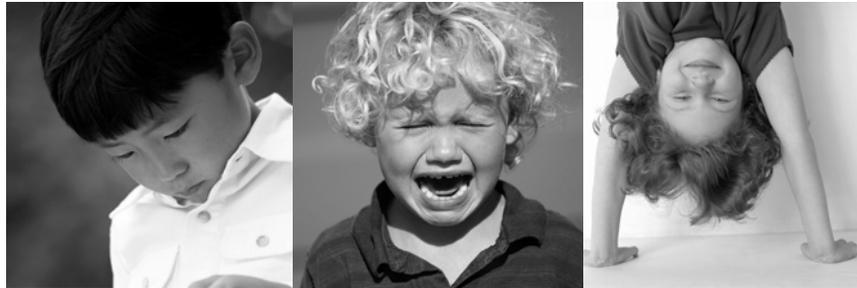


A Guide to Choosing Interventions for Children with Autism Spectrum Disorders



With so many intervention options available for children with autism, it is often hard to know which one to try, or which ones might work.

This guide is designed to help those who need to choose interventions for children with autism. It will not tell you which interventions to try but will give you information about how to evaluate the options and make more informed decisions.

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Autism Spectrum Disorders (ASD): An Introduction

What are Autism Spectrum Disorders and What Difficulties Do Children with ASD Face?

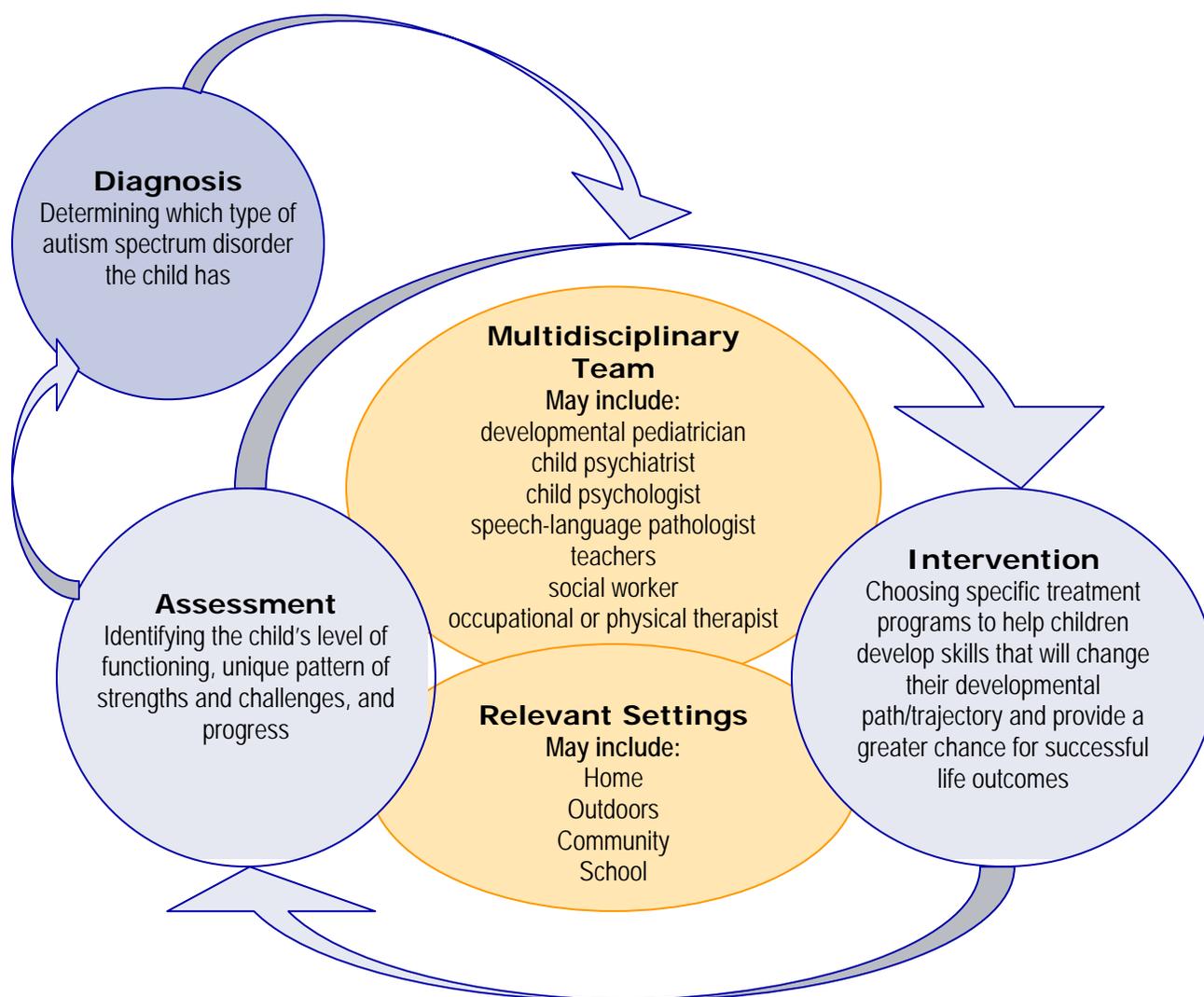
Autism is a developmental disorder believed to have neurological and genetic components. It was first identified in 1943. Since that time, research has shown that children with autism spectrum disorders (ASD) have difficulties in three general areas:¹

1. **Social Interaction** – qualitative difficulties responding to and interacting with other people in social situations, ranging from avoiding social interactions altogether at one extreme to being interactive but inappropriate at the other.
2. **Communication** – qualitative difficulties in verbal and non-verbal communication, ranging from a lack of language and gestures in some cases to the use of complex language in odd or inappropriate ways in other cases.
3. **Behaviour** - behaviours are often described as being repetitive and stereotypical, ranging from needing to perform daily activities in a very specific way to having a very restricted range of interests.

While all children with ASD have some sort of difficulty in each of these areas, the specific difficulties vary from child to child. It is important to remember that no two individuals will share the exact same pattern of difficulties.² This is why autism is now commonly referred to as a spectrum disorder—to represent the broad range of abilities and challenges found among those with autism. Diagnoses on the spectrum include the classic autistic disorder as well as Asperger’s disorder, Rett’s disorder, childhood disintegrative disorder, and pervasive developmental disorder-not otherwise specified (PDD-NOS).¹

Knowing Whether a Child has an Autism Spectrum Disorder

Because of the range of abilities in children with ASD, a clear diagnosis and thorough assessment is necessary. A multidisciplinary team, including as many professionals as possible, should be involved in the assessment and diagnosis of autism. This may include a developmental pediatrician, child psychiatrist, child psychologist, speech-language pathologist, teachers, social worker, and/or occupational or physical therapist.² A team assessment is important, first of all, because it allows professionals to determine the appropriate diagnosis (i.e. that the child does or does not have an autism spectrum disorder). A team assessment also allows professionals to identify the strengths and unique difficulties that a child faces. Ideally, children should also be assessed in as many settings as possible because they may behave differently in different settings³. An appropriate assessment and diagnosis is critical because it will help the intervention team (i.e. parents and professionals) tailor the intervention program to address the needs of the child. The flowchart below shows the ideal process for diagnosis, assessment, and intervention.



Choosing an Intervention Program: Making Informed Decisions

Interventions for Children with ASD

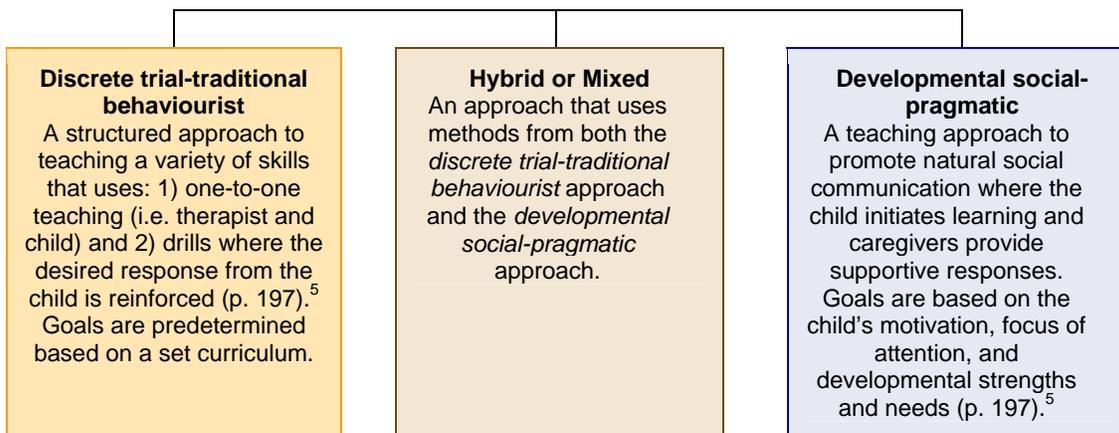
Interventions Help Children with ASD, But Can't Cure Them

To date, there is no cure for ASD. For children with ASD, the purpose of intervention is to help them develop skills that will change their developmental path/trajectory and provide a greater chance for successful life outcomes. It is important for families and care providers to recognize that children with ASD have unique abilities, like any other child. Therefore, each child's uniqueness should be considered in planning treatment or choosing an intervention.

There Is No One-Size-Fits-All Intervention

Since individuals with ASD have unique patterns of difficulties, choosing an intervention can be a complex task. There is not a one-size-fits-all intervention for ASD. Many different interventions are offered for children with ASD (e.g. developmental approaches, applied behavioural analysis, biological and medical approaches, psychotherapies, sensorimotor therapies, and play therapies).⁴ (Note that this booklet does not focus on biomedical approaches.) Each intervention views the treatment of autism from a different perspective and may focus on certain skills more than others. An appropriate intervention would have the flexibility to meet the needs of each child at different times and also be based on scientific evidence. It is important to remember that not all interventions are based on scientific evidence even if they are well-known.

Interventions are specific treatment programs that view the treatment of autism from a different perspective. Most interventions could be classified on a continuum:



Finding Interventions that are Based on Scientific Evidence

Not All Interventions Are Based on Scientific Evidence

Scientific research should be used to determine if an intervention works *before* it is widely used. Unfortunately, some interventions become widely used before there is enough evidence to justify its use. In many regions, there are no rules regulating the people offering autism interventions and no regulations stating that an intervention should be based on scientific evidence before it is offered. This means there is no guarantee that the person providing the intervention is concerned about evidence for their intervention. That is why informed choices are necessary to ensure optimal development for each child.

Some interventions become widely used before there is enough evidence to say they work.

BUYER BEWARE!!

Some interventions might do no harm, but if inappropriate, they could waste time and energy better spent on an intervention that would deliver more positive developmental outcomes.

For instance, the internet offers many intervention options, all claiming to work. In search of an intervention that works, parents and practitioners may sometimes choose to use one without taking the time to find out if it has been proven to work. Just because others are using the intervention or it is a new treatment claiming to be “cutting edge” does not necessarily mean that it will help a particular child. Some interventions have little or no scientific evidence saying they work, yet they cost families thousands of dollars and require huge investments of time. As consumers we typically check the facts before making a major purchase (e.g. consulting a consumer guide, having an inspection completed). Decisions regarding interventions for children with ASD should be approached with the same caution and diligence.

Research Evidence

Scientific research helps to determine which interventions are effective. Scientific research starts with a clear question that researchers would like to answer. For example, “Does a particular intervention increase the number of spontaneous social interactions?” or “Comparing two interventions, which one has the greater effect on cognitive outcomes?”. Currently, there is limited research that tries to answer questions about which intervention works best for which children and when (for example, by comparing interventions in a single study). This means that no one intervention has yet been proven to be better than another.

Good researchers design a study in a way that will best answer their question. Because there are many different kinds of questions that could be asked, there are many different ways to design a research study. However, as an intervention is studied further, there should be more control and precision (a.k.a. rigor) in the research to more carefully determine its effectiveness. Research designs with more control and precision are better suited to help us see if an intervention is effective. Such research is developing at this time. The chart on the next page summarizes current available evidence for specific types of interventions. Categories of interventions are placed on the chart based on professional judgment by experts in the field of autism. Remember that new research is always developing, so the position of an intervention on the chart could change over time.

Classification Based on Evidence	Interpersonal relationship	Skill-based	Cognitive	Physiological/ biological/ neurological	Other
<p>Gold Standard Practice</p> <p>Rigorous, systematic and objective evidence supports that the intervention is effective for some children with ASD. Research findings are reliable, valid and relevant to interventions for specific types of children with ASD (e.g. age groups, cognitive levels, etc.).</p>					
	Research in progress. No intervention has this level of evidence yet.				
<p>Scientifically Based Practice</p> <p>Significant and convincing evidence supports the intervention is effective for some individuals with ASD.</p>		<ul style="list-style-type: none"> ✦ Applied behaviour analysis ✦ Discrete trial training ✦ Pivotal response training 	<ul style="list-style-type: none"> ✦ <i>Learning Experiences: An Alternative Program for Preschoolers and Parents</i> 		
<p>Promising Practices</p> <p>Some evidence emerging that supports the intervention may be effective with some individuals with ASD, but more rigorous research is required.</p>	<ul style="list-style-type: none"> ✦ Play-oriented strategies ✦ Incidental teaching 	<ul style="list-style-type: none"> ✦ <i>Picture Exchange Communication System</i> ✦ Structured teaching ✦ Augmentative alternative communication ✦ Assistive technology ✦ Joint action routines 	<ul style="list-style-type: none"> ✦ Cognitive behavioural modification ✦ Cognitive learning strategies ✦ Social stories ✦ Social decision-making strategies 	<ul style="list-style-type: none"> ✦ Sensory integration 	
<p>Limited Supporting Evidence for Practices</p> <p>Evidence is limited, not objective, or not convincing. The effectiveness of the intervention is unknown, possible or potential. Much more rigorous research required.</p>	<ul style="list-style-type: none"> ✦ Gentle teaching ✦ Option method ✦ Floor time ✦ Pet/animal therapy ✦ Relationship development intervention 	<ul style="list-style-type: none"> ✦ Van Dijk curricular approach ✦ Fast ForWord 	<ul style="list-style-type: none"> ✦ Cognitive scripts ✦ Cartooning ✦ Power cards 	<ul style="list-style-type: none"> ✦ Scotopic sensitivity syndrome: Irlen lenses ✦ Auditory integration training ✦ Megavitamin therapy ✦ Feingold diet ✦ Herb, mineral, and other supplements 	<ul style="list-style-type: none"> ✦ Music therapy ✦ Art therapy ✦ Smell therapy
<p>Not Recommended</p> <p>Evidence suggests the intervention is not effective and/or is potentially harmful.</p>	<ul style="list-style-type: none"> ✦ Holding therapy 	<ul style="list-style-type: none"> ✦ Facilitated communication 			

Adapted from Simpson R, de Boer-Ott S, Griswold D, Myles B, Byrd S, Ganz J, et al. Autism spectrum disorders: Interventions and treatments for children and youth, pp. 9-11, copyright 2005 by Sage Publications, Thousand Oaks, CA. Reprinted by Permission of Sage Publications Inc.

While the study of existing interventions and the development of new interventions is essential to improve our ability to treat autism spectrum disorders, it is important to know that good research takes time. Thorough scientific research will help determine if an intervention works and for which children it is most effective.

Be Aware:

- ✘ Not all research is conducted well.
- ✘ All interventions claim that they will help the child but not all interventions have good research evidence to support this claim.
- ✘ Although a practitioner may claim to offer a particular intervention, they may or may not deliver the actual intervention.
- ✘ A “new” intervention may actually be an intervention that has been around for a while but has never been proven to work. It may just be going by a new name.

What We Know So Far About Interventions for Children with ASD

According to a panel of experts, common elements of current programs with the best evidence are:²

- ✘ **Early Intervention** - Entry into intervention programs should happen as soon as an autism spectrum diagnosis is seriously considered.
- ✘ **Intensity** – School-aged children should be actively engaged in a full school day, 5 days (at least 25 hours) a week, with full year programming varied according to the child’s chronological age and developmental level.
- ✘ **Individualized Scheduling** - Repeated, planned teaching opportunities are recommended. These would be generally organized around relatively brief periods of time for the youngest child (e.g. 15-20 minute intervals), including sufficient amounts of adult attention in one-to-one and very small group instruction to meet individualized goals.
- ✘ **Family-Centred** – Family should be included in the intervention, including parent training.
- ✘ **Inclusion** – There should be low student/teacher ratios (no more than two young children with autistic spectrum disorders per adult in the classroom).
- ✘ **Dynamic Program Planning** - Plans for ongoing program evaluation and assessment of individual children’s progress, with results translated into adjustments in programming, are recommended.
- ✘ **Individualized Intervention Plans** – Ongoing assessment of a child’s progress in meeting objectives should occur to further refine the individualized education plan. Lack of objectively documented progress over a 3 month period should be taken to indicate a need to assess the program (p. 219).



Questions To Ask When Looking at Intervention Programs

Parents, service providers and practitioners who act as advocates for children with ASD may need help to make choices about interventions. The following questions provide a guide towards making a more informed treatment decision for each child with ASD.^a

^a Some of these questions are based on a clinical practice guideline published by New York State.⁶

Evidence that It Works	About the Intervention
<p>Research</p> <ul style="list-style-type: none"> ✦ What kind of scientific research indicates the intervention is effective? <ul style="list-style-type: none"> ○ Does the child share necessary characteristics with those in the research study (e.g. ability, age)? ✦ Can you provide me with research articles about this intervention that I can read? <p>Evaluation of Progress</p> <ul style="list-style-type: none"> ✦ What goals or outcomes do you hope to achieve with this intervention? ✦ How will this intervention help each child function better? ✦ How will each child's progress (skills and functioning) be evaluated? <ul style="list-style-type: none"> ○ Using what measurements? ○ How often? ✦ How will the program be adjusted according to each child's progress? 	<p>Multidisciplinary Intervention Team</p> <ul style="list-style-type: none"> ✦ What qualifications, training, and knowledge do members of the intervention team have? ✦ What is the involvement of the professionals in the intervention? <ul style="list-style-type: none"> ○ Who is involved in the intervention on a daily basis? ○ How often are the pediatrician, child psychiatrist, child psychologist, speech-language pathologist, teachers, and/or occupational or physical therapists with the child? ○ How often will the team meet? <p>Child's Experience</p> <ul style="list-style-type: none"> ✦ What will a day be like for the child? ✦ How will the intervention be adapted to meet each child's unique needs? ✦ Is this the best intervention for this child given his/her personality, temperament, and needs? ✦ What risks are there to the child's physical or emotional health? <p>Family Focus</p> <ul style="list-style-type: none"> ✦ Does this intervention meet the goals or needs of the family? ✦ Will this intervention fit the family's lifestyle? ✦ How are families involved in the intervention? <ul style="list-style-type: none"> ○ Is there parent training included?

Because there are many intervention options that have some supporting evidence, it is important to choose those options that will provide the most benefit for each child and family. Asking questions about the intervention is the first step to providing the best intervention for each child with ASD.

The Intervention Process: What to Expect

Possible Intervention Outcomes

How Should an Intervention Help the Child?

It is important to establish goals with specific predicted outcomes before the intervention begins. These goals should serve as the road map as the intervention journey begins. Setting goals provides the whole team with ways to measure the effectiveness of the intervention. According to a panel of experts, the following are general developmental objectives:²

- ✦ **Social Skills** - that enhance each child's participation in family, community, or school activities (e.g. progressing from imitation to social initiations and response to adults and peers, and from parallel to interactive play with peers and siblings)

- ✦ **Communication** - a functional communication system that might include non-verbal communication skills, receptive language, and expressive language
- ✦ **Interacting within the Environment** - increased engagement and flexibility in developmentally appropriate tasks of daily living and play, including the ability to attend to the environment and respond to an appropriate motivational system
- ✦ **Motor Skills** - fine and gross motor skills used for age appropriate functional activities, as needed
- ✦ **Cognition** - cognitive skills, including symbolic play and basic concepts, as well as academic skills
- ✦ **Behaviour** - replacement of problem behaviours with more conventional and appropriate behaviours
- ✦ **Executive Functioning** - independent organizational skills and other behaviours that underlie social and academic success in regular education classrooms (p. 218).



Setting Goals for the Child

The above are broad long term objectives that should translate to achievable short-term goals. Best practice suggests using an Individualized Program Plan (IPP) to identify goals for each child. The goals outlined in the IPP should be:^{2,7}

1. **Measurable** - There must be a way to measure progress made towards each long- and short-term goal to assess whether the intervention is working.
2. **Relevant** - The goals should be relevant and functional, resulting in useful changes to the daily life skills of the child.
3. **Regularly Monitored** - Progress towards the goals should be monitored regularly with a specified system of measurement. Based on this information, new goals should be set to make sure the child continues to progress.
4. **Measured in All Relevant Settings** – Because the skills and behaviours should generalize to all relevant aspects of the child's life, skills should be measured/evaluated in all relevant settings.

Parents play an important and active role in developing the goals for their child. Developing and setting new goals for an IPP offers a unique opportunity for parents and professionals to come to a common understanding. It is important that everyone supports the plan for the child's treatment.

Progress of the Child in the Intervention

A critical part of any intervention is ongoing evaluation and assessment. Since any decision regarding intervention can have a lasting impact on a child, the same careful and critical thinking that drove the initial intervention choice should guide ongoing evaluation and future intervention choices.

What to Do When a Child Is Not Progressing?

The needs of children with ASD will change with age and progress. Assessing each child's progress will help the team set new goals to make sure progress continues. When a child is not progressing, it is important to ask questions to discover why:

Goals

- Is the goal developmentally appropriate?
- Is the goal meaningful to the family?
- Has the goal been achieved in any setting?

Multidisciplinary Intervention Team

- Is the team consistent in their approach to the intervention?
- Do all the interventionists have the training, knowledge, and skills for the intervention to succeed?

Child's Experience

- Are there significant events or changes in the family life that might be affecting the child's progress?
- Is there enough opportunity for the child to practice new learning?
- Does the personality of the therapists and/or intervention team fit with that of the child?

Change Within an Intervention

- Would changes to any aspect of the intervention achieve more progress (e.g. changing the setting)?



The answers to these questions will help to avoid quick and rash decisions about switching intervention programs and completely changing a child's routine. Since children with ASD often thrive on schedule and routine, making minor adjustments to the current intervention—without completely changing a child's routine—should first be considered to help keep children focused on learning skills.

Some Change is Necessary Along the Way

In most cases, there will come a time when an intervention is no longer effective for a child and minor changes do not make a difference. When such a point is reached, it is time to change the intervention. As children grow, it is normal that the level and type of intervention will also change. During times of change, it is important to go back to the "Questions to Ask When Looking at Intervention Programs" to help decide on the next intervention.

For More Information

There are many different interventions offered for children with autism—some with evidence that say they work and some without. Learning how to evaluate intervention options will help you make an informed decision and ensure that children with autism are provided with the best care possible.

More Information on Interventions for Children with ASD

If you are looking for more information on interventions for children with ASD, these are some books that may help along the way:

Goldstein H, Kaczmarek LA, English KM, eds. **Promoting Social Communication: Children with Developmental Disabilities from Birth to Adolescence**. Toronto, ON: Paul H. Brookes; 2002.

Koegel LK, LaZebnik C. **Overcoming Autism**. New York: Viking Press; 2004.

Koegel R, Koegel LK. **Pivotal Response Treatments for Autism**. Baltimore: Brookes Publishing Co.; 2006.

National Research Council. Lord C and McGee JP, eds. **Educating Children with Autism**. Washington, DC: National Academy Press; 2001.

O'Brien M, Daggett JA. **Beyond the Autism Diagnosis: A Professional's Guide to Helping Families**. Baltimore, MD: Paul Brookes; 2006.

Prizant BM, Wetherby A, Rubin E, Laurent A, Rydell P. **The SCERTS Model: A Comprehensive Educational Approach for Children with Autism**

Spectrum Disorders, Vol. 1: Assessment. Baltimore: Brookes Publishing Co.; 2006.

Prizant BM, Wetherby A, Rubin E, Laurent A, Rydell P. **The SCERTS Model: A Comprehensive Educational Approach for Children with Autism Spectrum Disorders, Vol. II: Program Planning and Intervention**. Baltimore: Brookes Publishing Co.; 2006.

Quill KA, ed. **Teaching Children With Autism: Strategies to Enhance Communication and Socialization**. Toronto, ON: Delmar; 1995.

Wetherby AM and Prizant BM, eds. **Autism Spectrum Disorders: A Transactional Developmental Perspective**. Toronto, ON: Paul H. Brookes; 2000.

More Information on Research into Interventions for Children with ASD

Although we do not yet know which interventions are most effective and for which children, research into interventions for children with ASD is ongoing. The following is a list of some organizations that conduct or gather leading edge research in this area:

- ✦ **Canadian Autism Intervention Research Network**
<http://www.cairn-site.com>
- ✦ **The Collaborative Programs of Excellence in Autism (CPEAs)**
<http://www.nichd.nih.gov/about/cdbpm/mrdd/autism/cpea.cfm>
- ✦ **National Institutes of Health Autism Research Network**
<http://www.autismresearchnetwork.org/>
- ✦ **National Alliance for Autism Research**
<http://www.naar.org>
- ✦ **Autism Research Centre, Cambridge University**
<http://www.autismresearchcentre.com/arc/default.asp>
- ✦ **Organization for Autism Research**
<http://www.researchautism.org/>
- ✦ **Autism Spectrum Disorders Canadian-American Research Consortium**
<http://www.autismresearch.ca/>



References

- (1) Filipek PA, Accardo PJ, Baranek GT et al. The screening and diagnosis of autistic spectrum disorders. *J Autism Dev Disord.* 1999;29:439-484.
- (2) National Research Council. *Educating Children with Autism.* Washington, DC: National Academy Press; 2001.
- (3) Kaczmarek LA. Assessment of Social-Communicative Competence. In: Goldstein H, Kaczmarek LA, English KM, eds. *Promoting Social Communication: Children with Developmental Disabilities from Birth to Adolescence.* Toronto: Paul H Brookes; 2002:55-115.
- (4) Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders: Recommendations of the Collaborative Work Group on Autistic Spectrum Disorders. 1997. Sacramento, California Department of Education.
- (5) *Autism Spectrum Disorders: A Transactional Developmental Perspective.* Toronto, ON: Paul H. Brookes; 2000.
- (6) Clinical Practice Guideline: Report of the Recommendations. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). 1999. Albany, NY, New York State Department of Health.
- (7) Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders: Recommendations of the Collaborative Work Group on Autistic Spectrum Disorders. 1997. Sacramento, California Department of Education.