Frequently Asked Questions on Autism

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What is Autism?

Autism is a neurobiological disorder that typically appears during the first three years of life. It is a spectrum disorder that can take several forms and is estimated to affect 1 out of 166 children. Individuals with autism demonstrate characteristics in three areas:

- Difficulty forming social relationships
- Impaired understanding and use of language
- Restricted patterns of activities and interests

Although all three features must be present for a diagnosis of autism, the specific behaviours exhibited can vary widely from person to person. Autism is considered a spectrum disorder because the symptoms and characteristics can be present in different combinations and at different levels of severity.

The disorders on the autism spectrum are:

- Autistic Disorder
- Asperger's Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

What is Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)?

The term "Pervasive Developmental Disorder Not Otherwise Specified" (abbreviated PDD-NOS) refers to a type of diagnosis found in the Manual of the American Psychiatric Association that doctors use to identify a disorder. This Manual (Diagnostic and Statistical Manual of Mental Disorders, abbreviated as DSM) is updated periodically to keep up with research. The most recent version was published in 2000.

In the DSM Manual, PDD-NOS is one of several types of diagnoses within the general area of Pervasive Developmental Disorders. Other diagnoses within Pervasive Developmental Disorders include Autistic Disorder and Asperger's Syndrome. The category of Pervasive Developmental Disorders describes individuals who show atypical development in three areas: (a) reciprocal social interactions, (b) verbal communication (spoken) and nonverbal communication (for example, gestures), and (c) repetitive behaviours (for example, rocking, hand-flapping), interests or activities. The specific types of diagnoses within this category differ from one another in age at which they begin, how severe and the course of the symptoms. These classifications can be used to diagnose children as well as teenagers and adults.

PDD-NOS is a diagnosis of exclusion. This means it is used only when a person's symptoms do not fit the criteria for one of the other Pervasive Developmental Disorders. PDD-NOS is used for individuals who show impairment in the development of reciprocal social interactions along with either an impairment in the development of reciprocal social communication or a pattern of repetitive behaviour, interests and activities (and who do not meet the diagnostic criteria for one of the other classifications within the category of Pervasive Developmental Disorders. For example, some individuals may receive a diagnosis of PDD-NOS rather than Autistic Disorder if they do not show all of the symptoms required for a diagnosis of Autistic Disorder of if their symptoms are milder in nature. The diagnostic criteria used for PDD-NOS are much less precise than those for the other diagnostic classifications within the category of Pervasive Developmental Disorders.

Because the diagnostic criteria for PDD-NOS are less specific than those for Autistic Disorder, there has been less research on it and less is known about the nature and course of PDD-NOS. In some cases, parents of children diagnosed with PDD-NOS may benefit from reading information on Autistic Disorder. Often the difference between Autistic Disorder and PDD-NOS is subtle and professionals do not always agree on where to draw the line between them. Because individuals in both groups of diagnoses share some similar features, they often require similar kinds of educational intervention. For example, taking part in early intervention programs is usually strongly recommended for children with PDD-NOS or Autistic Disorder.

What are recommended practices for the screening and diagnosis of autism?

In an effort to promote best practices, including early identification, the American Academy of Neurology and the Child Neurology Society recently published a set of Practice Parameters for the screening and diagnosis of children with autism (Filipek et al., 2000). These guidelines were drafted by a multidisciplinary panel of autism specialists led by Dr. Pauline Filipek, a child neurologist and autism researcher at the University of California at Irvine. The panel consisted of professionals in the fields of paediatrics, psychiatry, neurology, psychology, speech-language pathology, audiology and occupational therapy. Wendy Stone, TRIAD director, was invited to participate on this panel as a representative of the American Psychological Association.

The Practice Parameters were developed and refined during a 2-year process that began with an NIH-sponsored conference on the State of the Science in Autism in June 1998 and was followed by a focused working meeting in January 1999. In addition to publication of the Practice Parameters, the work of this panel also led to publication of a background paper on screening and diagnosis of autism spectrum disorders (Filipek et al., 1999).

The Practice Parameters establish firm guidelines for best practices in the screening and diagnosis of children with autism. Both empirically-based and consensus-based recommendations are provided. Highlights of the recommendations are:

- **During each well-child visit from infancy through school-age, children should receive routine developmental surveillance for atypical development.** Surveillance should include observing the child, eliciting parental concerns and probing for age-appropriate skills in each developmental area.

- **Failure to attain the following language milestones is associated with a high probability of a developmental disability and requires referral for further evaluation:**

  - No babbling by 12 months
  - No gesturing by 12 months
  - No single words by 16 months
  - No spontaneous 2-word phrases by 24 months

- **Autism-specific screening should be performed on all children failing the routine developmental surveillance and all siblings of children with autism.**
  The need for the development of additional screening measures was noted, as was the tendency of current measures to miss milder variants of autism.

- **The formal diagnosis of autism should be made by clinicians experienced in the diagnosis and treatment of autism.**
  Evaluation and monitoring of children with autism requires a comprehensive, multidisciplinary approach that includes medical and neurologic evaluation, cognitive assessment, and speech-language-communication assessment.

- **Audiologic assessment and lead screening are recommended for any child with developmental delay and/or autism.**

- **Genetic, metabolic, and EEG studies are indicated for some children with autism who display specific clinical indicators.**
  In contrast, event-related potentials and neuro-imaging are considered to be research tools rather than clinical tools at the current time.

By the time of publication, the Practice Parameters had received endorsements from professional organizations, including the American Academy of Audiology, the American Occupational Therapy Association, the American Psychological Association, the American Speech-Language-Hearing Association and the Society for Developmental Paediatrics, as well as autism organizations, including the Autism National Committee, Cure Autism Now and the National Alliance for Autism Research.

The full text of the Practice Parameters is available on the website of the American Academy of Neurology (http://www.aan.com).

References :

Filipek, P.A., Accardo, P.J., Ashwal, S., Baranek, G.T., Cook, E.H., Dawson, G., Gordon, B., Gravel, H., Johnson, C.P., Kallen, R.J., Levy, S.E., Minshew, N.J., Ozonoff, S., Prizant, B.M., Rapin, I., Rogers, S.J., Stone, W.L., Teplin, S.W., Tuchman, R.F., & Volkmar, F.R. (2000). Practice parameter: Screening and diagnosis of autism: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. Neurology, 55, 468-479.

Filipek, P.A., Accardo, P.J., Baranek, G.T., Cook, E.H., Dawson, G., Gordon, B., Gravel, H., Johnson, C.P., Kallen, R.J., Levy, S.E., Minshew, N.J., Ozonoff, S., Prizant, B.M., Rapin, I., Rogers, S.J., Stone, W.L., Teplin, S.W., Tuchman, R.F., & Volkmar, F.R. (1999). The screening and diagnosis of autism spectrum disorders. Journal of Autism and Developmental Disorders, 29, 437-482.

What are recommended practices in early intervention for children with autism disorders?

TRIAD is committed to promoting the development and use of empirically validated approaches for educating young children with autism. At the present time, there is no scientific evidence demonstrating that one type of early intervention is superior to another. Children with autism who participate in a variety of different early intervention programs that are structured, specialized and consistent with “best practices” can show dramatic improvements in their skills and behaviours.

Best practices for teaching children with autism

1. A variety of Applied Behaviour Analysis (ABA) techniques are effective in improving the behaviours and skills of young children with autism. Examples of ABA techniques include discrete trial training, structured teaching and incidental teaching. Each technique has strengths and weaknesses. TRIAD recommends an integrated approach toward early intervention that combines the strongest elements of each approach.

2. There are no definitive scientific data regarding the optimal number of hours of intervention that should be provided per week. However, based on reviews of the literature, TRIAD recommends that young children with autism receive about 20 to 25 hours per week of "directed intervention," which is time spent engaged in productive activity. Directed intervention may be provided in individual or group formats, at home or in school, by parents or professionals.

3. Intervention programming in the areas of socialization, communication, imitation, play and kindergarten readiness skills is recommended for most young children with autism. For each child, specific goals should be developed on the basis of individualized assessment information.

4. Speech-language-communication therapy is an important adjunct to other educational interventions for children with autism due to the communication deficits inherent to the disorder. Occupational therapy is also valuable for many children with autism.

5. It is critical that all intervention programs for children with autism be designed to promote the generalization of acquired skills to different people, to different materials and to different settings.

A compilation of best practices for educating young children with autism:

- Enrolling children in intervention at young ages.
- Encouraging family involvement in assessment and intervention.
- Using assessment information to develop intervention goals and providing individualized programming.
- Using a comprehensive curriculum and a variety of integrated intervention strategies.
- Employing a systematic and planned approach to teaching.
- Conducting periodic monitoring of progress and reassessment of goals.
- Providing specialized, developmentally based programming in the areas of imitation, language and communication, initiative and choice-making, smooth transitions between activities.
- Providing teaching activities to foster attention to and active engagement with the environment, initiative and choice making, smooth transitions between activities.
- Providing a structured and supportive teaching environment, establishing routines and predictability.

- Programming for generalization of skills to other settings.
- Employing a functional, proactive, positive approach to problematic behaviours.
- Providing regular and planned opportunities for interaction with typically developing peers.
- Preparing children for transitions to future educational settings.

—Wendy Stone, TRIAD director, April 2000

Can you recognize the early signs of autism?

Recent research has indicated that children with autism can be diagnosed accurately at the age of 2 years. In addition, studies of early intervention have revealed that children with autism can make significant—and sometimes dramatic—gains in cognitive, social, behavioural, and language functioning when they take part in appropriately specialized programs. These recent findings highlight the importance of recognizing the early signs of autism.

"Red Flags" for Autism in 2-Year-Olds
Information gained from parental reports as well as observational studies has shed some light on early behaviours that may be considered as "red flags" - follow link (http://kc.vanderbilt.edu/kennedy/triad/autism.html#3) for a list. These behaviours have been found to differentiate 2-year-old children with autism from children without autism functioning at comparable developmental levels. Although any one behaviour on this list is not necessarily indicative of autism, this diagnosis should be considered in 2-year-old children who demonstrate a pattern of deficits in social relating, communication, and restricted and repetitive play.

Challenges of Diagnosis
Autism can be difficult to identify in very young children because the characteristics that are most apparent at young ages reflect the absence of expected social and communicative behaviours, rather than the presence of unusual behaviours. For example, it is much more difficult to notice the absence of imitation than the presence of hand-flapping, though imitation appears to be more important for early diagnosis. Although many people think of children with autism as engaging in unusual behaviours such as flapping or rocking, these behaviours are not always present in young children, whereas social and communication deficits are universal. Another challenge associated with making an early diagnosis is that children with autism typically do not demonstrate a total absence of social and communicative behaviours. Rather, they display these behaviours less consistently—and their parents have to exert a great deal more energy to elicit them compared with other children.

—Wendy Stone, TRIAD director

How Can Parents Evaluate Different Treatment Options for Children with Autism Spectrum Disorders?

The following suggestions have been compiled from a variety of sources, including the articles referenced below. The purpose of these suggestions is to help parents evaluate different treatment options, not to promote any specific form of treatment.

Considerations for Evaluating Specific Treatments

Questions to Ask:	Things to think about:
Which behaviour(s) does it model?	Are these behaviours problematic for my child?
What positive effects should I expect?	How will I know whether the treatment is working?
How will the therapist assess the effectiveness of the treatment?	How often will I be given progress reports?
How long do I have to stay involved before I can expect to see any effects?	Do I have the resources to stick with this treatment?
Are there any side effects?	Can this treatment be physically or psychologically harmful?
What is the cost?	Can I afford this treatment? Will participation in this treatment mean we will have to drop other treatments?
How much time does it take per week?	Can I devote the required time? Is the treatment compatible with my child?
Is there scientific validation for this treatment?	What do professionals think about the pros and cons of this treatment?
Who has used this treatment before and what do they sat about it? (pros and cons)	What kind of experiences have other parents had with this treatment?
What training and qualifications are needed to provide this treatment?	Does this therapist have the appropriate training and/or credentials
Does the therapist belong to a professional organization	Can the therapist be held accountable to a professional code of ethics
What role do parents play in this treatment?	Will I be taught the skills necessary to help my child?
How are the challenging behaviours handled?	Is there a plan for preventing the occurrence of problematic behaviours?

Be cautious about any treatment that:

- Offers a cure for autism
- Promises to be effective for all children
- Claims to improve all of the symptoms of autism
- Requires you to suspend your belief system and adopt theirs (for example, asks you to "believe" in things that don't make common sense, or tells you that the treatment won't work unless you believe in it)
- Consists of a general package or predetermined curriculum that is not tailored to the needs of the individual child
- Does not provide routine and periodic assessments of the child's progress and the treatment's effectiveness
- Claims to be the best treatment for your child or the only treatment your child needs

References:
Autism Society of America. (1997). *Guidelines for Theory and Practice*. Available from ASA website (http://www.autism-society.org/site/PageServer).

What is Applied Behavior Analysis (ABA)?

"ABA" is an abbreviation for Applied Behaviour Analysis, which refers to a variety of systematic approaches and strategies for increasing desired behaviours and skills and decreasing undesired behaviours. ABA approaches include discrete trial training, pivotal response training, incidental teaching, functional communication training, and structured teaching. All of these strategies can be useful in working with children with autism -- as well as children without autism.

Many people think that ABA refers to a name brand therapy, such as that used by Lovaas, or that it refers to a 40 hour per week program, or that it was developed specifically for children with autism. These are all misconceptions. There are many types of ABA strategies and approaches, and the specific combination of techniques to be used should be determined after evaluating the child and identifying his or her strengths, needs, and learning style.

It is not TRIAD's policy to advocate one therapy approach over another, because all children are different and treatments need to be individualized. According to best practice guidelines, ABA therapy can be an important part of the 20-25 hours per week of intervention recommended for children with autism. However, it is not the only appropriate therapy for these children. For example, speech-language therapy

is another critical component of intervention programs for children with autism. We encourage families to seek out a combination of intervention approaches that represents the best fit for the child and the family.

Additional information about appropriate components of educational programs for children with autism can be found in the book, Educating Children with Autism, published by the National Academies Press in 2001. The text can be viewed online at http://www.nap.edu/.