WINTER 2011

CenterLines

Center for Disabilities and Development *Useful News for Families*

Interventions for Autism Spectrum Disorders

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Introduction

Substantial progress has been made in identifying interventions that address the core deficits of Autism Spectrum Disorders (ASDs) and improve the quality of life for many individuals with an autism spectrum diagnosis.

Identifying appropriate interventions can be an overwhelming and frustrating experience for parents. A recent Google search using the term "autism treatment" revealed over 750,000 results! Unfortunately, many of these "treatments" are costly, have limited scientific support, and may result in families failing to seek out interventions that are more likely to have beneficial effects.

In 2009, the National Autism Center released The National Standards Report, a comprehensive review of the level of scientific evidence available to support applied treatments for individuals with ASDs (www.nationalautismcenter.org). Based on a review of the research evidence, treatments were separated into three categories: (1) established, (2) emerging, and 3) not established. The authors of the report noted that the majority of the established treatments were developed in the field of Applied Behavior Analysis (ABA). The following is a brief overview of ABA treatments as well as information about selected other treatments for autism that have received support in the research literature.

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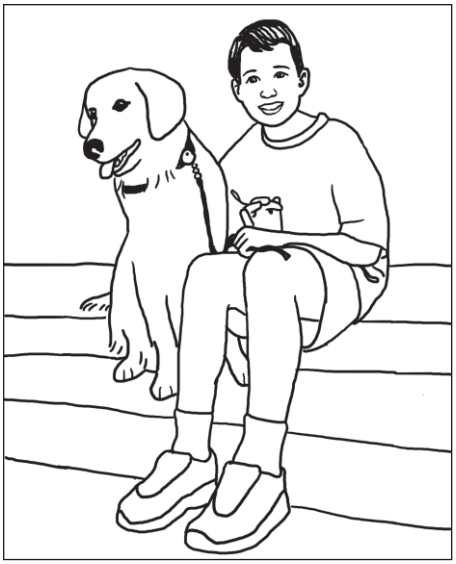
Applied Behavior Analysis (ABA)

ABA is the scientific study of the influence of environmental events on a range of socially significant behaviors. The term 'ABA' does not refer to any specific program or procedure. Instead, ABA is used more generally to describe programs that adhere to the following principles: (a) an emphasis on observable behaviors, (b) the systematic analysis and measurement of relations between environment and behavior, (c) the use of single-subject design to show the relation between behavior and the environment, and (d) a focus on behaviors of social relevance.

Within the field of autism, ABA programs typically focus on teaching new skills and generalizing the use of these skills across different settings, reinforcing desirable behaviors, and decreasing behaviors of concern. ABA procedures are used with children with ASDs to teach



specific academic and vocational skills; to increase speech, social skills, and play skills; and to decrease problem behaviors. Multiple studies published over the past four decades have demonstrated that many children who receive intensive

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ABA interventions make substantial growth in their learning, adaptive skills, and behaviors.

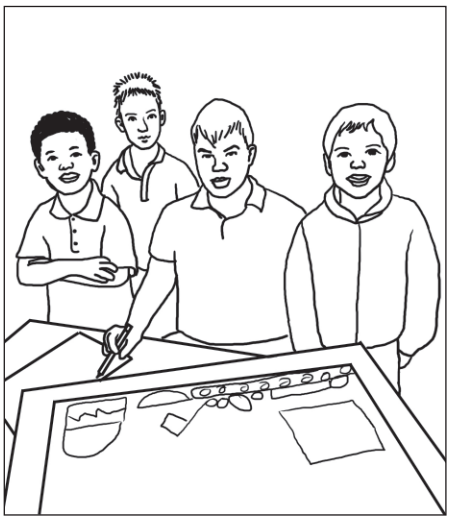
The specific approaches used in ABA programs vary. Some ABA programs focus on teaching specific skills through the use of massed learning trials, with trials conducted between a therapist and a child at a table. Recently, a greater emphasis has been placed on blending ABA principles into developmentally sequenced, play-based programs that are implemented in naturalistic settings. For challenging behaviors, the most common approach is to first conduct a functional analysis, an assessment of the environmental events that elicit and maintain problem behavior. After the function(s) for the problem behavior has been identified, the child is then taught to communicate for desired outcomes and to replace problem behavior with equivalent communications (e.g., to request a toy or a break from work).

Visual Supports

Many children with an ASD diagnosis experience difficulties in the areas of receptive and expressive language, attention, and memory. For many children with this learning profile, the use of visual supports has been shown to have a positive effect on learning, behavior, and social skills. Examples of visual interventions with research support include the use of schedules, story-based instruction (for example, Social Stories; www.polyxo.com/socialstories), picture exchange systems, and structured teaching (e.g., Project TEACCH; www.teacch.com). In many cases, visual supports are used as a package along with other interventions.

Other Therapies

Social skills training is important in reducing social deficits in ASDs, and effective approaches include ABA methods, peer-based intervention strategies, and social skills groups. Use of cognitive behavior therapy, especially structured "self-management" programs designed for higher functioning children/adolescents or adults with ASD, can support management of anxiety, depression, anger control, and social skill development. Targeted therapies (e.g., speech/language, OT) can be used to increase communication skills and to improve independence in activities of daily living. Although



many children with ASD have "sensory" issues that interfere with learning or social behavior, the theories behind sensory integration (SI) therapy for ASD lack scientific support. Despite this fact, some of the activities emphasized in "sensory" therapy may help children to become more physically active, to accept a wider range of sensory experiences, or to be more receptive to reinforcement for desired behavior when used as part of a comprehensive ASD intervention program.

Medical Treatment

Medications are sometimes used to target symptoms experienced by some children with ASDs. Currently, one medication, risperidone, has received approval from the Food and Drug Administration (FDA) for the treatment of irritability (including aggression, self-injury, and tantrums) in children with ASDs between the ages of 5 and 16 years. Although risperidone is the only FDA-approved medication, there are other medications with fewer side effects that may often be tried first. Other medications are often prescribed on an "off-label" basis to target symptoms such as aggression, depression, anxiety, obsessive-compulsive tendencies, sleep difficulties, and attention deficits. The term "off-label" means drugs that are typically prescribed one way, but are now being used to treat something else. Children with ASDs may not respond to medications in the same way as typically developing children. It is important for parents to work closely with a provider with expertise in the field of autism to closely monitor response to the medication. Additional medical care may be needed to manage problems with seizures, gastrointestinal problems, and dietary imbalances. Genetic testing using microarray analyses is also now being recommended for children with ASDs.

Complementary and Alternative Medicine (CAM) Treatments

It has been estimated that around 30 percent of parents with a child with autism choose to use complementary and alternative medicine

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(CAM). Common examples of CAM's include melatonin, a gluten-free, casein-free (GFCF) diet, different enzymes and vitamins (e.g., B6, Magnesium, B12, probiotics), and body-based systems such as deep pressure. Research has found that melatonin can help children with ASDs to fall asleep. At this time, limited research exists to support the efficacy of other CAM's. Some approaches, such as chelation (the administration of medication to help the body excrete heavy metals) lack scientifically valid research to support their efficacy and can pose serious safety concerns. Parents considering CAM's are encouraged to consult closely with their child's healthcare provider to receive up-to-date information about the intervention so that appropriate monitoring and evaluation can occur.

General Intervention Guidelines

Treatment is likely to be most effective when it is individualized and when it is conducted as soon as possible after concerns are noted. Before treatment begins, it is therefore important to conduct a comprehensive assessment of the child's developmental status. Key members of the assessment team often include a developmental pediatrician or other healthcare provider with expertise in autism, a speech and language pathologist, a psychologist, an educational consultant, and an occupational therapist. Results from the evaluation can be used by parents and the school team to develop a treatment program that is tailored to the child's strengths and needs.
As is true for any child with a serious neurodevelopmental disability, providing a "medical home" that can ensure care coordination, parent training, and family support is critically important to a comprehensive plan of care. For adolescents and adults with ASD, vocational training, job coaching, and interventions to improve social and behavioral adjustment are crucial to support independence in living and working in community settings. Although distinctions have been made between ASD services that are "habilitative" (building new skills) or "rehabilitative" (restoring lost skills), legal decisions have questioned the use of these distinctions. Current thinking supports the need for preventive, medical, and remedial services when these interventions have been recommended by a health care practitioner for the reduction of a physical or mental disability and for ensuring the best possible level of functioning. Whenever possible, recommended services should be based on proven interventions with a strong evidence base.

Resources for Additional Information

American Academy of Pediatrics (AAP) Toolkit:
http://www.aap.org/publiced/autismtoolkit.cfm#fam

Centers for Disease Control and Prevention (CDC) Autism Information:
http://www.cdc.gov/ncbddd/autism/index.html

"Intellectual Disability"

Rosa's Law

The term *retarded* has a long history as a word used in an insulting way to hurt people's feelings, even though it is also an official term. On October 8, 2010, President Barak Obama signed a new law that says we will no longer use the term *"mental retardation"* but instead will use the term **"intellectual disability."** The new law is called Rosa's Law after a 9-year-old girl from Maryland. Rosa has Down syndrome and her family worked long and hard with Special Olympics to get the term changed.

This law means that from now on, all federal laws, documents, and policies will use the new term **"intellectual disability."** Here at CDD, we will be using that term as well when talking with you and your child, and in our official reports.

Causes and Treatment of Autism Spectrum Disorders (ASD)

Causes

No one knows for sure what causes autism, but scientists believe both genes and the environment play a role. Research has shown that autism tends to run in families. Among identical twins, if one child has autism then the other is likely to be affected 75 to 90 percent of the time. Some parents worry that vaccines cause autism, but scientific evidence doesn't support this theory. There is some evidence that prenatal exposure to factors in the environment (such as viruses or infections) may play a role in causing some forms of autism. It is important to recognize that autism is a brain-based disorder and is not caused by inadequate parenting.

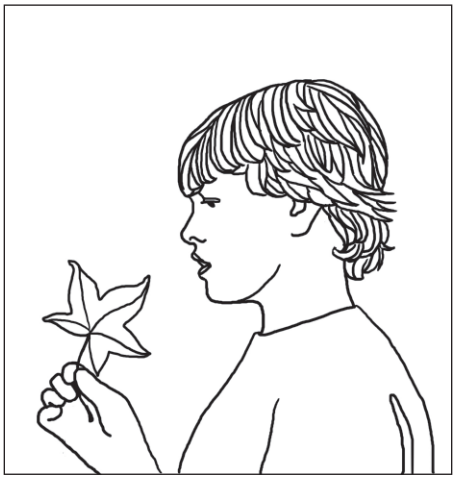
Identification

There are no specific medical tests for diagnosing autism, although there are genetic tests for disorders that may be associated with behaviors on the autism spectrum. An accurate diagnosis is based on observation of the child's communication, social interaction, behavior, and developmental level. Many signs of ASD can be observed by 18 months of age or even earlier. Some early signs that a child may have an ASD include:

- Lack of or delay in spoken language
- Repetitive use of language
- Little or no eye contact
- Lack of interest in other children
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects
- Poor response to his/her name
- Fails to imitate caregivers
- Motor mannerisms (e.g., hand-flapping)
- Fails to point or show joint attention

Treatment

Each person with ASD is unique and intervention plans must be individualized, based on the needs of the individual and family. Early intervention can make a significant difference in improving cognitive and social development for children with ASD, and intensive, highly structured educational programs based on the principles of applied behavior analysis (ABA) are the gold standard for autism treatment. The primary focus should be on the child's acquisition of communication, social, play, and academic skills. Structured programming should be provided throughout the year at an intensity of at least 25 hours per week.



When evaluating treatments, parents should consider the following issues (as recommended by the Autism Society of America):

- Will the treatment result in harm to my child?
- How will the failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- Are the assessment procedures specified?
- How will the treatment be integrated into my child's current program?

Treatments supported by scientific evidence:

- Early intensive behavioral intervention programs
- Applied Behavior Analysis (ABA), including Discrete Trial Training and Functional Communication Training
- Cognitive Behavior Therapy (CBT), especially self-management
- Social skills training, including peer-based strategies, social stories, and social skills groups
- Visual supports and schedules
- PECS when taught through ABA strategies
- Medication for attention, mood, aggression, and rigid behavior

Promising or emerging treatments:

- Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH)
- Technology-based treatments, using computers or other electronic devices
- Music therapy
- Developmental relationship-based therapies, such as Floortime

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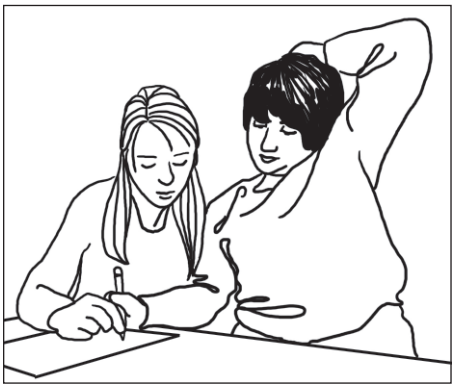
Treatments with limited supporting scientific evidence:

- Sensory Integration Therapy
- Gluten and casein-free diets
- Facilitated communication
- Auditory integration training

Treatments that are not recommended:

- Chelation to remove presumed heavy metals from the body
- Very high doses of vitamins



Other critical aspects of care for ASD

- "Medical home" to ensure care coordination, parent training, and family support
- Medical care to manage problems with seizures, gastrointestinal problems, dietary imbalances, or disrupted sleep patterns
- Targeted therapies (e.g., speech/language, OT) to increase communication skills and to improve independence in activities of daily living
- Intensive, individualized educational programming
- Supporting the independence of adults with ASD through job training and interventions to improve social-emotional adjustment

Prepared by the Center for Disabilities and Development of the University of Iowa Children's Hospital (Sept. 2010)

Iowa Autism Resources:

For patients, parents, and professionals dealing with autism spectrum disorders

The Autism Society of Iowa
Listed below is contact information for local chapters of the Autism Society of Iowa, a statewide nonprofit advocacy organization. Local chapters provide information and support and the society's website (http://www.autism-society.org) provides links to information and numerous national and state resources. The society also can be reached by calling the toll-free number (888) 722-4799.

Autism Society East Central Iowa Chapter
3928 Terrace Hill Drive North East
Cedar Rapids IA 52402-2849
(319) 378-1241
Email: ia-eastcentraliowa@autismsocietyofamerica.org
www.**autism-society.org/chapter157**

Autism Society Iowa Chapter
4549 Waterford Drive
West Des Moines, IA 50265-2059
(515) 327-9074
Email: autism50ia@aol.com
Website: **www.autismia.org/**

Autism Society Quad Cities Chapter
PO Box 472
Bettendorf, IA 52722-0008
Email: ia-quadcities@autismsocietyofamerica.org
Website: **www.autismqc.org**

Autism Society Siouxland Chapter
137 Nimrod
Salix, IA 51052-8078
(712) 946-7847
(712) 277-9365
Email: ia-siouxland@autismsocietyofamerica.org
Website: **www.siouxlandautism.org**

Regional Autism Services Program (RASP)
This program coordinates community-based screening, team-oriented interventions, interagency cooperation, and disseminates information on available resources. The website includes links to learning opportunities for parents and professionals, technical assistance and follow-up evaluation for schools serving youth with autism spectrum disorders, access to RASP statewide library holdings on autism issues and programming; reference lists on issues in autism; support for and checklists to use in community screening for autism; educational rules and regulations; and links to area education agencies. The RASP works cooperatively with the Autism Society of Iowa.

The University of Iowa
100 Hawkins Drive, Room 226
Iowa City, IA 52252-1011
(319) 356-4619
Contact: Sue Baker, M.S.
Email: sue-baker@uiowa.edu
Website: **www.medicine.uiowa.edu/autismservices/**

Resources for Additional Information

American Academy of Pediatrics
www.aap.org/publiced/autismtoolkit.cfm#fam

Centers for Disease Control and Prevention (CDC) Autism Information
www.cdc.gov/ncbddd/autism/index.html

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In this issue

CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uihealthcare.com/cdd. Click on Centerlines for Families.

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