

The Face of Autism

Segment I – Discovering Patterns

What is Autism?

Autism is a neurological disorder that affects how the brain functions. Autism may have various causes, and is a lifelong disability characterized by difficulties with social interaction skills and communication skills, as well as restricted or unusual patterns of interests and behaviors.

The degree of autism varies with an individual's age and developmental level. We know, however, that with a comprehensive intervention program and good support at home, most individuals with autism can improve. How far an individual can progress depends upon a variety of factors, including whether or not he or she also has intellectual disability or other conditions in addition to autism.

What Does Autism Look Like?

Autism is considered a *spectrum disorder*. That means that a variety of symptoms and characteristics are associated with this disorder, and can be expressed in a variety of combinations or levels of severity. The expression of autism may also change over the course of an individual's lifetime, and may or may not co-exist with other conditions.

Certain "classic" symptoms have been recognized in association with autism. These include stereotypical or unusual movements and behaviors, such as hand flapping, rocking, spinning, etc., interaction with people or objects in unusual ways, and an unusual persistence for following certain routines. In some cases, individuals may be aggressive or inclined to injure themselves.

Today, however, we are seeing less of these "classic" characteristics, and more of children who exhibit a milder range of symptoms.

In other words two children, each with a diagnosis of autism, can be very different from one another.

The Diagnostic Detective

There are no actual medical tests to determine the presence of autism. But while it is not as easy to diagnose as a medical condition, there are clear indicators, which can help with the diagnosis.

A diagnostician will look for a collection of symptoms, or characteristics, in three areas.

Developmental Disabilities: Faces, Patterns Possibilities

"Hallmarks" of Autism:

- Difficulties with social interaction
- Difficulties with communication
- Restricted, stereotyped or repetitive interests and behaviors

In some cases, early symptoms may include a lack of response to other people and a marked preference for passive, solitary activities. Some affected children may not make eye contact with others, and may avoid physical contact.

In other cases, delays in speech and in play skills are the characteristics parents often notice first. Many toddlers who are later diagnosed with autism are physically affectionate toward immediate family members, but some do not express affection or attachment in typical ways. Some children may even appear clingy with parents.

In some individuals with autism, responses to sounds and visual stimuli are unusual, ranging from seeming indifference to intense emotional outbursts.

Hyperactivity is common. Temper tantrums may occur if the child feels confused or is prevented from the pursuit of some activity.

There may also be a delay in the development of language skills. When speech does develop, it is often characterized by the repetition of another person's words or phrases, and lack of what we call pragmatic language, which is the social use of language to communicate with others.

Some children with autism have great difficulty learning to read and write; while many others read easily, but lack more functional skills. And still others exhibit extraordinary ability in music, mathematics or rote memory.

As you can see, autism is a complex and often puzzling disability. That is why we diagnose it best by a combination of observation, interview and history.

This multidisciplinary approach should include reports from the parents, observations of the child and his/her interactions, and clinical judgment, informed by cognitive, adaptive behavior and diagnostic assessments which collectively answer such questions as:

Does the Child Have Difficulty With:

- Social interaction/peer relationships?
- Sharing his/her enjoyment or interests with others?
- Eye contact? Understanding facial expressions?
- Understanding and expressing feelings?
- Communication?
- Is there impaired speech?
- Is there repetitive use of language or idiosyncratic language?
- Is there a need for routines or rituals?
- Does the child exhibit hand or finger flapping or twisting?

Developmental Disabilities: Faces, Patterns Possibilities

- Is the child preoccupied with parts of objects?
- Does the child pretend? Point to things to express interest?

What Are the Effects?

Autism impacts the ability to integrate information, so a child's ability to conceptualize and interpret can be diminished. There are also clear social deficits, such as:

- Limited desire to please others
- Limited response to social reinforcers
- Limited "incidental" learning by imitating adults/peers
- Limited drive to follow group norms

Difficulty with non-verbal communication means the individual:

- Has difficulty understanding facial cues or warnings of displeasure, and thus can appear to be defiant
- Often ignores pointing and other hand signals or head shakes designed to control behavior

In terms of play and exploring his/her environment, the autistic child shows characteristics such as:

- Lack of imagination in play
- Limited re-enactment of others' behavior and activities through play
- Stereotyped and repetitive interests
- In some cases, limited curiosity about other people, or things typical children are most curious about
- In some cases, limited learning through exploration

Segment II – Class Dis-Mythed...Focus on Facts

What Autism is Not

Because children with autism exhibit such a range of abilities and symptoms, and because they may also have other disorders, a number of myths have grown up around autism.

Let's Dis-myth Them

- Autism is not intellectual disability, even though many children with autism do have intellectual disability. A third of children with autism also have epilepsy. In fact, people with autism may have very good cognitive skills - in other words, a normal or above normal IQ - but are very challenged in their ability to use them in ways that typical children do.

Developmental Disabilities: Faces, Patterns Possibilities

- Autism is not a mental illness. Some children and adults with autism may develop mental health problems, however, which can be responsive to proper diagnosis and treatment by a mental health professional, and psychotropic medications where appropriate.
- Children with autism are not simply children who misbehave, or are spoiled or undisciplined. Behavior problems, which are frequently exhibited, may be caused by difficulty in communicating, a lack of social skills, and/or difficulty coping with the amount of stimulation in the environment.
- Autism is not caused by insufficient attention or affection, "coldness" on the part of the parents, or other psychosocial dynamics within the family environment. This once widely-held belief has been proven to be untrue.

Segment III – Exploring the Unknown

What Are the Causes?

Much about autism is still a mystery. But here's some of what we do know:

- Autism is an organic brain disorder.
- The symptoms are the result of a disorder of the central nervous system, which in turn may have multiple causes.
- We know that there are genetic factors.
- Certain viruses are known to be associated with autism.
- Several of the issues in autism can be traced to the central nervous system's lack of ability to integrate and respond to sensory input.
- There are no known factors in the psychological environment of the child that can cause autism.

What is the Incidence?

Anybody can be born with autism. It is found throughout the world, in families of all racial, ethnic and social backgrounds. Boys are affected four times more frequently than girls are. Recent studies suggest that autism *spectrum* disorders may now affect 1 in 88 children. Autism spectrum disorders include Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified, in the terms of the diagnostic manual in use through 2012 (the Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR).

Can It Be Prevented?

The best means of prevention that we know about at this time is to prevent certain disorders which have been associated with the development of autism, such as congenital rubella, traumatic brain injury, and infectious disorders. For example, taking safety measures such as use of seat belts, car seats, and bicycle helmets to prevent brain injury, having children immunized against infectious diseases, or getting early

Developmental Disabilities: Faces, Patterns Possibilities

treatment for these conditions might prevent some cases of autism from occurring. There is also secondary prevention-which means minimizing the effects of an existing condition - and this can best be accomplished through early identification and treatment.

Related Disorders

Autism is a form of PDD, in the terms of the DSM-IV-TR. PDD stands for pervasive developmental disorders, and children with PDD have some or all of these three features in common:

Social deficits - difficulty forming everyday relationships with people in their lives

Communication problems - trouble communicating both with and without words, and not being able to take part in imaginative play.

Limited interests and activities - children may repeat the same body movement over and over; become very upset about minor changes in their environment; may want to follow exact routines; and display unusual fascination with seemingly ordinary objects.

In addition to Autistic Disorder, these are other types of PDD, in the terms of the DSM-IV-TR:

Asperger's Disorder is a neuropsychiatric disorder. The major symptom is the patient's inability to understand how to interact socially. Other features include restricted or highly unusual interests, repetitive behaviors, or insistence on routines or rituals.

Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS). This is diagnosed when a child has a severe impairment in social skills, as well as impairment in communication and/ or a restricted range of interests and activities, but the symptoms do not fulfill the requirements for a diagnosis of other types of PDD.

Segment IV – Reaching Beyond Syndromes to Treatment

Autism is amenable to treatment. It requires intense involvement on the part of family and teachers, and it's very important to start interventions as early as possible and individualize the services to the child. Treatments should focus on systematic, continuous, organized teaching and a specialized curriculum that focuses on developing the child's ability to pay attention to other people, to imitate others, to communicate, to play, and to socially interact with others. To be effective, a treatment must allow for the unique characteristics of the individual being treated (e.g., developmental functioning, strengths, and challenges), and the needs of the individual's family or home environment.

Children with autism are unique in their needs and in the types of treatment that will help. They learn in complex ways that may change as they develop. What works for one child may not be good for another. The most successful approach is the one most tailored to the individual child's needs.

Developmental Disabilities: Faces, Patterns Possibilities

Children with autism are trying their best to adapt to an environment they don't always understand. Their reactions to that environment may be inappropriate or maladaptive. It is imperative, therefore, to teach the child to use socially acceptable ways to meet his or her needs.

The child with autism benefits most from learning opportunities that occur across all environments - home, school and community. Parental involvement is important to ensure that the behavioral and educational outcomes, goals and strategies most important to the family are addressed in the intervention. Parents also play a critical role by providing instruction in the home. For this reason, they should be trained to use methods which are consistent with any specialized training approach being used by professionals, so that they can support their child's learning over time.

Early Intensive Individualized Teaching

Early developmental intervention and comprehensive educational programs are the foundation of services for the child with autism. There is no cure for autism, but substantial evidence indicates that early, intensive, individualized education can enable the child to develop better social relationships, learn better communication skills, and lessen inappropriate behaviors.

Common Elements

Studies have identified common elements of model intervention programs for preschool children. The following characteristics appear to be associated with better outcomes:

- Intervention is started as early as possible in the life of the child, and the services are intensive.
- Services are individualized - tailored to the child's developmental and behavioral needs- and are responsive to the family's needs and resources.
- Services promote family involvement in the development and implementation of the intervention plan.
- The curriculum stresses the ability to pay attention to other people, to imitate others, to communicate, to play, and to socially interact.
- The teaching environment is highly supportive of the child's learning needs and involves systematic teaching of skills, with a very low child-to-staff ratio.
- Intervention utilizes predictability and routine.
- The teaching schedule allows children to spend a large amount of time in learning activities.
- The treatment utilizes a functional approach to problem behaviors, and strategies for generalization of learning.
- Behaviors that are the target of interventions have been clearly identified and defined with developmentally appropriate measures of mastery.
- There is coordination and collaboration among all individuals working with child and family, and a plan for transition from the specialized preschool setting.

Developmental Disabilities: Faces, Patterns Possibilities

Differences In Programs For Children Under 3 Years of Age

- Services are more likely to be provided in the home.
- Teaching is more likely to occur within the child's normal routine.
- Parents and caregivers play a greater therapeutic or instructional role.
- There are fewer hours of intervention per week and shorter sessions.

Applied Behavior Analysis

Applied Behavior Analysis (ABA) uses psychological principles of behavior to shape behavioral responses and decrease problem behaviors. It focuses on how behaviors are formed in the first place, what purpose they serve for the child, and how people's reactions to a child's behaviors can make the behaviors more – or less - likely to occur again in the future. Skills and behaviors are broken down into small steps and taught using positive reinforcement and prompts. Parents, child-care providers, and teachers should undergo training so that behavioral strategies will be consistently implemented in all environments. Behavioral approaches range from more directive to more naturalistic instruction styles.

Discrete Trial Teaching

Discrete Trial Teaching (DTT) is a specific ABA teaching approach using applied behavior analysis. It is designed to develop targeted skills. In a discrete (short, defined) trial, the teacher presents an antecedent, such as an instruction, the child responds, and the teacher presents an appropriate consequence. For example, a teacher shows the child a picture and gives a reinforcer when the child names the picture correctly. The teacher prompts the child as needed, fading the prompts when possible. Any teaching session consists of multiple discrete trials. The skills or behaviors being taught are broken down into small, sequenced tasks. There is a prescribed teaching structure and sequenced curriculum. The training is intensive, and usually one-on-one with the child. The teacher uses a high level of positive reinforcement.

Pivotal Response Training

Naturalistic approaches attempt to use antecedent stimuli and reinforcers that are related to the child's usual environment and everyday activities, and are patterned after the procedures by which typical children learn. Pivotal Response Training is a naturalistic behavioral teaching technique, in which the natural environment is arranged by the therapist to allow for multiple opportunities for the child to practice a desired behavior.

Teaching follows the interest, lead, and choice of the child and is based on behavioral principles. The intervention takes place in the child's home, school, park, and other natural environments and the focus is on teaching functional skills. Pivotal Response Training goes beyond targeting a single behavior, and focuses on a set of specific procedures to increase responsiveness to multiple stimuli, thereby potentially influencing a large number of individual behaviors. Milieu Teaching and Natural Language Paradigm are other examples of naturalistic teaching techniques.

Developmental Disabilities: Faces, Patterns Possibilities

Developmental, Relationship-Based Approach

This comprehensive intervention approach is relationship-based. The focus is on opportunities for spontaneous relating, including interactive play between the adult and child. It is sometimes informally referred to as "floor time" because it includes a component that encourages the therapist and parent to spend a great deal of time on the floor interacting with the child. The goals include helping the child learn to attend, relate, interact, engage in two-way purposeful interactions using nonverbal or verbal communication, and, if the child is ready, to use words and ideas in creative and logical ways. To do this, the adult follows the child's lead, and interacts with the child in activities which the child chooses. The adult uses "gentle obstruction" to turn the child's avoidance or withdrawal into interactions, and gradually encourages more complex and purposeful interactions.

TEACCH: Treatment and Education of Autistic and Related Communication-Handicapped Children

TEACCH is a broad intervention program, which originated in North Carolina. The philosophy is to focus on the individual with autism and design a program around that person's interests, skills, and needs. A primary aspect of TEACCH is called structured teaching. This is an attempt to teach in an environment that is more comfortable so individuals with autism can understand expectations. The classroom is organized to provide the student with clear visual cues about what he/she needs to do, and to limit distracting details. There is an emphasis on schedules, work systems, and using visual materials. Tasks incorporate concrete visual cues. These techniques help to make expectations clear and allow an individual with autism to independently engage in tasks with less adult intervention.

Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) is an augmentative communication system, which helps children acquire functional communication skills. The goal of PECS is to teach children how to initiate communication and to express their needs. Children are taught to give a picture of a desired item to a "communication partner" (usually an adult) in exchange for the item. Nonverbal children who learn to use PECS often later develop oral speech.

Additional Therapies

Speech Therapy

Speech therapists help to determine the best system of communication and the most appropriate communication goals for the child at any given time, in coordination with an overall intervention program. They also focus on any specific physical difficulties, which interfere with the child's ability to produce clear speech.

Occupational Therapy

Occupational therapy using sensory integration techniques is commonly used for children with autism who have difficulties because they are under-reactive or over-

Developmental Disabilities: Faces, Patterns Possibilities

reactive to sensory input such as sound or touch. The goal is to help the child be able to be calmer, and therefore more attentive and able to learn.

Medication

Though medication does not cure autism, it can be helpful when used in combination with developmental, educational and behavioral interventions, in the management of behaviors such as aggression, obsessive-compulsive behaviors, self-injurious behaviors, attention deficit/hyperactivity and anxiety.

Segment VI – Understanding People, Exploring Possibilities

We know that, among individuals with autism, there is a wide range of levels of impairment, and that this does have an impact on how far the individual can progress. However, we also know that with early diagnosis, appropriate intervention, education and support, individuals with autism are able to progress and develop.

Individuals of all ages are able to become active participants in their community, with varying levels of support as needed. Children attend schools and participate in social recreational activities in their communities, which help them to develop their skills and to form positive relationships with others. As adults they may attend college or become employed, live independently, use public transportation or drive cars. The range of possibilities is becoming wider and more promising every day.

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