer superstition or false beliefs — that most people feel confused about what to do. The worst aspect is that families (and professionals) feel that there is something else they should be doing and by not doing it, they are not providing the best treatment for the person with ASD. In the same line, very often there is a disregard for local limitations and possibilities. Thus, programs developed over the years in wealthy countries are copied or applied in completely different areas of the world without regard for the local circumstances, opportunities and feasibility of future maintenance.

While there is no cure for ASDs, there is strong evidence that appropriate, lifelong educational approaches, support for families and professionals, and provision of high quality community services can dramatically improve the lives of persons with ASD and their families. There are up to date practice guidelines in many countries such as Spain and the UK, which have reviewed the available evidence for a great variety of treatments advocated for ASD. The UK departments for Education and Skills and for Health have also produced guidance for the education of students with ASDs. Much has been learned about the practices that are supported by evidence and those that are not, and about which programs make a real difference to the lives of individuals with ASD. Unfortunately, this knowledge has not yet been incorporated into clinical practice around the world, even in more affluent societies. Thus, there remains a gap between knowledge and opportunity; it is evident that very few people with ASDs receive state-of-the-art support

Recent reviews of the evidence conclude that relatively few treatments meet the necessary criteria when assessing the value of interventions.

Nevertheless, evidence is improving, with growing numbers of well-conducted studies. Randomized control trials are also increasing in number. However, even when outcome is positive, most research still focuses on very short-term goals and on a limited number of outcome measures. There is little attempt to address questions such as whether treatment succeeds in maximizing the longterm potential of the individuals involved or if it truly improves their quality of life. Such issues may require very different research strategies such as audits and reviews, systematic analysis of problems, and measures of satisfaction. It is also crucial to collect the views of individuals with ASD themselves.

To date, programs involving behaviourally based interventions, those designed to improve parent-child interaction, and those with an emphasis on developing social and communication skills appear to have the strongest supporting evidence, at least in the short term. As Autism Europe states, there are many other elements that are essential to improve longer-term outcome:

- Education, as early as possible, with special attention to social, communication, academic and behavioural development, provided in the least restrictive environment by staff that has knowledge and understanding of both autism and the individual student.
- Accessible community support in terms of appropriate, well-informed, multiagency services that will help each individual to realize their potential and lifetime goals (either chosen by the individuals themselves, or those who know, love and legally represent them).
- Access to the full range of psychological and medical treatments (adapted as necessary to meet the needs of individuals with ASD) that are available to the general population.

According to Autism Europe, interventions that are best supported by evidence as examples of good practice include four principles:

1. Individualization. There is not a single treatment that is equally effective for all persons with ASD. Diversity in the manifestations of this spectrum as well as individual skills, interests, life vision and circumstances mandate personalization.

2. Structure. That is, adapting the environment to maximize each individual's participation by offering varying degrees of predictability and stability, more effective means of communication, establishing clear short and long-term goals, defining the ways in which these goals can be met and monitoring outcomes.
3. Intensity and generalization. The interventions used should not be sporadic or short term, but applied in a systematic manner on a daily basis, across different settings, and by all those living and working with the person with autism. This will ensure that the skills acquired in more structured settings can be maintained in real life situations as well. Those responsible for carrying out the intervention should also have access to appropriate support and guidance from professionals with expertise in ASDs.
4. Family participation. Throughout childhood and beyond, parents must be recognized and valued as the key elements of any intervention. Information, training and support, always within the context of family values and culture, should be the common denominator of any professional intervention. Other important sources of support, such as babysitting, respite care, short breaks, or tax benefits should be available

to avoid the discrimination that many of these families still face. Adequate support for social, medical and educational services is necessary to ensure that these families are able to enjoy the same quality of life as everyone else.

Globally, given that the vast majority of people with ASDs are not receiving specialized treatment — more often than not, they are not receiving what could be considered adequate generic treatment — child mental health professionals should be devoting their efforts to the development of resources in the community where they practice and to support these children's families. Regardless of their age, most people with ASDs around the world live with their families. It is of these families that one needs to ask how they want to be supported, what are their priorities, what are their dreams, what life project they would like for their child. The person with ASD should

participate in this dialogue, directly or helped through interpersonal support and augmentative communication means; in the minority (at least 25%) that cannot express themselves at all, by delegation from people who know them well. Families are the essential support networks that cannot be replaced by governments. Their role should be gratefully recognized, our task being to maximize their potential in their own terms. We are talking not only about a health goal but also about fighting ignorance and discrimination.

In the present situation, when most countries have launched large scale community mental health programmes, it is even more important to assess the parents' burden of the children with autism, and help the parents' and family members to cope with situation.

A brief review of literature in support of the above observations highlighting the nature and assessment of burden on parents' and family members is presented in the next chapter.

## II. REVIEW OF LITERATURE

This chapter deals with the review of the literature relating to the parental burden and effect of socio-economic status on their burden levels.

M. Burke and T. Heller (2016) compared to parents of adults with other types of disabilities, parents of adults with autism spectrum disorder (ASD) experience worse well-being. Thus, it is crucial to identify the individual, parent and social—environmental correlates of care giving experiences among parents of adults with autism spectrum disorder. For this study, 130 parents of adults with autism spectrum disorder responded to a survey about care giving satisfaction, self-efficacy and burden. The results indicated that, greater future planning and community involvement related to more care giving satisfaction and increased care giving self-efficacy, respectively. Less choice making of the adult with autism spectrum disorder related to greater care giving satisfaction and self-efficacy. Maladaptive behaviors and poor health of the adult with autism spectrum disorder related to greater care giving burden.

EwaPisula (2007) conducted a study to determine the stress in mothers whose children have autism and to compare it with the stress in mothers whose children have Down's syndrome.

For this study 50 mother whose children had autism or Down's syndrome completed the Questionnaire on Resources and Stress (QRS) and answered some demographic questions. The results indicated that, mothers of children with autism presented higher stress levels on seven of the 15 scales of the QRS. The results are discussed in the context of the unsatisfactory care system for children with autism in Poland.

Vicki Bitsika and Christopher F. Sharpley(2004) conducted a study on of a 107 Gold Coast parents'. They were completed questionnaire that assessed their demographic backgrounds, anxiety and depression scores on standardised inventories. Also, tapped several aspects of those factors that may have contributed to their wellbeing. The result indicated that, 90% of parents sometimes unable to deal effectively with their child's behaviour. Also they found that, nearly half of the participants were severely anxious and nearly two thirds were clinically depressed. Factors that emerged as significant in differentiating between parents with high versus low levels of anxiety and depression included access to family support, parents' estimation of family caregivers' expertise in dealing with the behavioural difficulties of a child with autism spectrum disorder(ASD), and parental health.

Tim Cadman and et.al (2012) research on autism spectrum disorder (ASD) and attention deficit/hyperactivity disorder (ADHD) are associated with significant costs and burdens. However, research on their impact has focused mostly on the caregivers of young children. Similarly, few studies have examined caregiver burden as children transition into adolescence and young adulthood. Also, no one has compared the impact of autism spectrum disorder (ASD) to other neuro developmental disorders. They conducted an observational study of 192 families caring for a young person with a childhood diagnosis of autism spectrum disorder (ASD) or attention deficit/hyperactivity disorder (ADHD)in the United Kingdom. A modified stress-appraisal model was used to investigate the correlates of caregiver burden as a function of family background, primary stressors, primary appraisal, and resources. The results indicated that , both disorders were associated with a high level of caregiver burden,



but it was significantly greater in autism spectrum disorder (ASD). In both groups, caregiver burden was mainly explained by the affected young person's unmet need. Domains of unmet need most associated with caregiver burden in both groups included depression/anxiety and inappropriate behaviour. Specific to autism spectrum disorder (ASD) were significant associations between burden and unmet needs in domains.

Andrea Regina Nunesmisquiatti and colleagues (2015) discussed about the burden of family caregivers of children with autism spectrum disorders. They were examined 20 participated, of both genders, aged between 22 and 60 years (mean = 32.6), ten families of children with autism spectrum disorders and, to compose the control group, ten family members of children with disorders language. The children were between three and ten years of age (Mean = 5.8). The control group was selected from the pairing of age, education and gender of children. In order to evaluate the caregiver burden Scale was used Burden Interview and socio demographic data were collected from participants. The statistical analysis was performed from the Mann-Whitney and Spearman correlation analysis ( $p < .05$ ). The result indicated that, mean overload index of family caregivers of both groups was 28, therefore, no difference was observed statistically significant and indicated that the G1 and G2 were moderately overloaded. Participant characteristics were not significant in overload index.

Also, they found out that, caring for children with autism spectrum disorders can overwhelm their families similarly to the relatives of children with other disorders of development.

Erin Tehee, Rita Honan and David Hevey (2009) a study done in, the experiences of parents of individuals with autistic spectrum disorders (ASDs), and examines the influences of parent gender and child age on perceived stress, stress and coping, child-rearing involvement, support and information /education accessed. For this study, 23 mothers and 19 fathers 0B- to 18-year-old individuals with autistic spectrum disorders (ASDs), completed the questionnaires on general perceived stress, involvement, stress and coping related to caregiving, social support, and amount of information/education The findings indicated that

When compared with fathers, mothers were significantly more stressed, more involved, and reported higher levels of stress and coping related to caregiving. Differences were found according to child age, regarding helpfulness of support and access to information/education. Parent gender and child age moderated correlations between some variables. Content analyses identified factors contributing to parental stress and its alleviation. Also, they conclude that, the positive relationships between the amount of information accessed and the quality of support received by parents, and between parental stress and involvement vary according to the life stage of the child. Mothers experienced a greater caregiving burden when compared with fathers.

John I. Sanders and Sam B. Morgan (2008) reported about stress and adjustment in parents of three groups of families: (1) those with an autistic child, (2) those with a Down syndrome child, and (3) those with only developmentally normal children. For this study, a total of 54 families participated, with 18 representing each group. The results indicated that, parents of autistic children generally reported more family stress and adjustment problems than parents of children with Down Syndrome who, in turn, reported more stress and adjustment problems than parents of developmentally normal children. Although parents of disabled children reported more stress associated with caring for their child, they generally showed resilience in adjusting to the presence of a severely disabled family member.

Ling —Yi Lin (2011) conducted a study on factors associated with care giving burden and maternal pessimism in Taiwanese mothers of adolescents with an autism spectrum disorder (ASD). They were examined, 50 adolescents with an autism spectrum disorder (ASD) living at home in Taiwan and its association with care giving burden and maternal pessimism. The age range of adolescents with an ASD was from 10 to 18 years and mothers, aged 35 to 55 years. They completed self-report written questionnaires regarding their child's adaptive functioning and their own perceptions of care giving burdens and concerns. Findings indicated that functional independence, severe maladaptive behaviours and severity of autism were predictive of maternal care giving

burden. Maternal pessimism was associated with functional independence and severity of autism. However, the findings of this study indicated that occupational therapy practitioners could focus on training functional independence of the individual with an autism spectrum disorder (ASD) to meet the family's need in Taiwan. Researchers should pay significant attention to the lifespan issues of autism in Taiwanese families. The major limitations of this study were small sample size and without a comparison group.

A. Dabrowska and E. Pisula (2010) examined the profile of stress in mothers and fathers of preschool children with autism, Down syndrome and typically developing children. A further aim was to assess the association between parenting stress and coping style. They were examined 162 parents using Holroyd's 66-item short form of Questionnaire of Resources and Stress for Families with Chronically Ill or Handicapped Members and the Coping Inventory for Stressful Situations by Endler and Parker. The results indicated higher level of stress in parents of children with autism. Additionally, an interaction effect was revealed between child diagnostic group and parent's gender for two scales of parenting stress: (1) dependency and management and (2) limits of family opportunities. Mothers of children with autism scored higher than fathers in parental stress; no such differences were found in the group of parents of children with Down syndrome and typically developing children. Also, it was found that parents of children with autism differed from parents of typically developing children in social diversion coping. Emotion-oriented coping was the predictor for parental stress in the samples of parents of children with autism and Down syndrome, and task oriented coping was the predictor of parental stress in the sample of parents of typically developing children. The results strongly supported earlier finding on parenting stress in parents of children with autism. They also shed interesting light on the relationship between coping styles and parental stress.

Michael D. Kogan and et.al (2009) reported that increasing prevalence of autism spectrum disorder (ASD) and attendant health and family impact make monitoring of autism spectrum disorder (ASD) prevalence a public health priority.

The prevalence of parent-reported diagnosis of autism spectrum disorder (ASD) among US children aged 3 to 17 years was estimated from the 2007 National Survey of Children's Health (sample size: 78 037). A child was considered to have autism spectrum disorder (ASD) if a parent/guardian reported that a doctor or other health care provider had ever said that the child had autism spectrum disorder (ASD) and that the child currently had the condition. The point-prevalence for autism spectrum disorder (ASD) ASD was calculated for those children meeting both criteria. They examined socio demographic factors associated with current autism spectrum disorder (ASD) and with a past (but not current) autism spectrum disorder (ASD) diagnosis. The health care experiences for children in both ASD groups were explored. The weighted current autism spectrum disorder (ASD) point-prevalence was 110 per 10,000. We estimate that 673,000 US children have autism spectrum disorder (ASD). Odds of having autism spectrum disorder (ASD) were 4 times as large for boys than girls. Non-Hispanic (NH) black and multiracial children had lower odds of autism spectrum disorder (ASD) than Non-Hispanic (NH) white children. Nearly 40% of those ever diagnosed with autism spectrum disorder (ASD) did not currently have the condition; Non-Hispanic (NH) black children were more likely than Non-Hispanic (NH) white children to not have current autism spectrum disorder (ASD). Children in both autism spectrum disorder (ASD) groups were less likely than children without autism spectrum disorder (ASD) to receive care within a medical home.

Melissa Stuart and John H. MC. Grew (2009) conducted a study on factors impacting caregiver burden following diagnosis of an autism spectrum disorder (ASD). Primary caregivers of children diagnosed with an ASD within the past 6 months (n = 78) were assessed on variables thought to influence outcomes associated with family stress as proposed within the double ABCX model of family adaptation. ( i.e., severity of autistic symptoms, additional life demands, social support, appraisal, and coping strategies.) Burden was measured across three domains: individual caregiver, marital relationship, and the family as a whole. Most families reported high levels of

burden following their child's diagnosis. Symptom severity, additional pile-up demands, social support, and the use of passive avoidant coping strategies were strong and consistent predictors of increased burden.

B.C Shu and F.W Lung (2005) a study done in to explore the effect of support groups on the mental health and quality of life for mothers with autistic children. A quasi-experimental pre-post control group design was used in this study . The mother had children without chronic diseases diagnosed as autistic based on Diagnostic and Statistical Manual of Mental Disorder — Fourth Edition (DSM-IV) and were their primary caregivers. The mothers were assigned to control or intervention groups based on their willingness. The 10 weeks of the support group programme served as an intervention. There were three waves of data collection : pre-test, post-test, and after 1 month follow-up. A total of 27 mothers with autistic children were assigned into experimental and control groups. In total, there were eight mothers in the experimental group and 19 mothers served as the control group. The results of this study showed that mental health had not significantly improved in the intervention group compared to those in the control group at the end of the first month during follow-up. However, the subjective well-being and employment status had an effect on their mental health. Only the subjective well-being had an effect on their quality of life. According to the results of this study, recommendations included (1)-regularly promulgating a caregiver support group, (2)-the advancement of training skills within the group, and (3)-upgrading and promoting nurses' ability to lead support groups in the future.

Leonard Abbeduto and et.al (2004) reported that, the psychological well-being of mothers raising a child with a developmental disability varies with the nature of the disability. However, most research has been focused on Down syndrome and autism. But this study, added mothers whose adolescent or young adult son or daughter has fragile X syndrome. The sample was comprised of mothers of a child with fragile X syndrome (n 5 22), Down syndrome (n 5 39), or autism (n 5 174). The findings indicated that mothers of individuals with fragile X syndrome displayed lower levels of well-being than those of

individuals with Down syndrome, but higher levels than mothers of individuals with autism. Although, group differences varied somewhat across different dimensions of well-being.

Guillermo Montes and Jills Halterman(2008) conducted a study to estimate the loss of household income associated with childhood autism using a nationally representative sample. Parents of 11684 children enrolled in kindergarten to eighth grade were surveyed by the National Household Education Survey-After School Programs and Activities in 2005. They used ordinal logistic regression analyses to estimate the expected income of families of children with autism given their education level and demographic characteristics and compared the expected income with their reported income. The results indicated that, both having a child with autism spectrum disorder and having a child with other disabilities were associated with decreased odds of living in a higher income household after controlling for parental education, type of family, parental age, location of the household, and minority ethnicity. The average loss of annual income associated with having a child with autism spectrum disorder was \$6200 or 14% of their reported income. According to the results of the study, Childhood autism is associated with a substantial loss of annual household income. This likely places a significant burden on families in the face of additional out-of-pocket expenditures.

Richard P. Hastings and Tony Brown(2002) discussed about the, 26 mothers and 20 fathers of children with autism reported on their self-efficacy, anxiety, and depression. Teachers rated the behavior problems of the children. Regression analyses showed that self-efficacy mediated the effect of child behavior problems on mothers' anxiety and depression, but there was no evidence that it functioned as a mediator for fathers. However, there was evidence that self-efficacy moderated the effect of child behavior problems on fathers' anxiety. No evidence for the moderating effect of self-efficacy was apparent for mothers.

Tara A.Lavelle and colleagues reported that,(2014) the associations between autism spectrum disorder (ASD) diagnoses and service use, caregiver time, and cost outcomes. They used

national data from the Medical Expenditure Panel Survey linked to the National Health Interview Survey and a study-specific survey to estimate the annual utilization and costs for health care, school, ASD-related therapy, family-coordinated services, as well as caregiver time in children aged 3 to 17 years, with and without parent-reported ASD. Regression analyses estimated the association between ASD diagnosis and cost, controlling for child gender, age, race/ethnicity, insurance status, household income, country region and urban/rural classification, and non-ASD-related illnesses. The result indicated that, 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 care giving activities compared with control parents.

Jean E.Dumas and et.al (2009) assessed differences in parental reports of parenting stress, child behaviour problems, and dysphoria in 150 families who had children with autism ( $n = 30$ ), behaviour disorders ( $n = 30$ ), Down syndrome ( $n = 30$ ), or normal development ( $n = 60$ ). They measured stress with the Parenting Stress Index, child behaviour problems with the Eyberg Child Behaviour Inventory, and dysphoria with the Beck Depression Inventory. Results indicated that the following:

- (1) Parents of children with autism and behaviour disorders experienced statistically and clinically higher levels of parenting stress than parents in the other two groups.
- (2) Parents of children with behaviour disorders reported that their children presented behavioural difficulties that were statistically and

clinically more intense and numerous than those of all other children.

- (3) Mothers of children with autism and behaviour disorders experienced statistically and clinically higher levels of dysphoria than mothers in the other two groups, which appeared to be specifically related to the stresses of parenting exceptional children rather than to personal dysfunction. In contrast, mothers of children with Down syndrome did not differ from mothers of nondisabled children on any of the measures. Finally, no major effect of the children's age or gender was found across the four groups, except for the fact that mothers of younger autistic children reported greater dysphoria than mothers in the other three groups.

Stacey Tomanikasnd et.al (2004) conducted a study on the relationship between behaviours exhibited by children with Pervasive Developmental Disorders. Particularly autism and maternal stress levels. Participants consisted of 60 mothers, who had a child diagnosed with a pervasive developmental disorder by an independent practitioner using DSM-IV criteria. Children were between 2 and 7 years of age. Mothers completed the following self-report measures: the Parenting Stress Index (short-form), the Aberrant Behaviour Checklist, AAMR Adaptive Behaviour Scales and a Demographic Questionnaire. The result indicated that, two-thirds of the participants in the sample evidenced stress scores that were significantly elevated. Regression analyses revealed that child maladaptive behaviour and child adaptive behaviour accounted for a significant proportion of the variance in maternal stress.

The review of the studies indicates that Autism Spectrum Disorders increases burden on parents, caregivers and family members. However, each disorders are associated with a high level of parents or caregivers or family burden, but it is significantly greater in Autism Spectrum disorder. The above review of the studies shows this point. It is further indicated that, the mothers of children with autism presented higher stress levels.

### III. STATEMENT OF PROBLEM

The review of existing literature on the burden of care in the relatives of person with autism raises several issues. As autism is a major

psychiatric disorder, the burden of care would be severe on the parents or caregivers or family members. Even if, everybody recognized that the tendency to discharge psychiatric patients in to the community increases the burden on the family and community, systematic research in these areas started late. Most studies on the Autism Spectrum Disorders have been etiological and comparatively few researchers have looked at the parent's burden or how parents cope with children with autism. Majority of studies were done outside India. Among the studies done in India most are on autism severity and a few on quality of life, and problem behaviour of child with autism. Moreover, no study has been done yet in Odisha to assess burden caused by children with autism on their respective parents or caregivers or family members. As a result of deinstitutionalization, a large proportion of children with autism now live with their parents or caregivers or family members. Most of the needs of children with autism, previously met by care centre, are now being covered by parents' or caregivers or family members. With the absence of sufficient formal support services at the state level, the amount of burden has increased on the caregivers. Studies done in International and National level are inadequate and also, in conclusive in their findings regarding type and degree of various burdens on relatives of different children with autism. Hence, it is very relevant to have a study to assess the burden of care on the children with autism.

#### OBJECTIVE

Keeping the above views in mind the major objective was to evaluate the parents' burden caused by for their children with autism.

#### HYPOTHESES

On the basis of review of literature, the following hypotheses are formulated:

1. The female parent or mother shall experience more burdens as compared to that of the male parent or father.
2. The burden levels of parents' of autistic children will be affected by their socio-economic status levels. As such the parents' with low socio-economic status will be more burdens in comparison with that of others.

#### METHOD OF STUDY

The present investigation intends to make a comparative study of the burden of parents' with autistic children. Thus, the objective of the present study was to evaluate the relative burden levels of male and female parents' of different SES levels children with autism.

#### SAMPLE DESIGN

The sample consist 36 parents' of children with autism from the Centre for Autism Therapy, Counselling, and Help (CATCH), Bhubaneswar. The subjects were divided in to two groups:-

Group-I Father of 18 children with autism.

Group-2:- Mother of 18 children with autism.

As far as possible equal number of father and mother of children with autism were included. Age, gender, education, socio-economic status, type of family of the parents' was taken in to account. Similarly, the age and gender of children with autism were also recorded.

#### TOOL

The data for the present investigation was obtained by using by the following tools.

##### 1. Demographic Questionnaire

Demographic questionnaire was developed for the present investigation to obtain general information's regarding subject's age, sex, level of education, annual house hold income, ethnicity, marital status, and socio-economic status. The questionnaire also included questions about the child, including age, gender, and age at diagnosis.

##### 2. The Zarit Burden Interview

The ZaritBurden Interview, a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Zarit, Reever& Bach-Peterson, 1980). The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). The factor structure of the Zarit Burden Interview is somewhat unclear. A number of researchers have suggested different models, but the most frequently mentioned is the two-factor model, addressing personal strain and role strain. This model is



endorsed by Hérbert, Bravo, and Préville (2000), who provide the most frequently cited information on reliability and validity for the Zarit Burden Inventory. This study looked at a sample of 312 caregivers from the Canadian Study of Health and Aging. Results showed that the measure had good internal consistency reliability, with a Cronbach's alpha coefficient of .92, which was not significantly improved by the removal of any of the 22 items.

In the Hérbert et al. (2000) study, scores on the Zarit Burden Inventory were unrelated to age, gender, locale, language, living situation, marital status, or employment status, indicating the measure is appropriate for use with a variety of populations. Scores also were found to be significantly positively correlated ( $p < .001$ ) with behavioural problems in the older adult patients and depression scores of the caregivers ( $R^2 = .57$ ), as measured by the Centre for Epidemiological Studies Depression Scale.

Translations of the Zarit Burden Inventory have been studied as well, including versions in Chinese, French, Japanese, and Portuguese; the Chinese version was not shown to have good validity (Lai, 2007). Other translations may exist, but information on these was not readily available.

**PROCEDURE**

After the initial contact the consent of the parents' of children with autism was taken and then the demographic questionnaire was filled up with the help of subject. Then the Zarit Burden Interview scale administered, the investigator gave them the the following instruction: "We are trying to assess the various difficulties felt by the parents

of the children with autism and will ask you few question about them, please do not hesitate to express your true feelings".

During the interview, the investigator noted his rating for each individual item on a five point scale viz.

- Never -0
- Rarely - 1
- Sometimes -2
- Quite frequently -3
- Nearly always -4

The investigator was free to ask further on the given item wherever he felt necessary. Finally, completing the interview, the investigator assessed the burden of the parents' as a whole, looking in to responses in each individual items and give the rating on a similar five point scale.

**IV. STATISTICAL ANALYSIS**

The obtained data was statistically analyzed on following. The Mean and Standard Deviation for the burden scores are taken to indicate parents' burden. A "t" test was made to compare the levels of burden in parents' having children with autism. An Analysis of Variance was made the significance of SES and sex effect on burden level of the parents.

**V. RESULTS**

**Parents' Burden**

The results of the Mean and Standard Deviation of the burden scores turned out to be significant are presented in Table-I, and the result of t test corresponding of burden experienced by the parents' presented in Table-2.

**Table -1**  
 Mean and SD of Burden Scores of Parents' Having Children with Autism.

Sex of the Parents	Mean	SD
Father	42.72	14.98
Mother	45.17	13.39

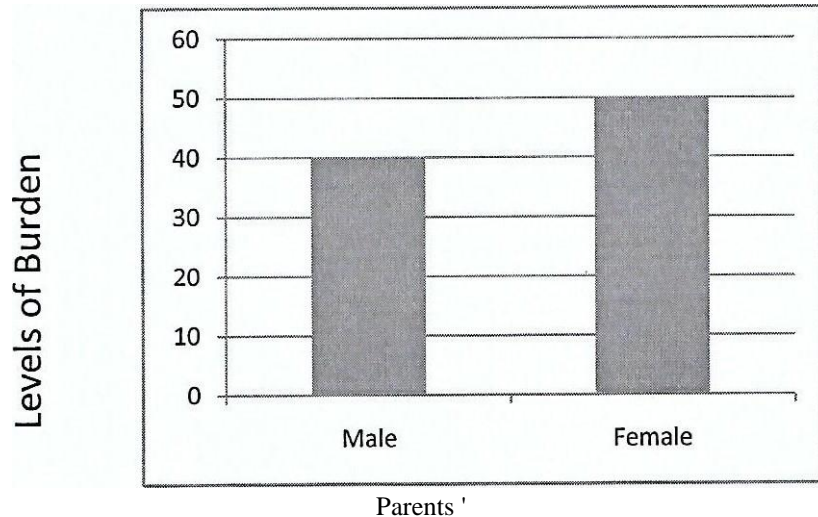


Fig. 1.1 Mean of Parental burden Scores.

**Table -2**

A "t" Test Performed on The Burden Scores of The Parents' of Children with Autism.

Sex of the Parents	Mean	SD	df	t value
Father	42.72	14.98	34	0.52
Mother	45.17	13.39		

P > .01

**Socio-Economic Status and Burden**

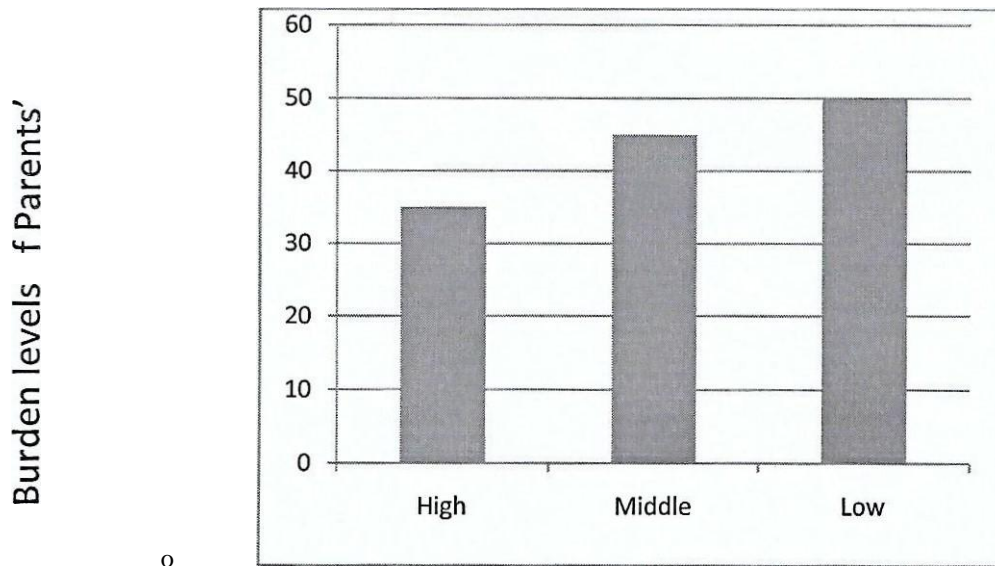
The result of Mean scores indicating the effect of Socio-Economic Status on the burden having children with autism presented Table -3, and Analysis Of Variance performed on the burden

scores of the parents' belonging to three different socio-economic status revealed significant differences with respect to their burden presented in Table -4.

**Table -3**

Mean Burden Scores of Parents' Belonging to Different SES Levels.

SES Levels	Mean	SD
High	37.5	16.67
Middle	43.71	15.39
Low	50.07	7.78



Socio — Economic Status Levels.

Fig 3.1 Mean Burden of Parents' belonging to different SES levels.

Table -4

Analysis of Variance Performed on Burden of The Parents' Belonging to Three Socio-Economic Status Groups Irrespective of The Children with Autism.

Source	SS	df	MS	F
Between groups	1144.03	2	572.01	2.92
Within groups	6469.86	33	196	

P > .05 p

The results of the present study focused on the assessment of burdens faced by the Parents' having children with autism.

While analyzing the effects of sex on burden levels, it was found that the mother had more burden than the father as indicated in figure 1.1. However, such difference was not found to be significant as indicated in a "t" test (see Table — 1). More burden in mothers despite, statistical insignificance, as observed may be due to the fact that, the female (mothers) because of their spending more time their children in home, get more disturbed emotionally, physically, and socially. On other hand, the male parents' or father get more opportunity to divert their attention to outside event. Thus, faceless burden. However, statistically insignificant indifference does not highlight any gender effect.

> .01 DISCUSSION

Similarly, while analyzing the effects of SES the burden levels of parents' no significant difference was found. Though the burden scores of parents belonging to low SES was indicated to be higher than that of the middle and high SES groups as shown in fig. 3.1. Such difference could not be statistically significant this may be due to the fact that, all the parents' irrespective of their SES levels, were facing a lot of burdens. However, because of such no significant statistical effects we can not stress up on the SES effects on the burden. Hence, the findings do not support the hypotheses.

However, I can conclude here that due to small sample size and the inherent problems in collecting data might have affected the result for which the hypotheses could not be verified.

## VI. SUMMARY AND CONCLUSION

As pointed out by several authors in the review of literature that burden of care on the parents' of children with autism was significant, it is interesting to know the extent of such burdens on the parents of children with autism in Odisha is insignificant. The present study carried out in the Centre for Autism the Therapy, Counseling and Help (CATCH), Bhubaneswar, and the objectives to assess burden faced by the parents having children with autism. In this study 18 parents of each gender and belonging to different socio — economic status were taken. The Zarit Burden Interview (developed by Zarit, Deever and Bach — Peterson, 1980) was administered and the "t" test and test of analysis of variance were used as the statistical techniques to analyses the data. The important conclusions drawn from the study are:

While analyzing the effects of sex on burden levels, it was found that the mother had more burden than the father as indicated in figure 1.1. However, such difference was not found to significant as indicated in a "t" test (see Table — 1). More burden in mothers despite, statistical insignificance, as observed may be due to the fact that, the female (mothers) because of their spending more time their children in home, get more disturbed emotionally, physically, and socially. On other hand, the male parents' or father get more opportunity to divert their attention to outside event. Thus, faceless burden. However, statistically insignificance indifference dose not highlight any gender effect.

So, the first hypothesis, "The female parents or mother shall experience more burden as compared to that of the male parent or father" is verified and rejected.

Similarly, while analyzing the effects of SES the burden levels of parents' no significant difference was found. Though the burden scores of parents belonging to low SES was indicated to higher than that of the middle and high SES groups as shown in fig. 3.1. Such difference could not be statistically significance this may be due to fact that, all the parents' irrespective of their SES levels, was facing a lot of burdens. However, because off such no significant statistical effects we cannot stress up on the SES effects on the burden. Hence, the findings do not support the hypotheses.

So, our second hypothesis, "The burden level of parents' of autistic children will be affected by their SES levels. As such the parents' with low —socio —economic status will be more burdens in comparison with that of others" is verified and rejected.

However, I can conclude here that due to small sample size and the inherent problems in collecting data might have affected the result for which the hypotheses could not be verified.

## VII. LIMITATION AND SUGGESTION

Though a lot of care had been taken to complete the study and efforts have been made to overcome the difficulties, there still remained certain limitations. A few such are as follows:-

1. The sample size was small which made generalization of results somewhat questionable.
2. The data have been mostly collected from urban places.

Considering all these limitations, some suggestions can be given for further research on the same problem like:

1. Sample should be large enough.
2. The data have been equally collected from urban and rural places. Had it been collected from village or rural places the low SES groups could have been better identified and the SES effects could have been more significant. Moreover, the burden levels of parents both (fathers and mothers) could have also been more pronounced.

The findings of this study may have far-reaching implication and may be useful in the formulation of policies to provide effective support services for children with autism and their families. A considerable reduction in the financial burden can be achieved through the provision made by the Government as free and much subsidized psychiatric treatment. The establishment of community psychiatric clinics at strategic rural locations could also reduce financial burden through reducing the expenses on transportation for follow up visits. The use of community psychiatric personnel in regular and frequent domestic visits may further enhance this as well as facilitate intervention work, and thus, reduce the burden due to impairment of family interaction and routine.

Community psychiatric personnel could also (as part of a public enlightenment campaign) advise on timely referral to a modern psychiatric facility bypassing less effective spiritual and traditional facilities that add to their financial and subjective burdens.

The establishment of regional community based rehabilitation centres where stabilized patients may be gainfully employed (with stipend/wages) may also be encouraged. This will improve their self-worth and their families' attitude towards them. Small steps as such may be taken; however, in addition to this a large scale programme is needed to ease the burdens of the parents'.

### BIBLIOGRAPHY

- [1]. Newschaffer, co J. ,Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., et al. (2007). The epidemiology of autism spectrum disorders\*. AnnualReview of Public Health, 28(1), 235-258.
- [2]. Ganz, M. L. (2006). The costs of autism. Understanding autism: From basic neuroscience to treatment (1st Ed., pp. 475—502). Boca Raton, FL: CRC Press.
- [3]. Carothers, D. E. ,& Taylor, R. L. (2004). How teachers and parents can work together to teach daily living skills to children with autism. Focus on Autism and Other Developmental Disabilities, 19(2), 102—104.
- [4]. Järbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental service, and cost impacts of children with Autistic Spectrum Disorder: a pilot study. Journal ofAutism and Developmental Disorders, 33, 395-402.
- [5]. Center for Disease Control and Prevention. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. Morbidity and Mortality Weekly Report, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s cid=ss6302a1>
- [6]. Ozonoff, S., Young, G. S. , Carter, A., Messinger, D. , Yirmiya, N., Zwaigenbaum, L., & ... Stone,W. L. (2011). Recurrence risk for autism spectrum disorders: A Baby SiblingsResearch Consortium study. Pediatrics, 128(3), 488-495.
- [7]. Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. Pediatric Research,65, 591-598. doi:10.1203/PDR.Ob013e31819e7203
- [8]. Bailey, A., Le Couteur, A., Gottesman, I., Bolton, P., Simonoff, E., Yuzda, E., et al. (1995).
- [9]. Autism as a strongly genetic disorder: Evidence from a British twin study.PsychologicalMedicine, 25, 63-77.
- [10]. Rosenberg R. E., Law J, 1<., Yenokyan G, McGready J, Kaufmann W. E., Law P. Ao (2009).
- [11]. Characteristics and concordance of autism spectrum disorders among 277 twin pairs.
- [12]. Archives ofPediatric and Adolescent Medicine, 163(10), 907-914.
- [13]. Taniai H, Nishiyama T, Miyahci T, Imaeda M, Sumi S. (2008). Genetic influences on the board spectrum of autism: Study of proband-ascertained twins. American Journal ofMedical Genetic Part B: Neuropsychiatry Genetics, 147B(6): 844-849.
- [14]. Rosenberg R. E., Law J. K., Yenokyan G, McGready J, Kaufmann W. E., Law P. A. (2009).
- [15]. Characteristics and concordance of autism spectrum disorders among 277 twin pairs. Archives ofPediatric and Adolescent Medicine, 163(10), 907-914. Ronald A, Happe F, Bolton P, Butcher L. M. , Price T. S., Wheelwright S, Baron-Cohen S,
- [16]. Plomin R. (2006). Genetic heterogeneity between the three components of the autism spectrum: A twin study. Journal of the American Academy of Child and Adolescent Psychiatry 45(6), 691-699.
- [17]. Hallmayer J, Cleveland S, Torres A, Phillips J, Cohen B, Torigoe T, Miller J,
- [18]. Fedele A, Collins J, Smith K, Lotspeich L, Croen LA, Ozonoff S, Lajonchere C, Grether J. K., Risch N. (2011) Genetic heritability and shared environmental factors among twin pairs with autism. Archives of General Psychiatry, 68(11), 1095-1102.



- <https://en.wikipedia.org/wiki/Parent>
- [19]. Miller P, Goodnow J. Cultural practices: Toward an integration of culture and development. In J. Goodnow, P. Miller & F. Kissel (Eds.) Cultural Practices as Contexts for Development. San Francisco, CA: Jossey-Bass, 1995.
- [20]. Molnar P. Social and personality conditions of students' requests to continue studies in higher education. *MgyarPzsichologicalSzemle*, 1979, 225-237.
- [21]. Shah B, Lakhera SK. Family climate and adjustment: A resume of research findings. *Indian Psychol. Re.*, 1986; 31 : 10-25.
- [22]. Lam, Ching-Man.(2003). Parent Education: Revision and Vision. *Asian Journal of Counselling*, 2003, vol. 10 No. 2, 147-168 0 The Hong Kong Professional Counselling Association 2004
- [23]. U.S. Disability Facts and Statistics of School Aged Children. (2011). Available at <http://disabledworld.com/disability/statistics/child-stats.php>.
- [24]. Nielsen, K. M., Mandelco, B., Roper, S. O. , Cox, A., Dyches, T. , & Marshall, E. S. (2012).
- [25]. Parental perceptions of sibling relationships in families rearing a child with a chronic condition. *Journal of Pediatric Nursing*, 34-43  
doi:10.1016/j.pedn.2010.08.009
- [26]. Nolbris, M., Enskar, K. ,&Hellstrom, A. (2007). Experience of siblings of children treated for Minnes, P., & Woodford, L. (2005). Well-being in aging parents caring for an adult with a developmental disability. *Journal of Developmental Disability*, 11 , 48-66.
- [27]. Sosbey, D., & Calder, P. (2006). Supports for families of children with disabilities state of the evidence review. Annotated Bibliography. Alberta Centre for Child, Family and Community Research. Available at <http://www.ualberta.ca/jpdasddc/famsupport/final.htm>Weiss M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism and children with mental retardation. *Autism*, 6(1), 115-130. doi:10.1177/1362361302006001009
- [28]. Wang, P., Michaels, C. A., Day, M. S., (2010). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism Development Disorder*, 41. 783-795d. doi:10.1007/s10803010-1099-3
- [29]. Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31, 1-12. doi:10.1080/1366825050034
- [30]. Mulroy, S., Robertson, L. ,Aiberti, H. L., & Bower, C. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research*, 52, 216-229. doi: <http://dx.doi.org/10.1111/j.1365-2788.2007.01005.x>
- [31]. 2788.2007.01005.x
- [32]. Burke, P. (2010). Brothers and sisters of disabled children: The experience of disability by association. *British Journal of Social Work*, 40, 1681-1699. doi: 10.1093/bjsw/bcp088
- [33]. Hastings, R. P. (2003a). Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33, 99-104. doi: <http://dx.doi.org/10.1023/A:1022290723442>
- [34]. Hastings, R. P. (2007). Longitudinal relationship between sibling behavioral adjustment and behavioral problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37, 1485-1492. doi:10.1007/s10803-006-0230-y
- [35]. Kaminsky, L. ,& Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 43, 225-232. doi:10.1111/1469-7610.000.15
- [36]. Pilowsky, T., Yirmiya, N., Doppelt, L., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child*

- Psychology and Psychiatry, 45, 855-865. doi:10.1111/j.1469-7610.2004.00277.x
- [38]. Hastings, R. P. (2003b). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, 33, 141-150. doi: <http://dx.doi.org/10.1023/A:1022983209004>
- [39]. Verte, S., Roeyers, H., & Buysse, A. (2003). Behavioral problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health and Development*, 29, 193-205. doi:10.1046/j.1365-2214.2003.00331.x
- [40]. Williams, P. D. (1997). Sibling and pediatric chronic illness: A review of the literature.
- [41]. *International Journal of Nursing Studies*, 34, 312-323. doi:10.1016/S0020-7489(97)00019-9
- [42]. Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55(2), 139-150. doi:10.1037/a0019473
- [44]. Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), 626-636. doi:10.1542/peds.2004-1689
- [46]. Nguyen, M. (2009). Nurse's assessment of caregiver burden. *Medsurg Nursing*, 18(3), 147-151.
- [47]. Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19, 371-379. doi:10.1207/s15374424jccp1904\_9
- [48]. Warfield, M. E. (2005). Family and work predictors of parenting role stress among two-earner families of children with disabilities. *Infant and Child Development*, 14, 155-176. doi:10.1002/icd.386
- [49]. Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, 2, 971-10. doi:10.1080/09362839109524770
- [50]. Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youth with autism, Down syndrome, or fragile X syndrome. *American Journal of Mental Retardation*, 3, 237-254. doi:10.1352/0895-8017(2004)109<237:PWACIM>2.0.CO;2
- [54]. Manor-Binyamini, I. (2011). Mother of children with developmental disorders in the Bedouin community in Israel: Family functioning, caregiver burden, and coping abilities. *Journal of Autism Developmental Disorder*, 41, 610-617. doi: 10.1007/s10803010-1080-1
- [56]. Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, 31, 1-12. doi:10.1080/13668250500349367
- [58]. Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal of Mental Retardation*, 111(1), 1-12. doi:10.1111/j.1365-2788.2006.00906.x
- [59]. Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, 50, 883-889.
- [60]. Suarez, L. M., & Baker, B. L. (1997). Child externalizing behavior and parents' stress: The role of social support. *Family Relations*, 46, 373-381. doi:10.2307/585097

- [62]. Baker, B. L., & Heller, T. L. (1996). Preschool children with externalizing behaviors: Experience of fathers and mothers. *Journal of Abnormal Child Psychology*, 24, 513-532. doi:10.1007/BF01441572
- [63]. Baker, B. L., McIntyre, L. L., Blacher, J., crnic, K., Edelbrock, C., & Low, C. (2003).
- [64]. Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230.
- [65]. doi:10.1046/j.1365-2788.2003.00484.x
- [66]. Al-Krenawi, A., Graham, J. R., Gharaibeh, F. A. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence.
- [67]. Disability
- [68]. & Society, 26(2), 139-150. doi:10.1080/09687599.2011.543861
- [69]. Cavallo, S., Feldman, D. E., Swaine, B., & Meshefedjian, G. (2008). Is parental coping associated with the level of function in children with physical disabilities? *Care, Health and Development*, 35(1), 33-40. doi:10.1111/j.1365-2214.2008.00884.x
- [70]. Cavallo, S., Feldman, D. E., Swaine, B., & Meshefedjian, G. (2008). Is parental coping associated with the level of function in children with physical disabilities? *Child: Care, Health and Development*, 35(1), 33-40. doi:10.1111/j.1365-2214.2008.00884.x
- [72]. McManus, B. M., Carle, A., Avededo-Garcia, D., Ganz, M., Hauser-Cram, P. , McCormick, M. ,
- [74]. (2011). Modeling the social determinants of caregiver burden among families of children with developmental disabilities. *American Association on Intellectual and Developmental Disabilities*, 116(3), 246-260. doi:10.1352/1944-7558116.3.246
- [75]. Al-Qabandi M, Gorter JW, Rosenbaum P (2011). Early autism detection: are we ready for routine screening? *Pediatrics*, 128:e211-217.
- [76]. American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, Text Revision. Washington, DC: APA.
- [77]. Amir RE, Van Den Veyver 1B, Wan M et al (1999). Rett syndrome is caused by mutations in X-linked NIECP2, encoding metil-CpG-binding protein 2. *Nature Genetics*, 23:185-188.
- [78]. Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and*
- [79]. *Developmental Disability*, 31, 1-12. doi:10.1080/13668250500349367
- [80]. Asperger H (1938). [Das psychischabnormale Kind]. *Wiener KlinischeWochenschrift*, 51:1314-1317.
- [81]. Asperger H (1944). [Die "AutistischenPsychopathen" imKindesalter]. *Archivfürpsychiatrie und nervenkrankheiten*, 117: 76—136. Translated ana annotated by Frith U (1991). *Autistic psychopathy in childhood*. In Frith U (ed), *Autism and Asperger*
- [82]. *Syndrome*. Cambridge, UK: Cambridge University Press, pp37—92.
- [83]. Baghdadli A, Picot M, Michelon C (2007). What happens to children with PDD when they grow up? Prospective follow-up of 219 children from preschool age to midchildhood. *Acta Psychiatrica Scandinavica*, 115:403-412.
- [84]. Bakare MO, Munir KM (2011). Autism spectrum disorders in Africa. In
- [85]. Mohammad-Reza Mohammadi (ed), *A Comprehensive Book on Autism*
- [86]. *Spectrum Disorders*. In Tech, pp183-184
- [87]. Barnev1ck-Olsson,M, Gillberg C, Fernell E (2008). Prevalence of autism in children born to Somali parents living in Sweden: a brief report. *Developmental Medicine & Child Neurology*, 50:598-601.
- [88]. Baron-Cohen S (2009). Autism: the empathizing-systemizing (ES) theory. *Annals ofthe New York Academy ofSciences*, 1156:68-80.

- [89]. Baron-Cohen S, Ashwin E, Ashwin C et al (2009). Talent in autism: hypersystemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 364:1377-1383.
- [90]. Belmonte MK, Allen G, Beckel-Mitchener A et al (2004). Autism and abnormal development of brain connectivity. *The Journal of Neuroscience*, 24:9228-9231.
- [91]. Billstedt E, Gillberg C, Gillberg I (2011). Aspects of quality of life in adults diagnosed with autism in childhood. *Autism*, 15:7-20.
- [92]. Bodfish JW, Symons FJ, Parker DE, (2000). Varieties of repetitive behavior in autism: comparisons to mental retardation. *Journal of Autism and Developmental Disorders*, 30, 237-43.
- [93]. Brugha TS, Mc Manus S, Bankart J et al (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68:459-65.
- [94]. Courchesne E, Karns CM, Davis LR et al (2001). Unusual brain growth patterns in early life of patients with autistic disorder. *Neurology*, 57, 245-254.
- [95]. Courchesne E, Redcay E, Kennedy DP (2004). The autistic brain: birth through adulthood. *Current Opinion in Neurology*, 17:489-496.
- [96]. Finn M (1997). In the case of Bruno Bettelheim. *First Things*, 74:44-48.
- [97]. Fombonne E (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, 65:591-598.
- [98]. Fuentes-Biguel J, Ferrari-Arroyo MJ, Boada-Muñoz L et al (2006). [Good practice guidelines for the treatment of autistic spectrum disorders]. *Revista de Neurología*, 43:425-438.
- [99]. Frazier T, Youngstrom E, Speer L (2012). Validation of proposed DSM-5 criteria for autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51:28-40.
- [100]. Freitag CM (2007). The genetics of autistic disorders and its clinical relevance: a review of the literature. *Molecular Psychiatry*, 12:2-22.
- [101]. Freitag CM, Staal W, Klauck SM et al (2010). Genetics of autistic disorders: review and clinical implications.
- [102]. *European Child & Adolescent Psychiatry*, 19:169-178.
- [103]. Gillberg C, Schaumann H, Gillberg IC (1995). Autism in immigrants: Children born in Sweden to mother born in Uganda. *Journal of Intellectual Disability Research*, 39:141-144.
- [104]. Goodlee F, Smith J, Marcovitch H (2011). Wakefield's article linking MMR vaccine and autism was fraudulent. *British Medical Journal*, 342:c7452.
- [105]. Grafodatskaya D, Chung B, Szatmari P et al (2010). Autism spectrum disorders and epigenetics. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49:794-809.
- [106]. Grant WB, Soles CM (2009). Epidemiological evidence supporting the role of maternal Vitamin-D deficiency as a risk factor for the development of infantile autism. *Dermato-Endocrinology*, 1:223-228.
- [107]. Happe F, Frith U (2006). The weak coherence account: Detail focused cognitive style in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 36:5-25.
- [108]. Hazlett HC, Poe M, Gerig G et al (2005). Magnetic resonance imaging and head circumference study of brain size in autism: birth through age 2 years. *Archives of General Psychiatry*, 62:1366-1376.
- [109]. Johnson CP, Myers SM (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120: 1183-215.
- [110]. Jones W, Carr K, Klin A (2008). Absence of preferential looking to the eyes of approaching adults predicts level of social disability in 2-year-olds with autism spectrum disorder. *Archives of General Psychiatry*, 65:946-954.
- [111]. Kanner L (1943). Autistic disturbances of affective contact. *The Nervous Child*, 2:217-



250. Reprinted in *Acta Paedopsychiatrica*, 1968, 35:100-136.
- [113]. Kim YS, Leventhal BL, Koh YJ et al (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*, 168:904912.
- [114]. Kinney DK, Barch DH, Chayka B et al (2010). Environmental risk factors for autism: do they help cause de novo genetic mutations that contribute to the disorder? *Medical Hypothesis*, 74: 102-106.
- [115]. Klin A, Lin DJ, Gorrindo P et al (2009). Two-year-olds with autism orient to non-social contingencies rather than biological motion. *Nature*, 14:257-261.
- [116]. Kuhn R (2004). Eugen Bleuler's concepts of psychopathology. *History of Psychiatry*, 15:361-366.
- [117]. Lainhart JE (2006). Advances in autism neuro-imaging research for the clinician and geneticist. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, 142C:33-39.
- [118]. Lehnhardt FG, Gawronkia A, Volpert K et al (2011). [Autism spectrum disorders in adulthood: clinical and neuropsychological findings of Asperger syndrome diagnosed late in life]. *Fortschritte der Neurologie — Psychiatrie*, 79:290-297.
- [119]. Li N, Chen G, Song X et al (2011). Prevalence of autism caused disability among Chinese children: a national population-based survey. *Epilepsy & Behavior*, 22:786-789.
- [120]. Lombardo M, Baron-Cohen S, Belmonte M et al (2011). Neural endophenotypes for social behaviour in autism spectrum conditions. In J Decety, J Cacioppo (eds),
- [121]. *The Handbook of Social Neuroscience*, Oxford: Oxford University Press. Lotter V (1978). Childhood autism in Africa. *Journal of Child Psychology & Psychiatry*, 19:231-244.
- [122]. Ma D, Salyakina D, Jaworski JM et al (2009). A genome-wide association study of autism reveals a common novel risk locus at 5p14.1. *Annals of Human Genetics*, 73:263-273.
- [123]. Marriage S, Wolverson A (2009). Autism spectrum disorder grown up: A cKart review of adult functioning. *Journal of Canadian Academy of Child and Adolescent Psychiatry*, 18:322-328.
- [124]. Mottron L, Dawson M, Soulieres I et al (2006). Enhanced perceptual functioning in autism: an update, and eight principles of autistic perception. *Journal of Autism and Developmental Disorders*, 36:27-43.
- [125]. Muhle R, Trentacoste SV, Rapin I (2004). The genetics of autism. *Pediatrics*, 113:472-486.
- [126]. NICE (2011). *Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum*. London: Royal College of Obstetricians and Gynaecologists.
- [127]. Nordin V, Gillberg C (1998). The long-term course of autistic disorders: update on follow-up studies. *Acta Psychiatrica Scandinavica*, 97:99-108.
- [128]. Rimland B. *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*. New York, NY: Appleton-Century-Crofts.
- [129]. Robins DL, Fein D, Barton ML et al (2001). The Modified Checklist for Autism in Toddlers: an initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 31,131-144.
- [130]. Rutter M, Andersen-Wood L, Beckett C (1999). Quasi-autistic patterns following severe early global privation. English and Romanian Adoptees (ERA) Study. *Journal of Child Psychology & Psychiatry*, 40:537-549.
- [131]. Sadock BJ, Sadock VA (2008). Kaplan & Sadock's Concise Textbook of Child and Adolescent Psychiatry.
- [132]. Philadelphia, PA: Wolters Kluwer/Lippincott William & Wilkins, pp 65-74.
- [133]. Towbin KE, Dykens EM, Pearson GS (1993). Conceptualizing "borderline syndrome of childhood" and "childhood schizophrenia" as a developmental disorder.



- Journal of the American Academy of Child & Adolescent Psychiatry, 32:775-782.
- [134]. Smalley SL (1991). Genetic influences in autism. *Psychiatric Clinics of North America*, 14:125-139.
- [135]. Wakefield A, Murch S, Anthony A et al (1998). Ileal-lymphoidnodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet*, 351:637-641 (retracted).
- [137]. Weiss LA, Arking DE, Daly MJ et al (2009). A genome-wide linkage and association scan reveals novel loci for autism. *Nature*, 461:802-808.
- [138]. Wetherby AM, Woods J, Allen L et al (2004). Early indicators of autism spectrum disorders in the second year of life. *The Journal of Autism and Developmental Disorders*, 34:473-493.
- [139]. William P, Charman T, Skuse D (2012). Testing the construct validity of proposed criteria for DSM-5 autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51:41-50.
- [141]. Wing L (1997). The history of ideas on autism: legends, myths and reality. *Autism*, 1 : 13—23.
- [142]. Wing L, Gould J (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9:11-29.
- [144]. Wing L, Gould J, Gillberg C (2011). Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV? *Research in Developmental Disabilities*, 32:768-773.
- [145]. World Health Organization (1993). *International Classification of Diseases, Tenth Edition*. Geneva: WHO.
- [146]. Zwaigenbaum L, Bryson S, Rogers T et al (2005). Behavioral manifestations of autism in the first year of life. *International Journal of Developmental Neuroscience*, 23 : 143-152.
- [147]. Zwalgenbaum L, Bryson S, Lord C et al (2009). Clinical assessment and management of toddlers with suspected autism spectrum disorder: insights from studies of high-risk infants. *Pediatrics*, 123:1383-1391.
- [148]. Burke, M. & Heller, T. (2016): Individual, parent and social—environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder. *Journal of Intellectual Disability Research*, 60, 401—411.
- [149]. Pisula, Ewa. (2007): A Comparative Study of Stress Profiles in Mothers of Children with Autism and those of Children with Down's Syndrome. *Journal of Applied Research in Intellectual Disabilities* , 20, 274—278.
- [150]. Abbeduto, Leonard. , Krauss, Marty Wyngaarden. , Orsmond, Gael. , & Murphy, Melissa M. ,(2004): Psychological Well-Being and Coping in Mothers of Youths With Autism, Down Syndrome, or Fragile X Syndrome. *AMERICAN JOURNAL ON MENTAL RETARDATION*, 109, 237-254.
- [151]. Montes, Guillermo. , & Halterman, Jill S. (2008): Association of Childhood Autism Spectrum Disorders and Loss of Family Income. *American Academy of Pediatrics*, 121.
- [152]. Bitsika, Vicki. & Sharpley, F. Sharpley, (2004) : Stress, Anxiety and Depression Among Parents of Children With Autism Spectrum Disorder. *Australian Journal of Guidance & Counselling*. 14, 151-161.
- [153]. Cadman, Tim., Eklund, Hanna., Howley, Deirdre., Hayward, Hannah., Clarke, Hanna., Findon, Jame., Xenitidis, Kiriakos., Murphy, Declan. , Asherson, Philip., & Glaser, Karen., (2012): Caregiver Burden as People With Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder Transition into Adolescence and Adulthood in the United Kingdom. *JOURNAL OF THE AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY*. 51, 879-889.
- [154]. Lavelle, Tara A. , Weinstein, Milton C., Newhouse, Joseph P. , Munir, Kerim., Kuhlthau, Karen A., and Prosser, Lisa A. : (2014) *Economic Burden of Childhood*

- Autism Spectrum Disorders. The American Academy of Pediatrics. February 10.
- [155]. Misquiatti, Andréa Regina Nunes., Brito, Maria Claudia Fernanda Terezinha .,
- [156]. Ferreira, Schmidt Francisco., & Junior, Baptista Assumpção. (2015) FAMILY BURDEN AND CHILDREN WITH AUTISM SPECTRUM DISORDERS: PERSPECTIVE OF CAREGIVERS. *Rev. CEFAC*.17(1),192-200.
- [157]. Tehee, Erin., Honan, Rita. , and Hevey, David.,(2009) Factors Contributing to Stress in Parents of Individuals with Autistic Spectrum Disorders. *Journal of Applied Research in Intellectual Disabilities*. 22, 34—42.
- [158]. Sanders, John L ., & Morgan, Sam B.(2008) Family Stress and Adjustment as Perceived by Parents of Children with Autism or Down Syndrome: Implications for Intervention. *Journal of child & behavior Therapy*, 19, 15-32.
- [159]. Kogan, Michael D. , Blumberg, Stephen J., Schieve, Laura A., Boyle, Coleen A. , Perrin, JamesM. , Ghandour, Reem M. , Singh, Gopal K. , Strickland, Bonnie B. , Trevathan, Edwin., and Dyck, Peter C.:(2009) Prevalence of Parent-Reported Diagnosis of Autism
- [160]. Spectrum Disorder Among Children in the US, 2007. The American Academy of Pediatrics. 124 , 1-12.
- [161]. Stuart ,Melissa.,& McGrew, John H. , :(2009) Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 3, 86-97.
- [162]. Shu,B.C., and Lung, F.W., (2005) The Effect of Support group on the mental health and quality of life for mothers with autistic children. *Journal of Intellectual Disability Research*., 49 ,47-53.
- [163]. Montes, Guillermo., & Halterman, Jill S., (2008) Association of Childhood Autism Spectrum Disorders and Loss of Family Income. *The American Academy of Pediatrics*, 121.
- [164]. Hastings , Richard P. , and Brown, Tony., (2002) Behavior Problems of Children With Autism, Parental Self-Efficacy, and Mental Health. *ANIERCAN JOURNAL ON MENTAL RETARDATION*., 107,222-232.
- [165]. Dumas, Jean E., Wolf, Lucille C. Fisman, Sandra N.,&Culligan, Annie., :(2009) Parenting stress, child behavior problems, and dysphoria in parents of children with autism, down syndrome, behavior disorders, and normal development. *A Special Education Journal*., 2, 97-110.
- [166]. Yi Lin, Ling.,: (2011) Factors associated with caregiving burden and maternal pessimism in mothers of adolescents with an autism spectrum disorder in Taiwan., *Occupational Therapy International*., 18, 95-105.
- [167]. Dabrowska , A., and Pisula, E., (2010) Parenting Stress and Coping Styles in Mother and Father of Pre-school Children with Autism and Down Syndrome. , *journal of Intellectual Disability Research*.
- [168]. Hérbert, R., Bravo, G., &Préville, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, 19, 494-507.
- [169]. Lai, D. W. L. (2007). Validation of the Zarit Burden Interview for Chinese Canadian caregivers. *Social Work Research*, 3 1, 45-53.
- [170]. Zarit, S. H., Reever, K. E., Back-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20, 649-655.
- [171]. American Psychiatric Association : Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). American Psychiatric Association D.C.
- [172]. World Health organization (1992): *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision(ICD-10)*. World Health organization; Geneva.
- [173]. Gupta, S.P, *Statistical Methods, Thirty Nineth Revised Edition(2010)*, Sultan Chanda and Sons, New Delhi.
- [174]. Kothari, C.R. and Garg, Gaurav, *Research Methodology Methods and Techniques*,

Third Edition (2014), New Age International Pvt. Limited, New Delhi.

[175]. Mangal, S.K., Statistics in Psychology and Education, Second Edition, (2012), PHI Learning Pvt. Ltd, New Delhi.

[176]. Garrett, Henry E., and Woodworth, R.S., Statistics in Psychology and Education, Ninth Indian Reprint (1979), Vakils, FEFFER and Simons Ltd, Bombay.

[177]. Singh, Tulika., Sharma, Sanju., Nagesh, Seetharamiah. (2017). Socioeconomic status scales updated for 2017. International Journal of Research in Medical Sciences. 5(7):3264-3267 .

APPENDIX - 1  
 DEMOGRAPHIC QUESTIONNAIRE

Date \_\_\_\_\_

Name \_\_\_\_\_ Parent Gender \_\_\_\_\_

Parent Age \_\_\_\_\_

Education of Parent \_\_\_\_\_

Ethnicity \_\_\_\_\_

Total house hold income \_\_\_\_\_

APPENDIX - 2  
 THE ZARIT BURDEN INTERVIEW

- O: NEVER  
 1 : RARELY  
 2: SOMETIMES  
 3 : QUITE FREQUENTLY  
 4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

Questions	Score			
	0	1	2	3
1. Do you feel that your relative asks for more help than he/she needs?	o	1 2 3		4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	o	1 2 3		4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	o	1 2 3		4
4 Do you feel embarrassed over your relative's behaviour?	o	1 2 3		4
5 Do you feel angry when you are around your relative?				
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1	2	3	'4
7 Are you afraid what the future holds for your relative?	0 1	2	3 4	

8 Do you feel your relative is dependent on you?	0	1	2	3	4
9 Do you feel strained when you are around your relative?					
10 Do you feel your health has suffered because of your involvement with our relative?	o	1	2	3	4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	o	1	2	3	4
12 Do you feel that your social life has suffered because you are caring for our relative?	o	1	2	3	4
13 Do you feel uncomfortable about having friends over because of your relative?	o	1	2	3	4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	o	1	2	3	4
15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	o	1	2	3	4
16 Do you feel that you will be unable to take care of your relative much longer?	o	1	2	3	4
17 Do you feel you have lost control of your life since your relative's illness?	0	1			4
18 Do you wish you could leave the care of your relative to someone else?	o	1			4
19 Do you feel uncertain about what to do about your relative?	o	1			4
20 Do you feel you should be doing more for your relative?					
21 Do you feel you could do a better job in caring for your relative?		0	1	2	
22 Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total Score

INTERPRETATION OF SCORE 0 to 20 Little or No Burden

21 to 40 Mild To Moderate Burden

41 to 60 Moderate To Severe Burden

61 to 88 Severe Burden

