

**Thesis Report**

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**“Mujhe Samjho, Mujhe Apnao”**

(An Awareness Campaign for Autism)

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## **ABSTRACT:**

Autism is a neurodevelopmental <sup>(1)</sup> disorder. As autism is still being discovered, the numbers of autistics are increasing as per day. The occurrence of autism is 1 in 58 in the U.S. In Pakistan, there is no data collection and there is zero to none awareness about autism. A stigma attached to this community, perceived as mentally retarded. Even the psychiatrists confuse them with schizophrenia <sup>(2)</sup>. A lot of misconceptions, lack of acceptance. It makes the life of an autistic individual more stressful when not understood and accepted. My project aims to change perceptions about the autistic community by creating awareness across Pakistan as well as breaking the stigma. To make this community understood and accepted.

Neurodevelopmental disorders are impairments of the growth and development of the brain and/or central nervous system. <sup>(1)</sup>

Schizophrenia may result in some combination of hallucinations, delusions, and extremely disordered thinking and behavior that impairs daily functioning, and can be disabling. <sup>(2)</sup>

## **INTRODUCTION**

Autism spectrum disorders (ASD) is a complex neurodevelopmental disorder characterised by failure to communicate, poor social interaction, and repetitive behaviour. The term “spectrum” refers to the wide variety of symptoms and severities within ASD. This disorder often impairs their social interactions with other people. Doctors typically diagnose ASD in childhood when symptoms can occur before 3 years of age, according to the American Autism Association. Always having a keen interest in children and their behavior is what led me to study this area thoroughly. Unfortunately in Pakistan, like in many other developing countries people choose to be oblivious<sup>(3)</sup> towards ASD and the level of awareness among the health professionals is very low, To achieve my goal, I started the initial research process of collecting data about what is little is being done about autism within Pakistan and all around the world.

### **3.1 Passion**

The main source of my inspiration came from the lack of awareness within the society, mainly lack of education in our teaching sector and lack of acceptance in parents.

Oblivious-  
not aware of or concerned<sup>(3)</sup>

## **1.2 Project Scope**

The project tends to create awareness and to make people think about how they treat someone with a disability and someone who is generally different from how they are, and to think of what the person with the disability feels when bullied and mistreated. When an individual cannot make someone or anyone as matter of fact, what they're trying to say. How frustrating could it be to not be able to communicate what you feel.

## **3.2 Design Statement**

Going through the research in depth, figuring out that lack of awareness, negligence and lack of acceptance causes the autistic individual much more trouble in his daily life. Empathy is the key. Trying to feel what they feel, imagining what they go through drove this campaign. The project approach is human-centered design, the campaign aims to make one wonder how an autistic individual goes through.

## **2. LITERATURE REVIEW**

### **2.1 Autism knowledge and attitudes among the healthcare professionals in Lahore, Pakistan.**

The survey being held in Lahore, Pakistan throws light on the autism knowledge and attitude among the various healthcare professionals. The diagnosis and treatment of Autism in Pakistan occurs in multiple settings and is provided by variety of health professionals but unfortunately, knowledge and awareness about this disorder is low among Pakistani healthcare professionals & the presence of inaccurate and outdated beliefs regarding this disorder may compromise early detection and timely referral for interventions. This study assessed the baseline knowledge and throws light on the misconceptions regarding autism among healthcare professionals in Pakistan which can impact future awareness campaigns.

Physicians and non-Physicians both participated in this study. Knowledge of DSM-IV TR criteria for Autistic Disorder, beliefs about social, emotional, cognitive, treatment and prognosis of the disorder were assessed.

Results suggests that current professionals in the field have an unbalanced understanding of autism due to presence of several

misconceptions regarding many of the salient features of autism including developmental, cognitive and emotional features. The study has clinical implications and calls for continued education for healthcare professionals across disciplines with regards to Autism in Pakistan.

In another study done in Karachi, Pakistan, General Practitioners who were less than 30 years of age and five or fewer years after acquisition of their medical degrees, were found to be more informed and accurate in their understanding of Autism. Hence generally in Pakistan, child psychiatric services are still in their infancy <sup>(4)</sup> as there are no formal referral pathways to psychiatric centers for children. There is a need to put focus on child and adolescent <sup>(5)</sup> psychiatry. An important finding is that the early onset of the disorder, that is before 36 months of age; (a diagnostic hallmark of Autism) is either unknown/undervalued and/or not applied in the diagnostic process. One of the main presentations of autism is speech delay but that is not considered atypical in Pakistan at thirty-six months or beyond resulting in many children being assessed, referred and diagnosed far beyond early childhood.

Infancy-the early stage in the development or growth of something. <sup>(4)</sup>

Adolescent-developing from a child into an adult. <sup>(5)</sup>

Instead of labelling autism as a temporary disability and rooted in emotional factors, early intervention should be done so as

not to delay the positive effects on the prognosis <sup>(6)</sup>. In developing countries like Pakistan, the health service structure should be improved and more child specialty centers should be made.

Other than that, family physicians and pediatricians in most cases have no formal child psychiatry exposure during their training and feel less confident in assessing and managing these children. Similar to the global trend, in Pakistan, family physicians and pediatricians are typically the first medical professionals to whom parents will express their concerns regarding the child's development due to the stigma attached with this disorder.

Various conference forums and the effective use of media to promote evidence-based medicine and the erosion of myths about Autism held by the general population and in particular among the healthcare professionals is much needed in Pakistan.

## **2.2 Pakistan County Report**

Although the case of Autism is still unknown, a number of coping strategies have been developed that have managed to save so many lives around the world. Over 60 million people

Prognosis-an opinion, based on medical experience. <sup>(6)</sup>



with autism across the world, of which many Third World countries in Africa and Asia, including Pakistan, do not even have access to any public services, creating an alarming situation. Pakistan, due to facing a financial crisis makes it difficult for an average person to receive basic education which is the first step towards being aware of this disorder. Apart from this it also makes rehabilitation services costly for autistic children.

In south Asia, the countries of India, Pakistan, Bangladesh, Sri Lanka and others have recently been exposed to the awareness, research and documentation on Autism spectrum disorders, that has existed in the developed world for decades. Due to which many children have been misdiagnosed as PDD-NOS (Pervasive Developmental Disorder - Not Otherwise Specified) or have been kept locked away in homes due to misguided belief in magic (primitive tribal/religious thought) or due to social stigma. Hence developed nations have a stronger hold over Autism.

In Pakistan only private institutions are seen working in this area through conducting seminars and workshops on this topic to create awareness among parents, professionals and government authorities. However, there is no institute at the government level, which specifically caters to the services for

children with autism. There is a need to create awareness about this disorder at the government level. Moreover, there needs to be an understanding of early detection, sensory issues and home-based interventions by child care specialists. Medical and rehabilitation teams should be well trained and maintained to cope up with all the diversities of this disorder. Usually the professionals use ABA <sup>(7)</sup>, TEACCH <sup>(8)</sup> in combination with Picture Exchange Communication System (PECS), speech therapy and drugs (if required) as treatment options for such children. The basic approach is eclectic. The choice of treatment depends upon the needs of the child though. There is a dire need for introducing Sensory Integration Therapy in more institutions.

Summing up, the major challenges that Pakistan faces are lack of awareness and lack of resources. In Pakistan, there are two institutes for the professional training of Clinical Psychologists: Institute of Clinical Psychology, Karachi, and Centre for Clinical Psychology, University of the Punjab, Lahore. The people who are trained from these institutes are given exposure and training under supervision. A few schools are striving to create an inclusive environment through experimentation with various approaches. These approaches include establishing new inclusive schools; giving access to children with disabilities to existing schools; persuading

Applied Behavior Therapy <sup>(7)</sup>

Treatment and Education of Autistic and Communication related handicapped Children <sup>(8)</sup>

children without disabilities to join special education institutions; keeping children with special needs within regular school although in separate classrooms; and supporting schools with multi grade inclusive classrooms. These schools should also be made accessible to children with disabilities living in rural areas along with urban ones.

It is important to recognize that it is less costly to provide education for disabled children in mainstream inclusive schools rather than establishing special schools. The additional/marginal cost to transform mainstream schools to inclusive ones is minimal and affordable for the government. There should be legislation that makes it compulsory for every public school to admit all children irrespective of their special needs.

There have been many achievements and breakthroughs, due to the hard work of parents, doctors, special educators and researchers in Pakistan, all have been recent efforts and have started a series of events which will get us where we want to be, maybe not in a year's time, but soon enough. Increased awareness has made parents of autistic children come out from the shadows to seek education and therapies for their children. The recently opened Autism Centre at Gulshan-e-Iqbal at Karachi is a step in the right direction as training in the

structured TEACCH and other systems is now being imparted to mothers and special educators here. increasing awareness and getting more government and private sector support to widen the reach and get those across all ages and spectrums into training programs, as well as increasing awareness for other learning disabilities, augurs well for better situation of autism in Pakistan.

### **2.3 Coping with autism spectrum disorder (ASD) in Pakistan.**

In this study, the authors have explored lived experiences of the mothers who have children with autism spectrum disorder (ASD) in the urban sociocultural context of Karachi, Pakistan. The study explored the lived experiences of the mothers of children with ASD, including but not limited to the mothers' stress, behavioral difficulties, coping strategies, religious, and social support related experiences, it incorporated the factors that played a part in mothers' experiences about ASD and whether they receive enough social and educational support. The second objective was to investigate how the process of diagnosis began, and how coping with ASD had changed over time.

Most mothers are part of the middle and upper-middle class as they can afford extensive therapies for their children. An interpretive phenomenological approach was adopted using 15 interviews conducted in the sociocultural context of Karachi. The interviews gave an in-depth analysis, showing the mothers to be loving and caring towards their child from the start of the journey. This article highlights the lack of institutional as well as emotional support for special populations in Pakistan; thus, the findings are crucial for the United Nations Sustainable Development Goals, to ensure inclusive and equitable quality education that has the potential to promote lifelong learning opportunities for all.

The findings showed that none of the mothers had any idea about ASD before the diagnosis, in fact, that was the first time most, almost all of the mothers had heard of the term. This was not unusual as the educational institutes in Pakistan don't incorporate the study of disabilities in their programs apart from a few ASD awareness workshops held in the country, but they are not enough. In a Pakistani society, it is very easy for onlookers to judge the children when they behave out of the norm in the public, however, the children aren't as judged as much as the mothers. Mothers' parenting style is labeled as "bad" as they are unable to control the behavior of their children. Despite the low level of empathy in society at large,

mothers of upper middle classes love and support their child as how they are, whether with special needs or without and as experience evolved over time, the children are not considered as autistic children, rather as children with ASD, with separate personalities to the disorder.

Talking about the coping strategies, initially the mothers were seen looking for escape strategies by avoiding any sort of social gatherings but gradually they started becoming more accepting towards their situation by exposing themselves and their child to the outer world. They realized the sense of responsibility on them that any negative actions from the closest person would have more adverse effects on the child's mental health.

Furthermore, according to the Pakistan Autism Society (PAS), there is no reliable data for the cases or prevalence of ASD in Pakistan, but the population has become more and more visible. PAS reports that developmental bodies from South Asia estimate indicate that in Pakistan there are 350,000 children with ASD. These statistics make the findings of this study very significant in the context of Pakistan.

It is important to note that several participants expressed disgruntlement <sup>(9)</sup> about the lack of educational support

stereotypical form such as frowning and annoyance <sup>(9)</sup>

available in Karachi. Mothers of children with ASD see the schools in Karachi as non-inclusive because they do not have an academic framework that includes children with special needs hence there is a dire need to make such facilitating academic changes' initiatives have the potential that people with special needs can become their own advocates in the future. The lack of societal acceptance is related to the lack of social support the parents receive, even from their own family members. Therefore, support mechanisms are needed for the mothers too so that they can gather social and emotional support for taking care of children with ASD. Moreover, even though men are not involved in the primary caregiving for children but it would be helpful to get an account of their experiences too in future.

#### 2.4 A boy called Po (Movie)

“A Boy Called Po,” is a sentimental, sympathetic and fairly well-acted look into the lives of an autistic child and his overwhelmed Dad. In this story of a young widower dad raising an autistic son, screenwriter Colin Goldman's clear intention is to chip away at some of the stigmas associated with

people—particularly children—on the autism spectrum. It's about the life of a dad and son who have to face many obstacles in various stages of life. It depicts the struggling life of a single parent and the challenges Patrick(po) has to face with this disorder after his mother passed away.

It's explanatory, showing us what clinicians mean by "regression," when they say a child on the spectrum is "drifting" — retreating further into his or her own world. And it's imaginative, offering fanciful speculation on what that child might see and experience in that world inside the mind.<sup>11</sup> years old and mainstreamed into a local elementary school.

Po drifts more and more into a dream-world, manifested in the film as a sunset-lit beach, or a green forest, where Po meets up with a pirate, or a cowboy, or a knight (all played by Andrew Bowen). In the dream-world, the pirate/cowboy/knight looks to Po for advice or help with things. Although this imaginary world of Po makes him disconnect with the realities of life but since his mother dies, for him it's his only escape more likely his headway. Along with that his imaginary world is the only place where he feels being respected in comparison to being bullied and rejected in his real life. However, David finds it harder and harder to connect with his son. Po "drifts" farther and farther away. The scenes between father and son are considered, complex, and authentic. It is very good on the bureaucratic nightmare that is a parent's reality in this situation:



overburdened school systems, multiple therapists, health insurance, impatient employers.

This story negates the fact that every child with autism comes under the same category which is primarily known to be having a slow and not so vigilant mind because po is a very intelligent kid with an active mind, the blackboard over his bed is covered in complex math and he reads the stock pages of the Wall Street Journal. The problem with this special child is that he has an extensive thinking which leaves his mind perplexed with imaginary scenarios but the society is not able to understand the reason for him being drawn towards his imaginary world due to a lack of empathy and awareness about ASD. With time things started getting better for Po when his father started devoting more of his time to him and the society became more understanding towards him. There were both negative and positive responses of a po towards his disability but with all that being said, po's negative coping methods overweigh his good ones when proper school and life accommodations were made for him.

## 2.5 Atypical (TV Series)

Atypical accurately captures the diversity and experience of individuals with ASD. It reflects on the fact that people with

this disorder find their hobby as a self-soothing ritual, repeatedly utilizing it to cope with their anxiety, just like Sam did with illustrations. Thirdly, it stresses on the fact that individuals with ASD may yearn for relationships like normal people do thus eliminating the thought that they just want isolation.

Sam being successfully employed at a computer electronics store shows a positive and more accepting nature of the society because autistic people are more likely discriminated against in the workplace or do not have the opportunity to work any job. This detail of Sam's character eases my fears about integrating autistic adults into the community. Being a high school senior with an after-school job where his boss and colleagues have a friendly and supporting behavior towards him also points towards inculcating the thinking that people with this disorder are not to be cornered, they also need support and love like normal individuals. So many parents are in denial that something is different about their children, and it was touching to see Doug come around and accept that autism is a large part of who Sam is, acceptance by parents is what can make such individuals feel secured and confident.

I appreciate the honesty of the statistic on this show that 4 out of 5 people manage to complete their studies on time. It shows

that, not only is it important for colleges to be ready to include people with autism at their colleges, but that some people with autism may need additional time to finish college.

In a world where the autism spectrum remains a mystery to many, the show captures real (and sometimes funny) moments of everyday life.

While Sam's stereotypical depiction may impair some viewers' understanding of real people with autism and their complexities, it simultaneously lends Sam a certain broad relatability for those who are on the autism spectrum by setting an example for how they can deal with their own problems. People with autism need a safe, accepting environment where they can try new things, and *A Typical* succeeds in communicating this.

## 2.5 Temple Grandin

“See it as a gift, not a curse.”

Temple Grandin is not just a typical movie that shows a person's perseverance in times of despair which people with Autism generally have to face alone due to the non-accepting

nature of our society, it's an uplifting story about how an autistic individual can come out of her shell and make something big out of her life just by a little help and guidance.

This biopic shows the inherent value of the person in the face of limitations or disability. The woman becoming a highly respected author, animal scientist and autism is so inspiring and impactful for all autistic people who feel caged and neglected because of the shallow mentality of the people around them.

The audience is given a glimpse of the world through Temple's eyes, and challenged to consider that autism may not be just an obstacle to overcome, but a gift that allows the person to see things in a way that others cannot. It is precisely her autism that allows her to design humane treatment in the cattle industry.

Moreover, her relationship with her mother Eustacia is the highlight. She being confident in her own love for her daughter and refusing to believe the psychiatrist who blames her for Temple's autism; the dominant thought/stigma in the 1960s was that autism was caused by a lack of bonding with the mother. She is an excellent example of motherhood and allows

us to showcase the importance of giving space and freedom to our children to grow.

### 3. METHADODOLOGY

#### 3.1 Project Aim

The project aims to aware citizens of Pakistan, the reason of choosing Urdu language as the primary, Awareness in the elite is present somewhat but there is none in other areas and public schools. So, the initially, a campaign for the non-autistics from the perspective of autistics.

#### 3.2 Project Structure

##### Phase 1

- To create an Agency for the Awareness of the Autistic Community.
- A campaign Design.

##### Phase 2

- Digital/Social media Awareness.
- Online Presence.

##### Phase 3

- Seminars of awareness and education for healthcare professionals.

- Concept of inclusive educational systems.
- Awareness seminars in schools for acceptance and understanding.

### **3.3 Campaign Content**

After all the research, the idea of the campaign is to communicate what the autistics can't. Going through all the issues that they face in Pakistan, the content generated is the voice of the autistic community. The title of the campaign is "Mujhe Samjho, Mujhe Apnao"

All they need is acceptance and understanding. The content generated further for the campaign highlights the variety of issues that they go through and cannot communicate.

### **4. CONCLUSION:**

The journey of thesis has evolved my thought process. Whenever I observe a child throwing a tantrum or having a behavior issue, I try to find the root of his/her trigger. I try to feel what they are feeling, in simple words, it has created acceptance within me. To understand what the other person is going through.

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