

**“PARENTAL AWARENESS ABOUT AUTISM  
SPECTRUM DISORDER (ASD): A CASE STUDY  
OF BHARA KAHU ISLAMABAD”**



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**CERTIFICATE**

This is to certify that this thesis entitled: **“Parental Awareness about Autism Spectrum Disorder (ASD): A Case Study of Bhara Kahu Islamabad”** submitted by **Amir Shah** is accepted in its present form by the PIDE School of Social Sciences, Pakistan Institute of Development Economics (PIDE), Islamabad as satisfying the requirements for partial fulfillment of the degree in Master of Philosophy in Public Policy.

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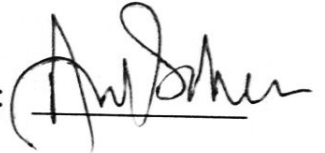
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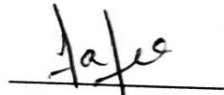
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## **Author's Declaration**

I, Amir Shah, hereby state that my MPhil thesis titled **Parental Awareness About Autism Spectrum Disorder (ASD); A Case Study of BharaKahu Islamabad** is my own work and has not been submitted previously by me for taking any degree from Pakistan Institute of Development Economics or anywhere else in the country/world.

At any time if my statement is found to be incorrect even after my Graduation the university has the right to withdraw my MPhil degree.

A handwritten signature in blue ink, appearing to read "Amir's", enclosed within a circular scribble.

Amir Shah

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## **ABSTRACT**

Millions of children are born all across the globe every minute but unfortunately not every born child is medically fit. Some of them are born with different disorders. The present study was initiated to investigate such a neurological disorder named as Autism Spectrum Disorder. It is a complex developmental condition that includes determining difficulties in social connection, which affects nonverbal communication, patterns of socialization, or behaviors in kids mostly up to 8 years of age. Developed countries including the US and Europe conducted intensive research on Autism and spread awareness about it in masses but it has been observed that people in developing countries are not familiar yet with this disease. After the outspread of Pandemic COVID-19, people's focus was more towards the pandemic but there is need to work on the other diseases as well that are especially affecting the kids. It has been observed over the past few years that in Pakistan, the number of births with this neurological disorder is increasing. According to the Autism Society of Pakistan, from every 60 kids, one child is facing the issues of Autism Spectrum Disorder. Hence, this study was designed with the objective to know about the awareness people of Pakistan have about this disease and for this purpose a research model designed. Data was collected from 200 respondents from area of Bhara Kahu, Islamabad through questionnaire. Descriptive analysis, correlation and regression analysis was done using SPSS. The results indicated that all the three independent variables including Symptoms or Physical Attributes of Autistic Child (SAC), Parental awareness (PA) and Treatment/ Cure for Autism (TA) have positive and significant impact on people's knowledge about Autism.

**Keywords: Autism Spectrum Disorder, Autism Awareness, Autism Society of Pakistan**

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# CHAPTER 1

## INTRODUCTION

### 1.1 Introduction to Chapter

This chapter starts by providing a thorough background of the study followed by the problem statement that discusses the problems related to the study. After the problem statement, the research questions are presented and then research objectives are discussed. The chapter also provides the significance of the research and concludes with a section stating the organization of the research thesis.

### 1.2 Background of the Study

The health sector of the world is facing an unexpected crisis due to the outspread of Covid 19 virus, which has developed world health system more resilient and more effective. In the last 2 years, the world has spent significant amount of dollars on improvement of health sector to combat diseases like Covid 19, which is an abrupt spread nature virus base disease. On one hand, it is a sign of improvement after taking a shock but on other hand it has reduced the attention of the medical community and residence of the planet towards other diseases, which are continuously undermining the capacity and life quality of humans.

Millions of children born all over the globe on daily basis but not every born child is medically fit or normal. Many of them can be referred as specials kids and these kids who demand distinct needs are the ones who possess limited physical and mental intellectual, social, as well as emotional characteristics that directly affect the growth and wellbeing as compared to other kids from the same age group(Khaula Sahida, 2017).

The author in this study is focusing on a single disorder, which is quite common in kids but yet an unknown phenomenon for many. Autism Spectrum Disorder (ASD) falls under the category of pervasive development disorders that is actually neurodevelopment disorder (Couteur, 2009). Autism was derived from a Greek word meaning self (Hye Ran Park J. M.-N., 2016) and is a complex developmental condition that includes determining difficulties in social connection, which affects nonverbal communication, patterns of socialization, or behaviors (Autism Society of Pakistan/ASP 2010). Autism was first used in 1912 by Paul Eugen Bleuler (Swiss psychiatrist) to highlight the indications of schizophrenia. Later, in 1938 Hans Asperger used the word autistic in order to outline the child psychology in a modern way(Hye Ran Park J. M.-N., 2016). Leo Kanner in 1943 referred Autism as a prototypical condition as well as infantile autism (Couteur, 2009) as it appears in the first three years of birth (Hye Ran Park J. M.-N., 2016). This disorder can be identified or understood through its symptoms. Autism is a long-lasting condition, which undermines the capacity of socialization and social development and turns into a big miss in later age of the life. It is also a disorder which causes long term anxieties in adults and teenagers (Autism Research Institute ARI 2021).

Several developed countries including North America and West Europe conducted wide research on Autism in order to identify it, spread awareness among the people, provide services to reduce its scale but it has been observed that developing or under developing countries are still struggling with it as they recently started conducting research on Autism. In addition to this, Autism has been observed as underdiagnosed in several countries across the world which includes United States, as individuals with the Autism are not spotted as well as treated (Simon Wallace, 2012).

Autism is a recognized disability worldwide, but it is not recognized disability in Pakistan till now. It has been observed that worldwide only therapies are recommended for Autism spectrum disorder. The speech and language therapy are mandatory for those children who are suffering from Autism Spectrum Disorder. Speech and language therapy is very expensive around the globe as well in Pakistan. Speech and language therapy improves understanding of speech and language. Behavior therapy is also needed for children with Autism disorder. Behavior therapy modifies bad behavior of children and makes them able to sit in speech therapy session. In Pakistan there is, lack of awareness about Autism Spectrum Disorder.

Autism is a recognized disability worldwide, as WHO added ASD in their portfolio for mental health (Simon Wallace, 2012) but it is not yet recognized as a disability factor in Pakistan. In Pakistan, only four categories are considered as a disability-hearing impairment, visual impairment, mental retardation, which is called (MR), and physical disability. Autism spectrum disorder can be seen in the list of disabilities in Pakistan, but no policy can be seen for this particular disorder, which is quite an unfortunate. An unconditional support from government can make it happen if the research base evidence is channelized for it. Autism Spectrum Disorder (ASD) is a complex developmental condition that includes determining difficulties in social connection, which affects nonverbal communication, patterns of socialization, or behaviors (Autism Society of Pakistan, 2010). The impacts of ASD and the seriousness of indications are diverse in every individual. The symptoms of ASD usually appear at the age of 2 or 3 years. According to CDC, one child in every 59 children has an Autism spectrum disorder (Autism Society of Pakistan, 2010). Autism spectrum disorder is likewise three to multiple times more normal in boys than in girls. According to a recent WHO report, one child in every 160 children has Autism spectrum disorder (World Health Organization, 2019). In the same

way, Pakistan is also facing this disorder. The number of children with Autism spectrum disorder in Pakistan is also increasing day by day. According to the Autism Society of Pakistan, the number of autistic children in Pakistan is 350,000, and one child in every 60 children is with an autism spectrum disorder. Many children have not been diagnosed with Autism Spectrum Disorder due to lack of awareness about Autism and its symptoms. This number may be higher because many children have not been diagnosed due to a lack of awareness and education (Autism Society of Pakistan, 2010).

There is no one medical test for diagnosing autism. A team of professionals with expertise in autism (e.g. a developmental pediatrician, psychologist or psychiatrist, pediatric neurologist, occupational therapist, speech pathologist) will typically give a diagnosis of autism based on observation of an individual's communication, behavior, and developmental levels. There is no known cause or cure, nor one known single effective treatment for autism. However, a basic rule for treating autism is the earlier the intervention – or therapies – the better. Early diagnosis is critical.

### **1.3 Problem Statement**

The health sector of Pakistan is facing many challenges and corona virus has added more to it and it has been identified that the kids with ASD are vulnerable due to the outspread of pandemic (Adrien A Eshraghi, 2020). The COVID-19 outspread created the sudden irregularity in the routine and made the reach to the specialist/ therapist difficult that led to the negative impacts on the behavior and health of kids as well as adults dealing with autism (Althiabi, 2021). But it is also important that other diseases, which undermine the quality of life, should be investigated and addressed through national health policy. Pakistani kids and adults are facing an uncommonly known but a very common disorder of autism spectrum disorder, which

cause several social issues to the person who is taken by it. Under such settings, it is very important to conduct research to find out the level of awareness of this disorder in a country like Pakistan that is categorized as developing nation and struggling with health-related issues. The present research is an attempt to address this problem as diagnosis of this disease at the early stage is very necessary to develop the sound policy measures according to the treatment, effective educational policies as well as supporting facilities for the families.

### **1.5 Significance of Research**

This research is undertaken to identify the factors that influence the Autism Awareness in Pakistan. On one hand, it carries the theoretical implications and on the other hand it carries practical implications for the health departments and masses to ensure awareness among the people in Pakistan about Autism. The study has come up with a comprehensive research model, which incorporates the key factors that affect the Autism Awareness. It provides new material and information to the already published literature on the variables that have not been studied before in the context of Pakistan, Therefore, the present study will contribute in the extension in literature present on this neurological disorder named as Autism Spectrum Disorder.

This study will create a base line study on perception and awareness about ASD among parents of children, who are facing this disease in Islamabad region. The study will help to provide more awareness about Autism Spectrum Disorder (ASD) at government level and among common masses. The awareness programs can be designed, once the awareness status is understood through research studies like the current research. In addition to this, the study will be beneficial for Autism Society of Pakistan that is a non-governmental organization working for the autistic kids in Pakistan. Moreover, study will contribute in designing the health policies and budget allocation to

the health-related facilities by the Health Ministry of Pakistan by Government of Pakistan. Further, all the institutes, therapy centers, rehabilitation centers and NGOs who are working on the Autism will get benefit from the present study not only in Islamabad but in the rest of the cities of Pakistan as well.

## **1.6 Research Question**

RQ1: What is the impact of Symptoms or Physical Attributes of Autistic Child (SAC) on Autism Awareness?

RQ2: What is the impact of Parental awareness (PA) on Autism Awareness?

RQ3: What is the impact of Treatment/ Cure for Autism (TA) on Autism Awareness?

## **1.7 Objective of the Study**

RO1: To analyse the impact of Symptoms or Physical Attributes of Autistic Child (SAC) on Autism Awareness.

RO2: To analyse the impact of Parental awareness (PA) on Autism Awareness.

RO3: To analyse the impact of Treatment/ Cure for Autism (TA) on Autism Awareness.

## **1.8 Organization of Thesis**

This study is organized in the following way:

Chapter 1 is the Introduction starting with the background of the study along with the problem statement. Finding the research gap through the review of literature, the research questions are

formulated. In the light of significance of study, research objectives are made. The chapter ends with the organization of the thesis.

Chapter 2 is Literature Review. In this chapter, the literature is reviewed on the key dimensions of Autism Spectrum Disorder. The existed theoretical and empirical work is organized and a supportive link between the variables is established.

Chapter 3 is Research Methodology. In the 1st section of this chapter, the research design and sampling procedure are discussed. Focusing on the target population is identified, the chapter provides the sampling procedures for the collection the data. Further, the chapter entails the discussion about instrument development/selection. The chapter ends with the description of data analysis techniques used in this study.

Chapter 4 is the Empirical Results. The chapter entails descriptive analysis of the data (with the help of frequency tables as well as bar graphs) and results are interpreted accordingly.

Chapter 5 is the Conclusion and policy recommendations. In the start of the chapter, a summary of the research findings is presented. Further, it presents the research limitations followed by future policy recommendations. Lastly, the policy relevance is also discussed.

After chapter 5, the references are presented for the literature cited throughout the thesis.



## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 Introduction to Chapter

In this chapter, the existing literature is reviewed and the previous work on Autism Spectrum Disorder is discussed.

#### 2.2 Autism Spectrum Disorder

Autism spectrum disorders (ASD) are weakness in a human related to neuro development which create challenges while communicating and socializing with people and create rigidity as well as repetition in the actions(Elizabeth O’Nions, 2018). Most of the previous studies (Ram A. Mishaal, 2014)(Hye Ran Park J. M.-N., 2016)(Rachel A Rhoades, 2007)(Mandell, 2007) highlighted that this disorder emerges at the age of three but few pointed out that the symptoms for autism appears in the early 2 years of the birth(Vincent Guinchat, 2012)(Ram A. Mishaal, 2014).

Leo Kanner is credited with coining the term "autism" in its current form. He first coined the term early infantile autism in 1943 after describing roughly 8 young boys and 3 little girls who had "an intrinsic inability to create the typically natural affective contact with humans." Leo Kanner and Hans Asperger are credited with creating the framework for the current field of autism research.(Hye Ran Park J. M.-N.). As already stated, the complicated brain development of ASD patients is influenced by a number of different factors, such as genetic, environmental, and social interactions. Genetic analyses of ASD have discovered mutations that obstruct normal neurodevelopment from fetal life through childhood. A pattern of defective neural

networks engaged in socio-emotional processing emerges as a result of the micro - structural, macro-structural, and functional irregularities that come from these developmental brain anomalies. Cortical layer disarray and a varying ratio of different sized axons are seen in the microstructure. Cortical and subcortical grey matter expansion in early brain development has been consistently seen in MRI studies examining brain volume in people with ASD. Functionally, research using functional magnetic resonance imaging (fMRI) in the resting state reveal extensive global Insufficient connection in socio-emotional networks, and studies using task-based fMRI reveal lower activation of networks implicated in socioemotional processing.(Sinha S, 2015).

Mental imbalance is a long-lasting neuro development state which influences the manner in which people process the world; Autistic people show contrasts in their social correspondence, social communications, tactile sensitivities, alongside limited and tedious interests and practices. Mental imbalance range issue is a term used to represent a star grouping of early seeming social correspondence deficiencies and monotonous tangible engine practices related with a solid hereditary part just as other reason. The term 'range' is utilized on account of the heterogeneity in the introduction and seriousness of Mental Imbalance manifestations, just as in the abilities and level of working of people who have Autism Spectrum Disorder. Mental Imbalance happens in all racial and ethnic gatherings, and over each financial status level. The finding of Autism Spectrum Disorder depends on demonstrative assessments that regularly include a group including a doctor and an analyst, and may incorporate different trains, for example, discourse and language pathology or word related treatment. The assessment ought to incorporate normalized perceptions of the individual, appraisals of his/her learning and

intellectual capacities, and meetings to assemble data about conduct over different settings and her/his clinical and formative history.

ASD has been linked to the well-preserved gene sets and genetic pathways, many of which are involved in the development, stability, and upkeep of functioning synapses. To understand the pathophysiology of ASD, it is crucial to combine these genetic factors with a thorough phenotypic examination of the molecular and behavioral traits. The set of genes associated with ASD that have already been identified offers hope that novel therapeutic approaches will be developed using this knowledge. Additionally, foundational research utilizing animal models is revealing important information about the many aspects of human ASD. The genomic, cellular, and circuit level abnormalities in ASD still require further research to be fully comprehend.(Banerjee S, 2014)

The association seen between amygdala and ASD is the people who have hippocampus- and amygdala-involved temporal lobe tumors. After a tumor had destroyed the temporal lobe, several authors claimed that patients began to exhibit autistic symptoms. Temporal lobe hamartoma also causes comparable symptoms in people with tuberous sclerosis, including facial expression. (Bolton PF, 1997)

The study of amygdala pathology in ASD has been made easier by recent advancements in neuro imaging, even though previous researchers' attempts to use magnetic resonance imaging (MRI) studies to look for structural abnormalities in mesial temporal lobe of autistic subjects were unsuccessful. Studies employing structural MRI found the amygdala and the related structure volumes in ASD patients and healthy controls with verbal IQ, age, and gender matching. Individuals with ASD had larger bilateral amygdalae and smaller hippocampus and

Para hippocampal gyrus sizes. Additionally, the autistic participants had significantly larger lateral ventricles and intracranial volumes; yet overall temporal lobe volumes were comparable between the ASD and control groups (Howard MA, 2000).

While formulating clinical observations, individuals with ASD and the control groups' whole-brain voxel-based scans showed a significant difference. Reduced grey matter volume was observed in the left inferior frontal sulcus, the right Para cingulate sulcus, and the left occipital-temporal cortex in people with ASD. Contrarily, there was an increase in the bilateral cerebellum's grey matter volume. Other than that, they displayed enlarged volume in the middle temporal gyrus, right inferior temporal gyrus, and left amygdala/per amygdaloidal cortex (Abell F, 1999)

Emergence of pandemic of covid -19 had some direct and indirect implications on Children mental health and its impact is also observed on the ones with autism. The external environment poses threats to children's mental and behavioral health, and COVID-19, as a major world event, will impact their growth (Clark H, 2020).

Physical issues in children may result from their lack of physical activity, poor sleep patterns, and prolonged use of smartphone screens. Long-term factors that may affect a child's mental health include prolonged duration, infection fear, sadness, boredom, lack of information, lack of face-to-face interactions with peers and teachers, lack of self-space at home, and financial hardship for the family (J., 2020).

Children who are isolated are also more likely to experience acute stress disorder, adjustment problems, and depressive symptoms. Thirty percent of the kids who were isolated had PTSD, according to clinical standards.

Every child may be affected by the effects of a pandemic, but those who have neurodevelopmental disorders, such as ASD, are more at danger. The danger of maltreatment of children with disabilities rises during the epidemic. (Seppala P, 2020). Due to the restrictions of social distance, children with ASD miss out on more opportunities to practice their social skills. Children with ASD have a hard time adjusting to their environment as it changes. It has been shown that when established surroundings are moved around or altered, children with Autism spectrum disorder become fidgety and may exhibit behavioral issues as well as an increase in self-mutilation. (Singh DS, 2020). Additionally, the discontinuation of social skills classes and speech therapy for kids with ASD may result in missed opportunities for fundamental skill development.

Specialized assistance and interventions can be offered once one gets aware of the physical and mental health of children with ASD. The age of the parents and the kid had an impact on attitudes toward caring for children with ASD, with moms being more impacted. Furthermore, compared to before, COVID-19, parents' anxiety levels were noticeably greater during. It was discovered that the link between anxiety or subjective mental health care was mediated by parents' mental states during COVID-19. Lastly, the open-ended questions revealed that throughout the pandemic spread, parents sought help from schools, family members, and therapists to deal with ASD children. In the context of perceived psychiatric care, additional measures such as practice sessions, online courses, etc., were advised in addition to psychological and financial support (Althiabi, 2021). The study's findings emphasized the significance of community and government health authorities' support for the introduction of therapies for parents and kids with ASD in order to enhance overall mental health.

Self-harm, fleeing, aggressiveness, property damage, and improper public behavior (commonly referred to as "challenging behavior") are among the particularly troubling characteristics of problematic behavior in ASD. Extreme irritation (such as rage, impatience, anguish, and meltdowns) and persistent disobedience to demands made of oneself daily are also very difficult. Children with ASD have been found to exhibit certain behaviors, which are crucial therapeutic objectives. The criteria for clinical depression are met by 30-42 percent of young people with ASD. In comparison with mothers of normal children, mothers of children with ASD spend 50% extra time with their children. (Elizabeth O’Nions, 2018)

In order to promote earlier intervention, suitable educational planning, and the organization of family support services, early diagnosis is essential for ASD children and their families. Delayed diagnosis results in delayed intervention, which can compromise the prognosis. After a child is diagnosed with ASD, it is crucial that parents get support and advice about the best services and treatments that are empirically supported. It is crucial to think about strategies to enhance the clinical recognition and recommendation for intervention programs for these reasons.

It is clinically observed that children are to benefit the most from if intervened and diagnosed at early age. Average age of ASD diagnosis of ASD (4 years, 10 months) is later than clinically recommended. The majority of clinicians, particularly developmental pediatricians, provided additional information to caregivers regarding ASDs, while a sizable minority did not. This can be an indication of inadequate training in the broad range of behaviors seen on the autism spectrum. Parents sought information about ASD from outside sources. In order to promote advance preview and diagnosis, we suggest all doctors get specialized training on ASDs. They should then inform caregivers about programmers that are backed by evidence.

Conducting epidemiological research on autism has advantages, such as raising public awareness and enhancing comprehension of the scope and effects of ASD on society (Simon Wallace, 2012). Parents may spend a lot of money on interventions because specialists lack the necessary expertise and training (Bakare et al., 2009; Daley, 2002).

The United Nations (Global Status Report on disability and prototype 2015, 2015) and the World Health Organization's recognition of ASD (mhGAP Intervention Guide, for mental, neurological, and substance use disorders in non specialized health settings) as a new public health concern calls for a prompt and well-coordinated response. ASD is a component of the WHO's mental health portfolio, and Saraceno (Benedetto Saraceno, 2007) identified five major obstacles to expanding psychological health services in LMIC: (a) a lack of funding and strong commitment; (b) an effect health system; (c) a failure to incorporate mental health care into the primary health service; (d) a lack of adequate training; and (e) insufficient understanding of mental disorders amongst mental health professionals.

To increase their potential to work at home, schools, or the community, an ASD youngster may need lifelong assistance and services (Shin Ying Chu, 2018). Having a child with an ASD may have a variety of negative effects on parents, such as increased stress (Hedda Meadan), increased mental health issues an increase in marital relationship issues thoughts and emotions of anxiety or depression feeling alone and cooped up at home because they are afraid to (Nadir Kheir, 2012).

Families with children who have ASD run the risk of financial hardship, sleep issues, social exclusion, unbalanced roles, grief, worry, and guilt. 5 The financial element of the family is also impacted by the requirements of the ASD children. In the US, the average cost of a kid's

health care was about \$10,709, which is six times more expensive than the cost for a child without ASD (Khaula Sahida, 2017).

Autism is a neurodevelopmental disease that affects a person's ability to talk and interact to others for the rest of their life. (Mayada Elsabbagh, 2012). A wealth of information has been accessible since the early epidemiological surveys in the 1960s, revealing a far higher frequency of the illness than was previously believed (Eric Fombonne, 2011). Nowadays, it is understood that some people with this condition can live independent and full lives, however for others, the condition can have a severe impact and dramatically lower standard of living.

Autism is on the rise all over the world. This disorder is also increasing day by day in Pakistan. Only those parents who are aware of the symptoms of autism can provide the best health and environment to their autistic children (Anwar et al, 2018). There is a great need for proper awareness about autism. This awareness is also important because the family members of autistic children go through a lot of financial and mental burden. The more unaware they are, the greater the risk of misdiagnosis. It is important for parents to be aware and aware of autism so that they can pave the way for their child's learning. Awareness will be helpful in relieving stress. Because they can discuss and consult their burden with the appropriate doctor and do research on the correct diagnosis(Anwar et al, 2018).

Misdiagnosis and late diagnosis are more likely to occur when parents lack awareness because parents are the first person to observe any abnormal behavior compared to other children or siblings of the same age(Anwar et al, 2018).

It is argued that the patents of ADS have at least one mental health condition (Connor Kerns et al., 2021). Autism is an inevitable, determinative problem that indicates that it is regardless of



age and gender, that it is evident among the youth, and that it influences all parts of a young person in terms of behavior and personality traits. The word autism was first utilized as a finding in 1943 (Kanner, 1943). The recent study by Goldstein and Ozonoff (2018) argued that autism spectrum disorder is a disease that can be described by the characteristics of problems in social interactions and sharing emotions, as well as an interest in people. Autism disorders are of many types, but problems with repetitive behaviors in children are common. But most of the parents are still unrevealed because they don't know about the problem and are hoping for self-correction in the child's behavior (Baron-Cohen, 2005).

For instance, individuals with Autism will in general show a better result than expected consciousness of refinements and capacity enhancements with behavior change of parents (1999). A few people with Autism have predominant capacities in discrete territories others don't have it but parents and family support can reduce the intensity of this issue. The issue is educating and training such type of children and adults because the Youngsters and youth with mental imbalance range issues (ASD) make huge difficulties for common schoolteachers and the instructors. The teaching method for such students is dependent on their disabilities and resistance. In this article the writers address these three center components that support the training of students with ASD and offer proposals for improving the current framework (Heflin, 2011).

The unfortunate situation is that treatment is not effectively given in many cases. The Department of Health has argued that numerous individuals with mental imbalance are prone to be undiscovered or misdiagnosed. The issue of misdiagnosing is also associated with lack of awareness among the parents and miss interpretation of symptoms. Ensuring that individuals with mental imbalance are perceived and upheld by the criminal equity framework was one of

the need territories in Think Autism: On the off chance that I overstep the law, I need the criminal equity framework to consider mental imbalance and to realize how to function admirably with different administrations (Elizabeth et al., 2018)

Medically introverted individuals may have distinctive instructive necessities that should be met to permit them to build up their maximum capacity. This perusing survey expects to plan EU and public custom curriculum approaches with the objective of checking the degree of satisfaction of the privilege to training of mentally unbalanced individuals (Yih-Kuen Jan, 2018). Individuals with chemical imbalance might be qualified for a scope of various advantages. It depends upon the policy of government, but parents can play important role in rehabilitating their kids from such type of disorders by reducing their reactions on certain acts and repetitions. Sahida, K., & Allenidekania, A. (2017) explored the relationship between characteristics of parent-child and level fatigue of parents with autism spectrum disorder and the study established a significant association between parents' level of exhaustion with autism spectrum disorder of their kids.

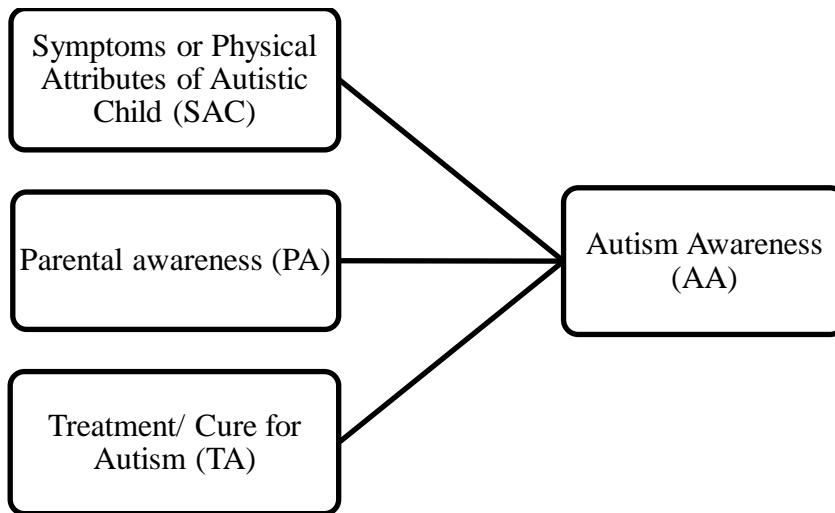
Multidisciplinary teamwork for the treatment of autism Intervention is compulsory for Autistic child it is based on the cognition interpersonal skills, physiological problems. Treatment based on the scientific based practices Applied Behavior Analysis (ABA). Applied Behavior Analysis (ABA) is an exhaustive treatment dependent on learning and conducting science. Thorough ABA treatment expects to improve the reactions and practices of kids through the use of conduct science methods in a wide assortment of true settings. ABA treatment advances improvement while zeroing in on the rules that portray how learning happens. Encouraging feedback has an essential impact in the treatment cycle. At the point when an ideal conduct is trailed by a reinforce (for example reward), the student is bound to rehash the conduct later.

Fortification backings the positive practices and expects to dispose of the negative practices through convention explicit to the student. Pivot response training (PRT) Learning experience Alternative program (LEAP).

Mental imbalance is a formative inability with beginning in early stages. Its clinical introduction is portrayed by impedances in proportional social connection and in correspondence with others, and by an inclination for tedious, stereotyped practices. Our comprehension of the clinical image of chemical imbalance has changed significantly over the previous decade because of a lot more prominent valuation for the conceivable scope of practices seen at various ages and degrees of working. Another key change has been the thankfulness that few firmly related "clutters" exist that share these equivalent basic highlights however contrast on explicit side effects, time of beginning, or normal history. These disarranges, which incorporate Asperger disorder, atypical chemical imbalance, and disintegrative issue are frequently conceptualized as lying on a range with mental imbalance.

Lack of awareness and knowledge regarding autism was observed in the studied population. According to Anwar et al. (2018), for early diagnoses and an appropriate treatment plan/therapy, awareness programs can be suggested to fill this gap. However, very few participants knew about established centers of autism in Karachi. General practitioners (e.g., speech pathologist, behavior therapists and occupational therapists) can play a significant role in counseling parents about autism (Anwar et al. 2018).

## 2.3 Research Model



**Figure 1: Research Model**

The model selected for the present research includes 4 variables in total where Symptoms or Physical Attributes of Autistic Child (SAC), Parental awareness (PA) and Treatment/ Cure for Autism (TA) are independent variables while Autism Awareness is the only dependent variable.

## 2.4 Hypothèses of Study

**H<sub>1</sub>:** There is a positive impact of Symptoms or Physical Attributes of Autistic Child (SAC) on Autism Awareness.

**H<sub>2</sub>:** There is a positive impact of Parental awareness (PA) on Autism Awareness.

**H<sub>3</sub>:** There is positive impact of Treatment/ Cure for Autism (TA) on Autism Awareness.

## 2.5 Variables

**Symptoms or physical attributes of Autistic Child:**

Recently, there is no medical test available for diagnosing Autism spectrum disorder worldwide. It can only be diagnosed by symptoms or physical attributes (e.g., flapping of hands or producing unusual sounds or preferably blue and yellow color).

**Treatment/cure for Autism:**

There is a lack of treatment/cure for autism spectrum disorder. No medical treatment is available worldwide for autism. Only therapies are recommended and suggested worldwide for children suffering from autism.

**Parental Awareness:**

Autism spectrum disorder awareness is not very common among parents in Pakistan. Although there is full awareness of autism spectrum disorder among parents whose kids were suffering from autism.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1 Introduction to Chapter**

In this chapter, the research methodology used for the research is discussed, which includes the study area, research design, sample of population, evaluation of the variables, data collection, and data analysis techniques specifically used for this study.

In this study the methodology is developed to explore the awareness of neurological disorder in the autistic parents and non-autistic parents.

#### **3.2 Research Instrument**

The data was collected through structured questionnaire from the autistic as well as non-autistic parents. The questionnaire was based on evaluating the awareness about this neuro disorder disease (ASD) among the parents of autistic as well as non-autistic children.

The questionnaire was divided into two sections. In the first section, the socio-demographic details of each participant included gender, age, profession, qualification and number of children. The second section consisted of questions to assess parents' knowledge and awareness of autism. It also includes questions related to symptoms and signs and in the last questions related to awareness of treatment options for Autism. The questionnaire was adopted and modified from already thesis (Shazia Bibi, 2020). The awareness related to ASD was measured on a five-point Likert scale.

### **3.3 Sampling**

The study is cross-sectional in nature where the data was collected from the respondents living in Bhara-Kahu (Islamabad). The samples were collected from 200 people who are autistic parents as well as those whose kids are not suffering from ASD. Samples were collected using non-probability convenience sampling. Convenience sampling was a sampling technique in which the relevant information is gathered from the sample or the unit of the study that are available conveniently (Rizwan et al. 2014). Usually, convenience sampling is used to collect a large number of information in a short period economically. In convenience sampling, the people are chosen according to our research title. The sample included both the male and female. In addition, the data was collected from rehabilitation department of Gulzar hospital and Speech and Language Therapy Center located at Bhara Kahu, Islamabad.

### **3.4 Locale**

The people approached for the present study were taken from the area of Bharakahu, Islamabad, Pakistan.

### **3.5 Data Collection**

The data was gathered from the Speech and Language Therapy Center and rehabilitation department of Gulzar Hospital located at Baharakahu, Islamabad. Data collection was performed for the research work in the first week of March 2022 and lasted until April, 2022. Data was collected from those parents who visited the Speech and Language Therapy Center Speech (SLTC and rehabilitation department of Gulzar Hospital for consulting the speech pathologist, behavior and occupation therapist in order to diagnose their children. The questionnaire was provided in the printed form to the concerned parents by hand. In addition to

this, questionnaire was developed using google forms and spread to the concerned people through online means including email and social media websites. In total, 200 properly filled questionnaires were received back through online means as well as spread by hand in hard form and considered appropriate to achieve objective of the present study.

### **3.6 Data Analysis**

The data was analyzed through Descriptive Analysis by using SPSS. First, the data was analyzed for its demographic factors including gender, age and education level. Descriptive statistics consist of statistical measures useful for providing the basic picture of the variables used in the study. This is done with the help of a frequency table. Further, correlation analysis is done to see the correlation between variables. Additionally, regression analysis is done to analyze the impact of independent variables on dependent variable.



## **CHAPTER 4**

### **RESULTS**

#### **4.1 Introduction to Chapter**

The results of the study are presented in this chapter. First part presented the Demographics followed by then Descriptive analysis. Demographics characteristics are explained with the help of graphs and tables.

#### **4.2 Descriptive Analysis**

Descriptive analysis includes demographics analysis through graphical presentation and frequency tables.

#### **4.3 Frequency tables**

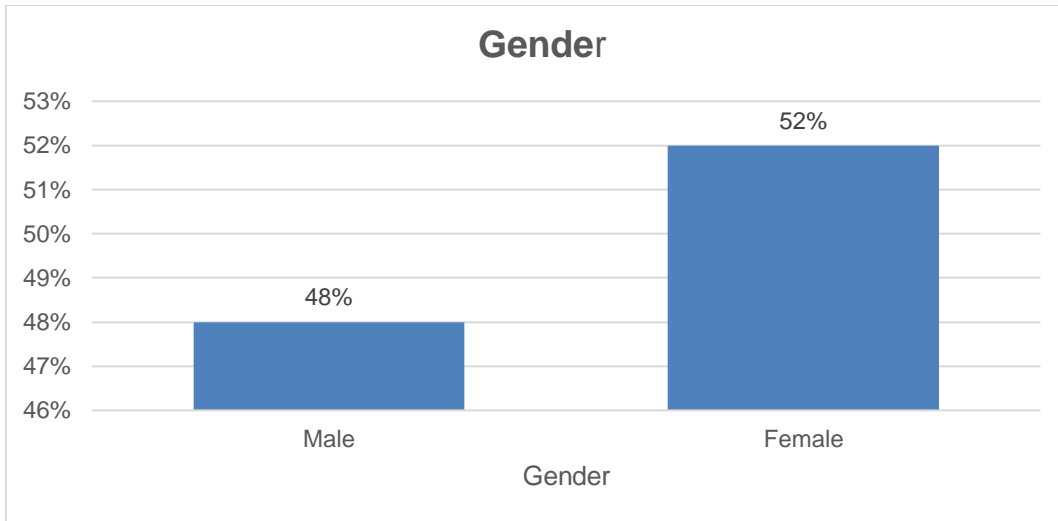
Under this section, the demographic information of the respondents is provided. In particular, the frequency tables are presented to describe the demographic characteristics.

Table 1 presents the pattern of respondents with respect to their gender (whether male or female), age (whether the respondent is between 20 to 39 years, 30 to 39 years, 40 years and above), their level of education (intermediate, having graduation degree, masters and PhD). Additionally, it covers responses of sample selected related to occupation (whether the person is working in private institutes, government employee or self-employed) as well as number of kids (including kids less than 2 in number, kids ranging between 2 and 4 and having kids more than 4)

**Table 1: Descriptive Analysis of Demographics**

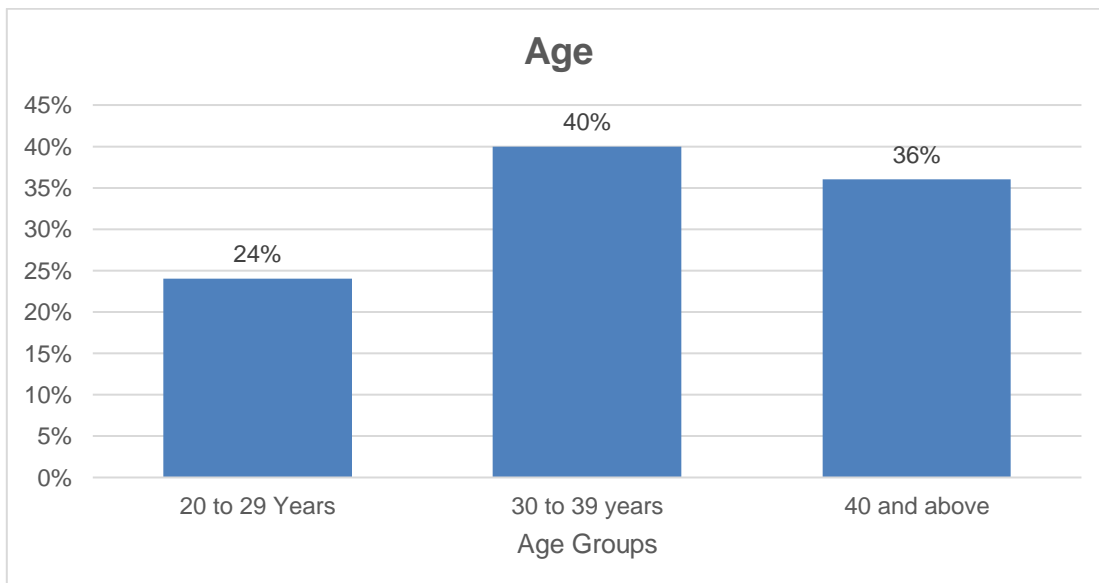
Category	Frequency	Percentage (%)
<b>Gender</b>		
Male	96	48%
Female	104	52%
<b>Age (Years)</b>		
20 to 29 years	48	24%
30 to 39 years	80	40%
40 years and above	72	36%
<b>Education</b>		
Intermediate	29	14.5%
Bachelors	119	59.5%
Masters	40	20%
PHD	12	6%
<b>Occupation</b>		
Private	82	41%
Government	65	32.5%
Self-Employed	53	26.5%
<b>Number of kids</b>		
Less than 2	78	39%
2-4	93	46.5%
More than 4	29	14.5%

The table 1 shows the demographic factors including gender, age, education level, occupation as well number of kids each respondent has. Total respondents were 200 and 48% of them were male while the females who took part in this study were 52% in number. Many people (40%) fall under the category of age between 30-39, people above 40 years were 36% in number and the age of 24% respondents lies between 20 to 29 years. The samples selected for the study was well educated as 60% people had completed their bachelors, 20% persons completed their master and 6% were PhD. It has been observed from the samples that 41% people were working in private organizations, 32.5% were government employees and 26.5% had their own setup of source of income. In addition, 39% of the people from the selected samples have children less than 2. 46.5% had kids between 2 to 4 and only 14.5% had kids more than 4 in number.



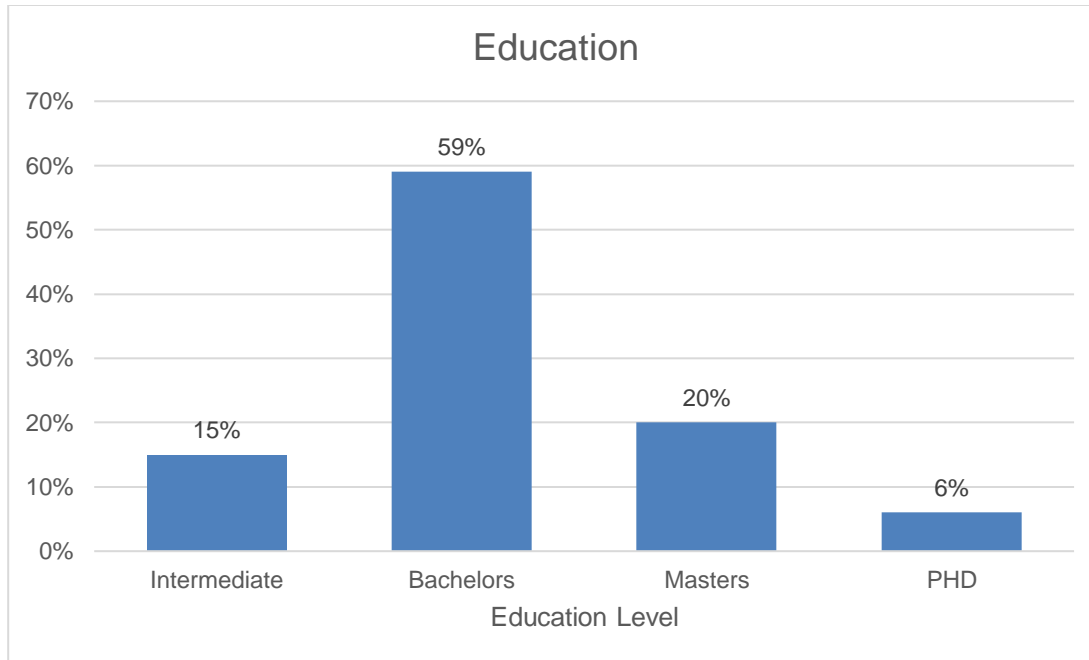
**Figure 2: Classification of data based on Gender**

Figure 2 above presents that out of total 200 respondents, 52% were female and 48% were male.



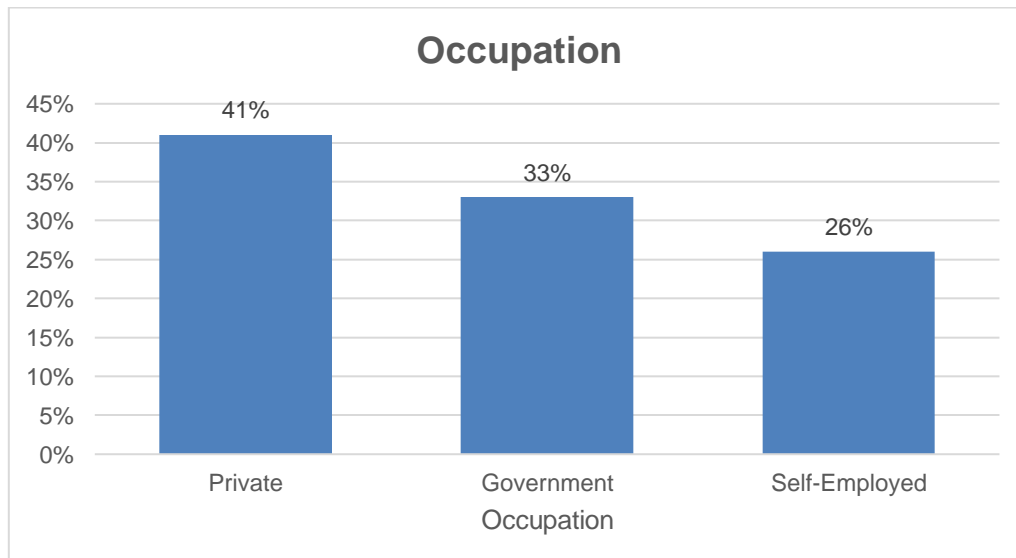
**Figure 3: Classification of data according to the age group**

Figure 3 shows that 24% samples had the age ranging between 22-29 years. 36% respondents were above 40 years while most of the respondents are almost 40% lies between 32-39 years.



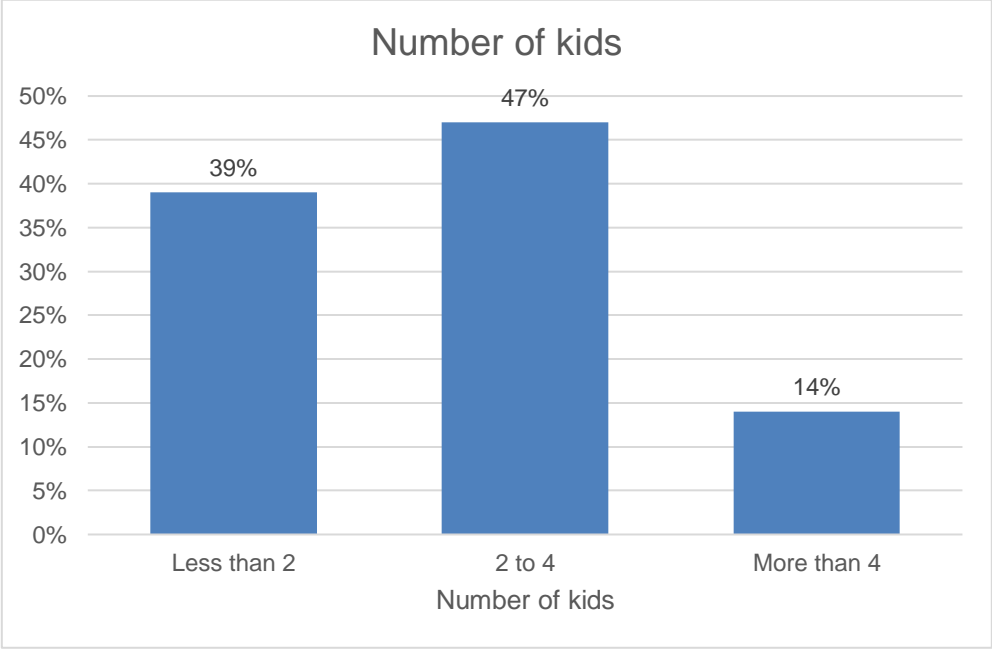
**Figure 4: Classification of data according to education level**

The information present in above figure 4 is related to education level of samples selected. 59 % of data set completed 14 years of education. 20 % completed their master levels education while 6% did PhD. In addition to this, 15% took formal education up to intermediate level.



**Figure 5: Classification of data according to occupation**

Figure 5 depicts that 41% respondents were working in private own institutions. In addition to this, 33% were employed by government while 26% were self-employed.



**Figure 6: Classification of data according on the basis of number of kids**

The above figure 6 represented the information related to number of children each respondent has. 39% of people in the selected sample has kids less than 2. 47% people had kids between 2 to 4 in number and just 14% people had kids more than 4.

#### 4.4 Correlation Analysis

Correlation Analysis is done in order to analyse the relationship between the variables. The value for the correlation ranges between -1 to +1. -1 represents the negative relation between the variables and positive value stands for the positive relation between the variables. However, zero value depicts that there is no relation between the variables. Table below clearly shows that all the variables are positively correlation where the highest correlation (0.605) is between Parental awareness and Treatment/ Cure for Autism. However, lowest correlation (0.448) is between Symptoms or Physical Attributes of Autistic Child and Treatment/ Cure for Autism. All the values are significant at 5% significance level.

**Table 2: Correlation Analysis**

Variables	Symptoms or Physical Attributes of Autistic Child	Parental awareness	Treatment/ Cure for Autism
Symptoms or Physical Attributes of Autistic Child	1	-	-
Parental awareness	0.453** (0.000)	1	-
Treatment/ Cure for Autism	0.448** (0.000)	0.605** (0.000)	1

Correlation is significant at the 0.01 level.

#### 4.5 Regression Analysis

Regression analysis is done by keeping Autism Awareness as dependent variable and other three variables as independent variable. As it can be seen from the table below that the p-values are less than 0.1, 0.05 and 0.01 for each variable including Symptoms or Physical Attributes of Autistic Child (0.001), Parental awareness (0.003) and Treatment/ Cure for Autism (0.000) therefore all the three variables are significant at 10%, 5% and 1% significant levels. As a result, we will accept all the three alternate hypothesis that states that there is a positive impact of Symptoms or Physical Attributes of Autistic Child (SAC) on Autism Awareness, there is a positive impact of Parental awareness (PA) on Autism Awareness and there is positive impact of Treatment/ Cure for Autism (TA) on Autism Awareness.

**Table 3: Regression Analysis**

<b>No. of Observations</b>	200			
<b>R square</b>	0.358			
<b>F Statistics</b>	36.78 (0.000)			
<b>Variables</b>	<b>Coefficient</b>	<b>Standard Errors</b>	<b>t-statistics</b>	<b>p-value</b>
Symptoms or Physical Attributes of Autistic Child	0.193	0.032	3.378	.001
Parental awareness	0.188	0.042	3.062	.003
Treatment/ Cure for Autism	0.449	0.052	7.269	.000

## CHAPTER 5

### CONCLUSION AND POLICY RECOMMENDATIONS

#### 5.1 Introduction to Chapter

This chapter concluded the research by describing the findings of the study followed by limitations of the study. Afterwards, future research areas has been mentioned along with the presentation of detailed policy. The chapter is concluded with the policy relevance and recommendations.

#### 5.2 Findings of the Study

The present study was carried out to examine the awareness about the neurological disorder; Autism Spectrum Disorder (ASD) among the parents of Autistic children and non-autistics kids. Study was carried out by collecting the responses of residents of Bharakahu, Islamabad. Responses were then analyzed to achieve the results based on the developed hypothesized. Results were just in accordance with the expectations. It has been observed from the result generated on the basis of responses collected that most of the people are not exactly aware of this disorder despite the fact that they are well educated and parents of 2 to 4 and even more than 4 kids. Even individuals having a little bit knowledge about ASD are still not completely aware about this disorder, its symptoms as well as the way to cure this disease.

The involvement of parents with the autistic child is critical with respect to the growth of the child. In addition to this, it has been observed that an autistic child is not interested in the interaction with other fellows as most of the parents agreed about this fact especially the ones whose children are suffering from this neurological disorder. However, parents identified that



the autistic children possess unique abilities and talents but this number was low as well, that depicts that most of the people have no knowledge about the special talents and interest an autistic child has.

In the present study, responses highlighted that people were not sure whether Autism is a disorder that kids face in childhood, or it will be prolonged for the whole life. Due to the lack of knowledge about this disease, it is underperceived or frequently missing in the general practice. This can lead to an immense increase in the number of kids with this disorder. There is high chance that people cannot easily identify kids with this disorder and that can lead to an increase in the intensity of disorder in a kid as he/she would not get the proper care and treatment for the disease.

Identification of a disease or any disorder is very important in the very first phase, but the cure and treatment has its own significance because without the proper treatment and care, one cannot control the disease. Particularly, in the case of Autism Spectrum Disorder (ASD), proper care and attention to the autistic kids is very important and parents can play a vital role in this regard. Our results also indicated that most of the respondents had a similar point of view that training and advising parents related to the treatment of Autism can be one of the foremost factors contributing to the treatment of a child at a very early age.

Basic knowledge and awareness regarding any disorder is undoubtably of great importance and it is incomplete without the knowledge of symptoms for a particular disease or disorder. In the case of Autism, it has been noted that people often overlap the symptoms of Autism with other disorders and mostly people do not consider Autism as a disease or a disorder that can be cured or can be reduced with proper therapies and treatments. Lack of eye-contact as well as poor

speaking skills are considered as the symptoms of Autism and the results showed that majority of people agreed but still majority of people disagree or have no knowledge about these symptoms. It has also been observed from the findings that majority people agree but a large number of people disagree or have no knowledge about few other symptoms of Autism Spectrum Disorder including flapping of hands and producing unusual sound. However, most of the people did not agree with the following idea that an Autistic child can play with the same toy for hours. Moreover, results also highlighted that most of the people had knowledge about the limited or reduced span of attention by the Autistic child.

A large number of individuals in the community are those who have very low nearly no knowledge about this disorder as the results depict from the responses collected from the sample. In addition to this, a large number of people have no idea about the attribute that whether this disease is curable or not and whether it is lifetime disorder or not. Despite the fact that the city from where the responses were collected is the capital of the country and has almost all type of the facilities, still the awareness about the Autism was found to be very limited as not expected.

### **5.3 Limitations**

Due to the limited budget and time, convenience sampling was done where the data was collected just from the residents of Bhara Kahu, Islamabad. It can further be studied in the different areas of Pakistan and can compare the level of awareness among the different areas of Pakistan.

## 5.4 Recommendations

- Based on the results of present study it has been observed the the overall awareness level of the people about Autism Spectrum Disorder is found to be very low in Bhara-kahu, Islamabad Pakistan. Even the parents who are dealing with their kids have very limited knowledge about this disorder. Therefore, there is dire need to intensive awareness compaign about this disorder to spread the knowledge about this disorder.
- This awareness compaigns should be organized at the government level. Different mediums can be used to spread awareness including electronic media, print media. As this is the era of technology and social media, so power of social media should not be underestimated.
- Proper digital compaign shouldbe designed and executed.
- In addition to compaigns organized by government, NGOs and Pakistan Austism Society (PAS) should arrange the awareness compaigns as well, as they can contribute significantly in this matter.
- The best mode of spreading awareness by these institutes is conducting seminars. Seminars should be conducted in every city of Pakistan including urban and rural areas for awareness about Autism Spectrum disorder. Peace walk should be conducted to spread awareness about autism spectrum disorder.
- Government should fix specific part of budget for the awareness and treatment of this disorder so that the parents must get facilitation to handle their autistic kids.
- Proper therapies centers shouldbe open all across the country so that the kids can get their required thearpies. Along with the therapies of kids, there is need of training and

guidance for the parents who are dealing with their autistic child because it is very hard to deal with such autistic kids without proper training.

- There is need of more therapists as well and special involvement from the experts and therapists are required in order to facilitate the parents as well as kids with this neurological disorder.

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## Appendix

### Questioner

#### SECTION I

**Tick the option that you find most suitable. Do not tick more than one option.**

1. Gender
  - Male
  - Female
2. Age (Years)
  - 20 to 29 years
  - 30 to 39 years
  - 40 years and above
3. Education
  - Intermediate
  - Bachelors
  - Masters
  - PHD
4. Residence
  - Urban
  - Rural
5. Occupation
  - Private
  - Government
  - Self-Employed
6. Number of kids
  - Less than 2
  - 2-4
  - More than 4

#### SECTION II

**Please indicate the degree to which you agree or disagree with each of the following statements.**

#### Symptoms or Physical Attributes of Autistic Child

1. Lack of eye contact is a sign of autism.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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2. A child with autism frequently improves visual contribution than hearable info.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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3. A child with poor language skills is autism sign.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

4. Autistic child has limited or deficient of attention span.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

5. Autistic child play with same toy for hours.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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6. Hand Flapping is a common sign of Autism.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

7. Autistic child produces unusual sound every time.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

8. Lack of attention in interact among other kids.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

9. Autistic children don't feel afraid.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

### Parental awareness

1. Autistic children's withdrawal is most part because of cold, rejecting parents.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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2. Autism is a kind of mental or psychiatric illness.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

3. Autism is under perceived and frequently missed in general practice.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

4. Autism is a neuro development disorder.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

5. Children with autism do not show social interaction, even to Family members.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------



### Treatment/ Cure for Autism

1. Parental advising on preparing methods is one successful treatment of Autism.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

2. Autism is treatable/curable.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

3. Autism can occur in mild as well as extreme form.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

4. I understand Autism is a for life condition.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

5. Motor developmental delayed is a sign of autistic child.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
----------------	-------	---------	----------	-------------------

### Autism Awareness

1. I know enough about autism spectrum

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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2. Autism is present just in childhood.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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3. Lack of awareness about autism among professionals or parents in Pakistan.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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4. Children with autism have special talents or abilities.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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5. Functioning level is poor in Autistic child.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
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