

# Autism Awareness Guide for Parents

Social Protection Resource Centre

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This guide is an information source for parents and care givers to guide them through the diagnosis, treatment and life care journey for a child and adult with autism. Keeping in view that every person on the spectrum is different in their own way, the information provided in this guide broadly covers the essential facts and guidance needed for the knowledge of parents and care givers.

 This is an open-source document for public information.

*We hope it would help people acknowledge that difference of minds is not inherently an obstacle on its own, rather it is more about how society views and deals with these differences that can be challenging.*

The Autism Awareness Guide is jointly developed by the Ministry of National Health Services Regulation and Coordination [MNHSR&C] and the Social Protection Resource Centre [SPRC], with input from the Research and Development group and independent experts. It is prepared by the SPRC in consultation with the R&D group, which included among others, Health Professionals from National Institute of Rehabilitation Medicine [NIRM], Parents, Caregivers and Autism Advocates for a knowledge partnership with the MNHSR&C and the Ministry of Human Rights [MOHR] to Make Islamabad Capital Territory a better place to live for the PWDs and the Elderly.





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## About this Publication

According to the Pakistan Autism Society, approximately 350,000 to 400,000 children in Pakistan are on the Spectrum. Autism Spectrum Disorder (ASD) is a condition associated with repetitive behaviors and difficulties in social-interaction or communication. As it manifests across a spectrum, individuals experiencing it may exhibit symptoms ranging from mild to severe. It often requires different ways of learning for basic life skills or education as well as to perform day to day activities. Consequently, the role of parents or caregivers becomes exceptionally crucial in assisting them to overcome challenges and lead a fulfilling, independent life. In recent times, the prevalence of autism has increased globally, with its diagnosis becoming more formalized and frequent. In Pakistan there is a lack of awareness about autism in general public as well as among many primary care health professionals. The purpose of this guide is to create awareness about the diagnosis, life experience and treatment of autism while discrediting the misinformation around it.

Considering the substantial time and dedication, required for care in autism, it is crucial for parents and caregivers to access both social support and informational resources, such as guides and toolkits. These materials serve as valuable sources of guidance and assistance in navigating the challenges associated with providing care for individuals on the autism spectrum. Studies conducted on autism care in Pakistan have revealed that lack of awareness among primary healthcare professionals and parents leads to delay in diagnosis and appropriate interventions. It also creates a problem in the social inclusion of children on spectrum as many educationists also tend to adhere to the wrong assumptions about autism. Studies have also revealed that mothers being the primary care takers, endure a lot of stress due to social attitude and ignorance.

The purpose of this guide is to provide necessary information to parents of children on the spectrum and for anyone else who seeks to understand the condition and extend help to the parent or the child.





# General Information

## Definition

Autism Spectrum Disorder is a neurodevelopmental disorder which persists as a wide range of conditions marked by difficulties with social skills, repetitive patterns of behavior, speech impairments, and nonverbal interactions with others. People with autism can learn, reason, and solve problems in a variety of ways, ranging from exceptionally competent to severely limited. While some persons with ASD require everyday assistance, others might only need minor assistance and in certain conditions could even live independently.



## Symptoms



### **Repetitive Behaviors and Restricted Interests:**

Engaging in repetitive movements, such as rocking, spinning, or hand flapping.



### **Sensory Sensitivities:**

Heightened or reduced sensitivity to sensory stimuli (e.g., sound, light, touch, taste, smell).



### **Challenges with Social Interaction:**

Not being able to effectively communicate with others or express oneself, verbally or otherwise. Difficulty understanding and responding to social cues, norms, and rules. Struggling to make friends and maintain relationships.

**Executive Functioning Problems:**

Trouble with organization, planning, and problem-solving which may impact academic performance and daily living skills.



Difficulty to have solid food due to over sensitivity with the texture and smell of the food

## Causes



**Genetics:** Autism has a strong genetic component. This means that certain genes passed down from parents can increase the chances of their child developing autism.



**Environment:** Environmental factors, such as prenatal exposure to certain medications, chemicals, or infections, can lead to the development of ASD. This also includes lifestyle and diet.



**Brain Development:** complications in early brain development, especially during pregnancy or childhood affect how the brain is wired and connected.



Though the reasons for autism are not yet objectively identified, in few cases a high amount of heavy metals were detected from the sample of new born babies who were diagnosed with autism later on. There is a possibility that heavy metals were present during the development of the child in the womb, which might have affected the structure of the neurons. Hence causing over (under) sensitivity of sensory responses. According to some studies the source of heavy metals is the over use of the fertilizers which contaminate the food. ASD is caused by a combination of genetic and environmental factors working together. Some individuals may have a genetic predisposition that makes them more vulnerable to certain environmental influences, increasing their risk of developing autism. The exact causes of autism are still being studied, and individual cases can vary in their specific factors and contributions.



# Signs in Children







## Signs in children



**Limited eye contact:** Infants with autism may show reduced eye contact or avoid making eye contact with others.



**Lack of social smiling:** Typically, infants start to smile in response to social interactions and stimuli. However, infants with autism may not exhibit social smiles or may display them less frequently.



**Delayed or atypical communication:** Infants with autism may have delays or differences in their communication development. They may not respond to their name, or display a lack of babbling or cooing.



**Absence of pointing or gestures:** Pointing and using gestures, such as waving or reaching out for objects, are important milestones in early communication. Infants with autism may show limited or delayed use of pointing or other gestures.



**Repetitive behaviors or movements:** Some infants with autism may engage in repetitive behaviors, such as hand-flapping, rocking, or repetitive body movements.



**Sensory sensitivities:** Infants with autism may display heightened or reduced sensitivity to sensory stimuli. They may become distressed or exhibit unusual responses to certain sounds, lights, textures, or other sensory inputs.



**Difficulty with transitions or changes:** Infants with autism may struggle with transitions or changes in routines. They may become upset or exhibit increased agitation when there are alterations in their environment or daily activities.



Eating difficulties



Mood Swings



Hyper activity





## Early age-wise indicators



Autism identification at early age is critical for diagnosis and timely intervention. Parents can monitor their child's development to identify any early signs of autism. If they notice any of these signs, it is crucial to consult with healthcare professionals who specialize in autism diagnosis and intervention. Early identification and support can lead to better outcomes and improved quality of life for children on the autism spectrum. Below some development milestones and subsequent signs of autism with respect to age group are mentioned. Parents can refer to a child psychologist/psychiatrist, pediatric neurologist or developmental pediatrician for an official diagnosis.

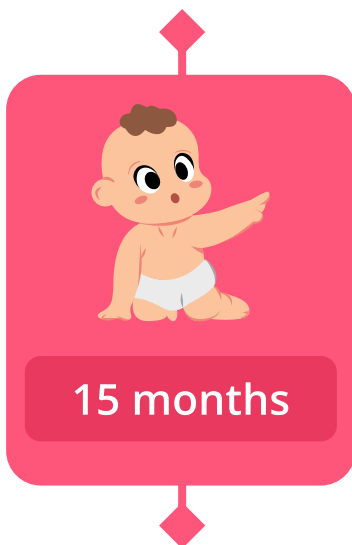
### DEVELOPMENT MILESTONES

Baby smiles and responds to gestures



12 months

Baby points at things and expresses wants



15 months

Baby can speak several words and identify objects



18 months

Limited eye contact and baby ignores gestures

Take Parents hands and guides them to the object instead

Baby doesn't speak or engage in playing with others

### SIGNS OF AUSTIM

# The Importance of Early Intervention





# The Importance of Early Intervention



Early intervention for autism is crucial as it can have significant positive impacts on a child's development and overall well-being. The main benefits of early intervention are:



**Optimal brain development:** During the early years of life, a child's brain undergoes rapid growth and development. Early intervention aims to capitalize on this period of plasticity, where the brain is most receptive to learning and change. By providing targeted interventions, therapies, and supports during this critical time, it can help promote optimal brain development and improve outcomes. This makes the individual more receptive to further treatment in later life and reduces complications.



**Enhanced social and communication skills:** Early intervention programs focus on improving social and communication skills, which are some of the main problem areas for individuals with autism. Through specialized interventions, such as speech therapy, social skills training, and behavioral therapies, children can develop effective communication strategies, enhance their social interactions, and improve their ability to connect with others. This helps them to better express their needs and allows an easier transition into society.



**Improved behavioral management:** Early intervention can help address challenging behaviors commonly associated with autism. By employing behavior management techniques, children can learn alternative coping strategies and develop self-regulation skills. This reduces behaviors that impede their learning or social engagement.





**Improved academic development:** Early intervention programs often include activities and interventions designed to promote cognitive and academic development. Through structured learning environments, individualized teaching methods, and early educational supports, children with autism can make progress in areas such as attention, problem-solving, and academic skills. This is also useful for improving employment opportunities in future.



**Support for families:** Early intervention not only benefits the child but also provides support and resources for families. Families can receive guidance on understanding autism, coping strategies, and techniques for supporting their child's development. Additionally, early intervention services can connect families with support networks, parent training programs, and community resources.



**Long-term cost savings:** Studies have shown that early intervention can lead to long-term cost savings. By providing necessary supports early on, it can potentially reduce the need for more intensive and costly interventions later in life. Early intervention increases the chances of individuals with autism achieving greater independence, therefore reducing the long-term burden on families and society.

## Four Basic Therapies:



Behavioral  
Therapy



Occupational  
Therapy



Speech  
Therapy



Physical  
Therapy

**Note for Parents:** Identifying the early signs of autism is crucial for helping children reach their full potential. If you suspect that your child has autism, immediately seek help from a specialist who can diagnose and treat autism. Early intervention is vital in helping children with autism develop the skills they need to succeed. As a parent, it can be difficult to come to terms with a diagnosis of autism, but it's important to remember that your child is still the person that they were before the diagnosis. With the proper support and treatment, children with autism can lead fulfilling lives and reach their full potential.

Creating a supportive environment for your child at home and school is important. This may include making accommodations for sensory issues, providing a predictable routine, and finding ways to support your child's social skills. Work with a team of professionals who specialize in autism, such as speech therapists, occupational therapists, and behavioral therapists, to create a personalized treatment plan for your child. Remember, you are not alone in this journey; resources and support are available to help you and your child. Moreover, instead of special education schools, inclusive schools may be more helpful to help the child in their academic journey.

# Treatment Approaches







## Treatment Approaches



**Behavioral** therapy helps individuals with autism learn new skills and improve their behavior. It uses techniques like rewards, reminders, and practice to encourage good behavior and reduce problematic ones. For example, a child may be rewarded with a sticker for completing a task.



**Developmental** approaches focus on meeting the specific developmental needs of individuals with autism. These approaches aim to improve social, emotional, cognitive, and physical development through structured interventions that match the person's abilities. This included speech and language therapy as well as occupational therapy. For instance, a therapist may use games and activities to improve a child's social skills.



**Educational** interventions provide specialized instruction and support to individuals with autism in school. These approaches involve creating personalized education plans, using special teaching methods, and making adjustments to help individuals learn and develop academic and social skills. For example, a student may have extra time to complete assignments or receive one-on-one support from a teacher.



**Social-relational** approaches focus on helping individuals with autism develop social skills and build relationships. They aim to improve social interactions, communication, and understanding of social cues. These approaches often involve learning from peers, participating in group activities, and receiving training to enhance social skills. For instance, a teenager may join a social skills group where they practice conversations and learn how to make friends.



**Pharmacological** treatment involves using medications to manage specific symptoms or conditions associated with autism. These medications are prescribed by doctors to address issues like hyperactivity, anxiety, depression, or aggression. For example, a child with autism may take medication to reduce anxiety and help them feel calmer.



**Psychological** therapies involve working with mental health professionals to address emotional and behavioral challenges associated with autism. These therapies may include talking therapy, play therapy, or other forms of therapy to help individuals develop strategies for coping with emotions. For instance, a therapist may help a child with autism learn ways to manage their anger.



**Complementary** treatments are alternative or additional approaches used alongside conventional therapies. These may include dietary changes, alternative medicine practices, sensory integration therapy, or other non-traditional treatments. It's important to consult with medical professionals and gather evidence-based information before trying complementary treatments. This includes equine, art and music therapies.



## Types of Therapies Available in Pakistan:



**Play therapy:** Autistic children usually play alone and in unusual or repetitive patterns. In play therapy therapists sit with children and include themselves in their play. Slowly they add new elements such as a new word or toy to help them accommodate to language and grow emotionally. Integrated play groups are also organized which include both children with and without ASD. By playing with their peers children with ASD can pick up typical ways to use their toys and improve their social skills.



**Occupational therapy:** This includes learning to navigate through everyday activities such as holding a spoon, buttoning a shirt or brushing teeth. This can be altered according to the individual's specific needs. Therapists observe children's skills, and behaviors and use them to create a personalized plan for each child which includes their tasks and goals. Achieving these goals helps improve overall quality of life for the children and helps them attain greater independence in their day to day lives.



**Speech therapy:** Most people who have autism struggle to communicate effectively both verbally and non-verbally. They are likely to grunt, shriek, hum, repeat what others say or have monotonous, robot-like speech. They also lack conversational skills such as eye contact, gestures, waiting for the other person to speak etc. For this purpose speech therapy is required to improve their communication skills, help them form relationships with others, express themselves, learn self-control and improve daily functioning. Those individuals with ASD who cannot communicate verbally are taught instead to use gestures or pictures instead of words to express themselves. It is recommended to start speech therapy as soon as possible since language delays in children can be detected at around 18 months of age. Early treatment can help children develop a better grasp of spoken language and makes it easier for them to integrate into society later on.



**Equine therapy:** horseback therapy involves children riding a horse guided by a therapist. This form of physical therapy involves controlling and guiding an animal which helps children become less irritable and improves their motor skills.

# ASD and Teenagers





## ASD and Teenagers



Puberty is something that all children struggle with. Bodily changes, hormone fluctuations and menstruation is a difficult transition for a young adult. For individuals with autism who have heightened sensory sensitivity and often difficulty expressing themselves these problems are magnified. Excessive and personalized counselling is required to help them transition into adulthood and cope with its subsequent changes. Sudden mood and bodily changes can cause them to lash out or become frightened.

For this family members need to prepare their children in advance and support them through every step of the transition. For example, young girls can be introduced to sanitary napkins and practice being accustomed to blood instead of fearing it. Pictures of men and women before and after puberty that reflect characteristics such as facial hair, different body figure etc. can be shown to children while instilling in them the concept that it is something normal that they will also go through soon. Preparation, patience and comfort is key in helping them transition into adulthood.

As they grow older, people have the innate need to become more independent, physically and financially. For those on the spectrum, achieving this independence involves learning basic life and professional skills as young adults. Persons with autism can acquire vocational training and certifications for employability. As certain autistic individuals suffer from extreme social anxiety, these trainings can also be undertaken online or be tailored according to their specific needs. It must be emphasized that autism is a spectrum and each person has different requirements, and limitations. Attaining basic life skills such as hygiene, cooking, using transport etc. can help autistic individuals achieve greater freedom in their everyday life and subsequently relieves caregivers of some of their duties. Similarly, having an income can allow autistic individuals to support themselves, their families and improve their sense of self-worth.

The mental wellbeing of autistic individuals is as important as their physical welfare. The Availability of social spaces for social interaction is crucial in this regard. Autism centered groups, events and social arrangements help develop a sense of solidarity and acceptance within the autism community. Support groups provide a platform for them to discuss their unique problems and receive validation and encouragement. It informs individuals and provides better access to autistic-centered facilitations as well. These aspects factor into the inclusivity of autistic individuals within the general society as well.



# Nutrition







## Nutrition



Many people with autism have **sensory sensitivities**, which can affect their perception of taste, texture, smell, and appearance of food. Some individuals may have heightened senses and may prefer certain types of foods based on their sensory preferences. For example, they may prefer bland or crunchy foods or have aversions to strong flavors or certain textures.



Individuals with autism often thrive on **routine and predictability**. They may feel more comfortable and secure when their meals are consistent and follow a set schedule. Changes in routine or new foods may cause anxiety or resistance to trying unfamiliar foods.



Some individuals with autism have a **limited range of foods** they are willing to eat, often referred to as "selective eating" or "food selectivity." They may have a strong preference for certain foods and refuse to eat others. This can lead to a restricted diet that may lack variety and essential nutrients.



Individuals with autism may **struggle with transitions**, including transitioning from one food to another. Introducing new foods or changing the presentation or preparation of familiar foods can be challenging and may require patience and support.



Some individuals with autism may engage in **sensory-based eating behaviors**, such as food rituals, repetitive chewing, or fixation on specific food items. These behaviors can serve as self-regulation strategies or provide comfort and sensory stimulation.



## Diet:



Gastrointestinal problems are very common in individuals with ASD. This includes constipation, stomach pain and diarrhea. A study found that the most common nutrient deficiencies in autistic children were folic acid, fiber, calcium, iron, zinc, as well as vitamins A, C, D, E, B6, B12, and K. Therefore, people with ASD should focus on consuming foods that are naturally higher in vitamins and minerals. This includes nutrient rich meat options such as beef, liver, fresh fruits and vegetables, eggs, fish, nuts, olive oil, dry fruit, rice and mushrooms.

Processed or “junk” foods that are less nutritious should be avoided. In some cases implementing a specialized diet such as a gluten-free/casein-free or ketogenic diet may also help to avoid health complications, depending upon the recommendation of the doctor.

# Government Support Available







## Government Support Available



### Services and financial support of Government

The eligibility towards government support through schemes and programs relies on the acquisition of the disability certificate and Special CNIC. The first step is to register with the Council on the Rights of Persons with Disabilities [CRPD] for a disability certificate. Having a disability certificate is a prerequisite for applying for the special CNIC. If you have not already acquired a disability certificate, this guide explains the process involved and things you will be required below.

### Acquisition of Disability certificate

#### Entitlements or benefits

01



**2%** employment quota

02



**40%** discount in air and railways travel.

03



Eligibility for government support services such as rehabilitation, financial support and assistive devices.



## How to apply for a disability certificate

01



Firstly, you must visit the CRPD (NARC Colony, Chak Shahzad Islamabad) for referral to a specialist doctor for initial medical assessment.

02



In Islamabad, referrals are made to the relevant doctor at the National Institute of Rehabilitation Medicine (Street# 9, G-8/2 Islamabad). The doctor will provide you with a medical assessment report for submitting at CRPD.

03



Submit the medical assessment report along with an application form for disability certificate. (Other requirements: Two passport size pictures, a copy of CNIC or B-form if a minor)

04



Once the medical assessment report is submitted, you will be given a date for visiting the CRPD in person for a Medical Assessment Board Meeting.

05



The medical assessment board is convened every 15 days, so you may plan accordingly for this process.

06



In the medical assessment board doctors medically check the person and ask the family some questions to identify the condition and its severity.

07



Upon the approval of the medical board the person is given a certificate signed by the chairman of the assessment board and the secretary of CRPD.





08



NADRA MRV may also be deployed at the CRPD to facilitate people in applying for Special CNIC on the day medical board is convened.

09



Otherwise, you may apply for the special CNIC at the nearest NADRA office as per the process described in the next section.

10



If the disability certificate is lost, an FIR must be registered for the certificate to be reissued

### What is a disability Certificate?

Currently, the CRPD certificate categorizes disability in four types; physical; visual; hearing and mental. The persons with autism are categorized under the mental disability. The severity and extent of disability is assessed during the certificate process by a medical board, which determines the type and ability of work a person can do.

## Applying for Special CNIC

### Requirements

01



Disability Certificate

02



Copy of CNIC of parents and B-form of the child.

03



For biometric verification it is compulsory to bring along parents or siblings.



## How to apply for special CNIC through NADRA Office

01



Visit the NADRA office nearest to you with the required documents mentioned above.

02



You will be given a token number for your turn to be announced at the designated desk.

03



At the designated desk your biometric verification will be done.

04



The rest of the process is the same as for general CNIC. If you need further information, contact Nadra helpline (**+92 51 111 786 100**).

## How to apply for special CNIC at home

01



In Islamabad, NADRA has launched a NADRA Bike Service for people who cannot visit the centre. The additional charge of at home service is 1000 PKR.

02



To request special CNIC registration at home, you may call the NADRA helpline on the following number **+92 51 111 786 100**

03



Your at-home booking will be confirmed once you receive a message of time and date of appointment.

04



NADRA registration officer will come to your home on the mentioned date for biometric verification

05



The registration documents will be received by the applicant through courier.



## Applying for Government support services and programs:



### Special Friends of Pakistan Bait ul Maal

Under this programme, Pakistan Bait ul Maal [PBM] provides financial and in-kind assistance to Person with Disabilities [PWDs]. A family having one member with disability can get support up to PKR. 30,000, whereas a family with more than one person with disabilities shall receive PKR. 60,000 for one year. Under this program in-kind support for wheelchairs and hearing aid is also provided. The requirements and process of application for financial assistance is explained below.

#### How to apply

01



Visit PBM district office in Islamabad (Street# 7, SectorH-8/4, Islamabad), fill in the form or write an application in the name of Managing Director PBM. You can also download the application form beforehand from the website of PBM. ([Download form here](#))

02



Attach a copy of the CNIC of your family member with the form. If the person is a minor, the B-form of the child along with a copy of the parent's CNIC must be attached.

03



Also attach the disability certificate with the form.

04



After submission you will be provided with an application number to track the progress of your request.



## Conditions

01



Provide disability certificate issued by CRPD or special CNIC

02



You can apply once a year

03



Financial assistance is provided by cross cheque only.

## Education Support

Rehabilitation centre for children with developmental disorder H-8/4 Islamabad

Children on the spectrum are provided free of cost education and therapy services at this centre. It has a dedicated autism unit, occupational therapy room and speech therapy room. The children of age group 5-14 are given admission here after going through medical and psychosocial assessment by doctors from NIRM.

If your child is able to and seeks to pursue higher education HEC has disability quota for PWDs. As per HEC guidelines, people with developmental disabilities may be given extra time in examination and computer assistance if required etc. You may read the details of government policy on for your child's higher education in detail before planning for his/her admission on the HEC [website](#).

## BISP financial support

If you have registered with CRPD, your household may also be eligible for BISP Kafalat programme. To check your eligibility SMS your CNIC to 8171. Your eligibility depends upon the assessment scores of BISP

## Medical services support

In government hospitals, the medical treatment of disabilities is covered by Pakistan Baitul Maal. The concerned doctor makes the case for facilitation of the person to PBM.



# Debunking Misconceptions about Autism





## Debunking Misconceptions about Autism



Autism is not caused by bad parenting or vaccines. It is a complex neurodevelopmental condition that has a strong genetic component. Extensive research has disproved any relationship between vaccines and autism.



People with autism do not lack empathy. Those on the spectrum experience difficulty understanding and interpreting emotions and social cues which can affect their ability to express themselves in conventional or “normal” ways.



Autism is not a temporary condition. There is no known cure for autism. However, with appropriate support, intervention, and therapies, individuals with autism can develop skills, improve their quality of life, and reach their full potential.



Autism does not prevent people from leading meaningful and fulfilling lives. With appropriate support, early intervention, education, and employment opportunities, individuals with autism can thrive and become valuable members of society.



Individuals with autism are not intellectually disabled. Intellectual disability can sometimes present itself as a comorbidity, but autism mainly affects social interactions, communication, and behavior. A lot of people who are on the spectrum have average or above-average intelligence.

It's important to promote accurate information about autism to combat misconceptions and create a more inclusive and understanding society. By understanding the realities of autism, we can provide better support and opportunities for individuals on the autism spectrum.



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# Autism Awareness Guide for Parents

Social Protection Resource Centre

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