An Introductory handbook for parents on Autism Spectrum Disorders

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An Introductory handbook for parents on Autism Spectrum Disorders

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What are Autism Spectrum Disorders?

Autism is a developmental disorder that typically becomes apparent in the first three years of life. This disorder appears as a cluster of symptoms and hence is known as Spectrum Disorder. Symptoms vary greatly from child to child. Two children with the same diagnosis may act very differently and have varying aptitudes. This disorder makes it difficult for the child to communicate verbally or non-verbally, to socially interact with others and to relate to the outside world. Many children with autism may however exhibit remarkable abilities in the area of art, music and maths.

Autism spectrum disorders (ASD's) / pervasive developmental disorders is a group of neurobiological developmental disorders i.e. they occur early in life and affect the child's development. They are pervasive i.e. they affect all aspects of an individual's life. Autism and the related variety of this group is a developmental disability that prevents individuals from properly understanding what they see, hear and otherwise sense. This disorder is characterized by an inability to:

1. Understand and use non-verbal and verbal communication
2. Understand and use social behavior which affects their ability to interact with children and adults.
3. Think and behave flexibly-which may be shown in restricted, obsessional or repetitive activities.
4. Engage in interactive and imaginative play.

Subgroups of ASD's / PDD

The umbrella term *pervasive developmental disorder* (PDD/ASD) covers a group of five developmental disabilities namely,

- Autism
- Asperger Syndrome (AS)
- Pervasive developmental disorder-not otherwise specified (PDD-NOS)
- Rett Syndrome
- Childhood disintegrative disorder

All five of these disorders share some characteristics but differ on a few parameters in terms of age of onset, regression (loss of acquired skills), severity of the disorder etc.,

What causes Autism?

The cause of Autism Spectrum Disorders (ASD's) is unknown. There is also no single established causative factor for autism. Current theory among autism research supports the idea of genetic factors. In addition to having a certain combination of autism-related genes, exposure to specific environmental factors may be necessary for autism to develop in some individuals. But, so far no one environmental agent, virus, or other toxin has been identified / proven yet to cause Autism.

Occurrence of Autism

Autism has been found throughout the world in families of all racial, ethnic, social background. It is four times common in males, than females.

At what age can Autism be identified?

It is a condition which becomes more apparent with the growth and maturity of the individual. It is not a condition that can be tested for during pregnancy or after birth because its precise cause is not yet known. Most of the children with autism show signs of the disorder by 2-3 years of age. Some children show significant signs at infancy (birth – 1 year of age) itself.

Clinical features

As a developmental disability, Autism affects children and adults, in a variety of ways and in varying degrees. Not all children show all the behaviors listed. Symptoms can vary due to the variety of characteristics and the range of severity (mild/moderate/severe) that is unique to each child. Even though children diagnosed with ASD share a common set of behavioral characteristics, no two individuals will be alike.

A. What are the early signs of ASD's?

For those children who demonstrate autistic tendencies from birth, the following signs are indicative of an ASD.

- Lack of eye contact
- Poor attention
- Lack of social smile (does not smile when smiled at)
- No desire to be picked up
- Lack of response to his/her name call.
- Ignoring people (shows no interest when people approach)
- Lack of emotional Expression (facial expression)
- Lack of babbling or meaningful gestures by 1 year of age
- Poor speech, language and communicational skills.

B. Later clinical signs

Few critical clinical signs in each skill are listed below.

Social Communication/Interaction

- Appears not to hear what has been said.
- Difficulty interacting with other children.
- Lack of interest towards others.
- Poor understanding of social rules.
- May know some social rules/concepts and apply them rigidly.
- Inability to know what others are thinking or feeling.
- Poor attachment to parents, but more difficulty in relating to other adults.
- Inability to seek comfort at times of distress.
- Preference to be aloof (seems to be in his/her "own world").
- Inability to share.

Play behavior

- Doesn't know how to play with toys.
- Gets "stuck' doing the same things over and over and can't move on to other things.
- Play may be rigid or repetitive.
- Prefers to play with selected/interested objects/toys.
- Lack of imaginative play.
- Lack of imitation of others.
- Lack of turn taking skills during play activity.
- Shows unusual attachments to toys, objects.
- Spends a lot of time lining things up or putting things in a certain order.

Sensory Issues

1. Apparent over / hyper sensitivity for
   (a) Auditory (Eg:- closing the ears for sounds)
   (b) Visual (Eg:-closing eyes while seeing lights)
   (c) Touch (Eg:- Pulls hands away when touched)

2. Apparent under / hypo sensitivity for

   a) Auditory : (Eg:- shows no reactions for sounds)
   b) Visual : - (Eg:- no reaction to approaching vehicles)
   c) Touch:- (Eg:- Lack of reactions for physical injuries)

3. Eats limited food choices and/or textures.
4. Walks on his/her toes.
5. Self-injurious behaviors.
6. Self stimulatory behaviours – (Such as hand clapping, rocking, making unusual vocal noise, making repetitive finger movements).
7. May be tolerant of very serious situations but overreacts to something minor.

Deficits/Deviances in Speech and Language skills

Comprehension (understanding) skills

- ❖ Poor in understanding of simple or complex instructions (Eg. Keep the ball on the table)
- ❖ Poor in responding for request (Eg. Give me the ball)
- ❖ Inability to answer even simple questions (Eg. What is your name?)
- ❖ Poor in understanding actions or imitating actions (gesture) related to communication (Eg. Actions for calling, giving etc.)
- ❖ Poor grasp of abstract concepts (imaginary concepts)
- ❖ Poor in understanding jokes.

Expression (Speech) skill

- No speech.
- Limited speech (use of single word utterances or short phrases)
- Speech may be present but not used for communication
- Desires or wants are communicated by leading an adult by hand to the wanted object.
- Improper use of grammar and pronouns

  Eg: Reversing "I" for "you" saying "you want water" for "I want water".
- Echolalia : Repeating words or sentences uttered by others in the same or different context. Such repetitions may be immediate or delayed or modified.

  Eg. Mother : you want milk?
Child : Yes want milk?

  The child repeats the mother's question instead of answering it albeit slight modification
- Monotonous pattern of speech. (Speech lacks in the normal pattern of rising or falling tone).

Communication and ASD:

It is not only the spoken language that is a problem for children with ASD but also non-verbal communication i.e. facial expression, tone of the voice, gestures, intonation (making appropriate variations in voice) and eye contact which is basic for communication.

Spoken language (consists of words and sentence) is abstract and has no visual representation, where as 3 D objects, pictures, symbols have strong solid visual representation. For children with ASD, it is easier to teach communication through gestures, written and then spoken words.

Find out the learning modality which is more efficient or dominant:

Visual learners: Those who rely more on stimuli through vision (visual mode) while learning. Visual learners will be good at making pictures, diagrams, graphic representations. The use of graphic softwares from computers may also help.

Auditory learners: Those who rely more on stimuli through hearing (auditory modality). These learners will be good at reciting stories and rhymes which they have been taught.

Kinesthetic learners: Those who rely more on tactile cues (through skin and touch). These learners will be good at drawing, constructing models. Each of these modality has a positive aspect that can be allowed and stimulated to flourish or progress.

The key is to find the preferred pre-dominant modality (i.e. most dominant modality) and work on strengthening it, but also try to in cooperate aspects of other modalities.

Why are these behaviours found in children with ASD?

Any form of the behaviours mentioned here are actually a means of communication used/expressed by the child with ASD i.e. these behaviours are used as a means of communication. The parent or the care giver who is with the child has to pay attention to the message the behavior conveys. The parents have to observe the situation and the child closely and try to understand the message being conveyed by the child. For eg:- The self stimulatory behavior may be distressing or embarrassing to watch but at the same time the child may be exhibiting the behavior to induce a feeling of calmness in him when he is stressed out. Hence the parent or caregiver has to understand the message

instead of asking the child to abruptly stop that particular behavior. The parents have to find out and effective way of calming down the child.

Eg: - Giving the child a "squeeze ball" whenever he flap his hand or give the child a toy which he likes.

Diagnostic evaluation and management for children and Youth with ASDs

It is important to identify children with Autism and begin appropriate management as soon as possible since such early management may help to speedup the child's overall development, reduce inappropriate behaviors, and lead to better long-term functional outcomes. If a child has been identified with developmental delays and Autism is suspected but not confirmed, it is still important to initiate appropriate early intervention/management services to address identified developmental delays as soon as possible.

Professionals representing a variety of disciplines are involved in an evaluation and treatment. The following are some of these professionals, along with a description of their role in assessment management for children and youth with ASD.

Speech-language Pathologist (SLP): SLP plays a critical role in enhancing the communication development and quality of life of children with ASD. Due to the pervasiveness of the social communication impairment, Speech Language and communication therapy is very much necessary for almost all children with ASD. A

classic characteristic of ASD is the qualitative impairment in communication. Even verbal (those who can speak) and high functioning ones still have significant deficits in the area of social communication and it calls for speech-language therapy. The aim is to provide maximum assistance to meet the communication challenges in day to day life and academic curriculum. Being able to communicate in the right manner at the right moment every day would seem to be important criteria for an educational outcome.

Audiologist: An Audiologist participates in evaluations when child's ability to hear is questioned/doubted.

Occupational therapist: Since children with Autism lack some of the basic and social and personal skills required for independent living, occupational therapists have developed techniques to work on them. (i.e. developing skills for handwriting, short button, shoe tying etc) and also provide training for the child in Sensory Integration (li.e. responding to information coming through senses). The intervention techniques may include swinging, brushing, playing in a ball pit etc. Hence this sensory processing disorder or dysfunction is treated with sensory integration.

Clinical Psychologists: Clinical Psychologists assess intellectual ability, behavior and personality characteristics, social behavior, academic achievement level, self help skills, perceptual and neurological strengths and weaknesses. To gather the necessary data, they use tests, parent and child interview, and direct observation.

Pediatrician: The Pediatrician is faced with the challenging task of suspecting an ASD diagnosis and making an immediate referal to either an SLP or OT.

Neurologist: Neurologists have an important role not only in the early recognition but also in the management of conditions associated with autism such as : -

- Seizures or epileptic attacks
- Sleep disturbance
- Hyperactivity (extreme hyperactivity)
-

Dietitian: Since most of the autistic children have nutritional deficiencies, food intolerance or gastro-intestinal disorders, the role of the dietitian is also important during rehabilitation. The goal of proper nutrition in Autism is to support the structure and function of child's brain and body to perform at his optimal level and to maximize the child's responses.

Psychiatrists: Psychiatrists are concerned with prescribing medication for children with Autism.

Special Educators: Special Educators mainly focus on testing academic strengths, identifying weaknesses and conditions under which learning is best achieved and management for the same. For this purpose, educator assesses the present level of ability and should identify the strengths & deficits, i.e. what the child can and cannot do. In what skills the child excels!! In the long run what skills are needed to seek employment and live in the community comfortably in adulthood.

Family members: Family members play an important role through out the child's life. Being a keen observer, parents are the first members to identify the abnormal / problem behaviors and enroll themselves in the entire treatment program offered by all the professionals for (re) habilitation/management.

Periodic in-depth reassessment

In making a decision either to start or change a specific intervention program for a child with Autism, it is recommended that periodic in-depth re-assessment of the child's progress and developmental status be done at least once every six months. Continuous monitoring however is necessary.

Teaching to communicate

- Be sensitive to the attempt to communicate and set up situations to encourage it.

  Eg:- Keep toys on a high shelf or behind a glass door, so that the child has to ask through either eye-gazing or pointing or vocalizing.

- Use speech economically i.e. simplify instructions
  - Use short sentences
  - Let the instructions be direct
  - Give adequate time to respond

  Eg:- Make your instructions clear – use concrete concepts

  i.e. Say we are going to the park – instead of asking questions like Do you want to go to the park?

Training for Communication:

The first stage of the child's training is to establish eye to eye contact as these children spend much of their time staring at walls, ceiling and their hands and often avoid looking at people.

- The parents can simply encourage (reinforce) the child whenever he makes eye contact.
- Eg: (a) The parent is required to hold up a bit of child's favourite sweet / meal at his/her (parent's) eye level and wait till the child makes eye contact.

(b) As soon as the child makes eye contact he/she should immediately praise, hug or pat the child and bite of food should be given to the child as encouragement for his action.

(c) If the child does not look at the parent, the parent should prompt the child by moving the food towards the eyes.

Pl. Note: When the child's eye contact improves, this activity can be faded out or discontinued.

Now the parent should be the prompt "look here", "look at me" and try to get the child's eye contact.

If the child makes eye contact, encourage the child as before

Simple manipulation tasks:

The parents can work on simple manipulative tasks:

- Stacking blocks
- Matching
- Sorting and arranging various coloured beads
- Solving simple puzzles.

Such tasks are included to increase the concentration of the child and teaching the child to attend to a particular task for a specified duration. Here the child gradually is made aware of the concepts, colour, size and shapes etc.,

Speech-language / training:

One of the first tasks in Speech Language training is to teach the child to at least respond nonverbally (i.e. by head nodding and head turning) especially for children who have not acquired speech at all.

Teach the child to imitate simple behavior like

(i) Raising the arm

(ii) Placing the hand on the table

- gradually try more fine behaviours like facial expression.

Pl. Note : Nonverbal imitation is taught first as it is easier than verbal imitation.

- Once the child has made a beginning in non-verbal imitation, try verbal prompts as shown in the fig.

Pl. Note : For a child with a little verbal out put or speech, try to get responses through verbal imitation.

Encourage the child for every spontaneous vocalization made.

Follow the steps given below:

(1) The child and parent should sit across the table with parent holding a bite of food item preferred by the child as his/her mouth level. This is only to draw attention to the child to the parent's mouths.

(2) Only when the child is looking at the parent's mouth, the parent should utter slowly and clearly the found that the child is to imitate.

(3) Wait for sometime:- If the child does not respond then lower the food, wait and after some time hold-up the food and repeat the same steps.

(4) The parent should prompt vocalization by touching the child's cheek, mouth/lips etc. so that some vocalization is elicited.

(5) Finally, when the child produces the sound, the parent should immediately reciprocate by praising and giving tangible item (like food, chocolate etc.)

(6) Gradually as the child produces the sound the parent should fade the prompt.

Pl. Note: Each step may take a very long time to achieve, and differ from child to child – Hence the parents should try it out with patience.

Labelling: Learning the names of the things are taught initially to develop functional speech.

The parent should teach the child to associate a particular word with a particular set up stimuli.

Generally the following steps are used to accomplish the tasks:

(1) Holding the object or picture

(2) Waiting & Prompting the child to look at the picture/object

(3) Asking the child to name the object – prompting with correct answer

(4) Rewarding the child when the prompt is imitated correctly

(5) Fading out the prompt, when the child gives the answer / responds

Eg:- Child : No response (remains silent)

Parent : What do you………. Want?

Child : B……..Ba…………

Parent: Ball

Child : No response

Parent : You want Ball?

Child : Ball –

Parent : Look here! …. Say……… I want…………

Child : I…………

Parent : I want Ball

Child: I ………. Want………

Parent: I want Ball

Child : I want…… Ball

Parent : Very Good !!! Here is the Ball.

Once such expressions are learnt … the parent should stimulate the child in different situations at home and try to elicit more and more speech through active interaction.

Pl. Note: The duration of teaching such expression varies with each individual child depending upon the severity of the disorder and other associated behavior etc.

Parental training / home training is of immense importance for the child's progress. The parents who have already observed speech-language therapy have to imbibe/incorporate all the suggestions/techniques seen or observed during therapy at home devote more time for more and more interaction and communication with child at home.

Apart from regular speech-language therapy and intensive home training, other alternative therapies may prove beneficial for over all development of the child. Some of them are:

Music Therapy: Music is used to facilitate positive change in human behavior. The child with ASD will show heightened interest and response to music as music is motivating and provides relaxation and self expression.

Yoga therapy: Yoga is an ancient act and science that aims for high level wellness of Physical, mental and spiritual. Yogic exercise may increase overall health and facilitate body awareness and concentration.

Whatever may the lines of treatment, all together should focus on improving quality of life in children with ASD.

The parents can also browse internet to get additional information about ASD.

Autism and Computers:

A vast number of children with ASD like Computers and are motivated by its use. Computers use visual images and are highly motivating for such children. But the level of the programs chosen should be on individual basis and suit each individual's ability.

Progress of children / individual's with ASD?

Progress of children / individual's with ASD depend on many factors namely, age of identification of the condition, severity of clinical symptoms, intellectual ability, age at which intervention is started, etc. The most important aspect is the involvement of family members in understanding and training the children with individual requirements.

It is true that teaching an autistic child can be difficult. It takes a lot of hard work, patience and significant understanding of the specific needs of the child and teaching methods that will be most beneficial to the child.

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