

Autism and Intellectual Disability (Mental Retardation)

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Table of Contents

What is Autism?	3
DSM V Autism Spectrum Disorder	3
DSM IV Autism Descriptions	6
Causes of Autism	8
Symptoms of Autism	9
Autism	11
Aspergers	12
Childhood Degenerative Disorder	13
Pervasive Developmental Disorder	14
Rett Syndrome	15
What is an Intellectual Disability?	15
Causes of an Intellectual Disability	16
Symptoms	17
Treatment	18
Statistics/Facts	38
TR Implications	40
Resources	42

What is Autism?

-Autism is a complex neurobehavioral disorder that includes impairments in social interaction and developmental language and communication skills and rigid, repetitive behaviors.

<http://www.webmd.com/brain/autism/understanding-autism-basics>

-Autism is classified by the American Psychiatric Association as a Pervasive Developmental Disorder (APA, 1994). It is defined by symptoms appearing before the age of three, which reflect delayed or abnormal development in three areas:

Language Development - doesn't understand or say many words, repeats things ("echoes") or uses the third person.

Social Skills - not interested in peers, no imitative play, poor eye contact, doesn't respond when spoken to, doesn't show/point to things.

Behavioral Repertoire - repetitively plays with objects in a specific way or insists that things be done the same way or engages in self-stimulatory actions such as hand flapping, staring at hands or fingers or smelling things.

<http://www.wiautism.com/defined.php>

-A pervasive developmental disorder characterized by severe deficits in social interaction and communication, by an extremely limited range of activities and interests, and often by the presence of repetitive, stereotyped behaviors.

<http://www.thefreedictionary.com/autism>

DSM V Autism Spectrum Disorder

Autism Spectrum Disorder 299.00 (F84.0)

Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of

behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
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<p>Level 3</p> <p>"Requiring very substantial support"</p>	<p>Severe</p> <p>deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches</p>	<p>Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.</p>
<p>Level 2</p> <p>"Requiring substantial support"</p>	<p>Marked</p> <p>deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.</p>	<p>Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.</p>
<p>Level 1</p> <p>"Requiring support"</p>	<p>Without</p> <p>supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.</p>	<p>Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.</p>

DSM IV Autism Description

Diagnostic Criteria

The American Psychiatric Association's Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) 1 provides standardized criteria to help diagnose ASDs.

Diagnostic Criteria for 299.00 Autistic Disorder

1. Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 2. Failure to develop peer relationships appropriate to developmental level
 3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 4. Lack of social or emotional reciprocity
 1. Qualitative impairments in communication as manifested by at least one of the following:
 1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 3. Stereotyped and repetitive use of language or idiosyncratic language
 4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 1. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
 3. Stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 4. Persistent preoccupation with parts of objects
1. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
1. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria for 299.80 Asperger's Disorder

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction
 1. Failure to develop peer relationships appropriate to developmental level
 1. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other

people)

1. Lack of social or emotional reciprocity
1. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
 1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
 2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
 1. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 1. Persistent preoccupation with parts of objects
1. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
1. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
1. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
1. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" - presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Diagnostic Criteria for 299.80 Rett's Disorder

1. All of the following:
 1. Apparently normal prenatal and perinatal development
 2. Apparently normal psychomotor development through the first 5 months after birth
 3. Normal head circumference at birth
1. Onset of all of the following after the period of normal development:
 1. Deceleration of head growth between ages 5 and 48 months
 2. Loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
 3. Loss of social engagement early in the course (although often social interaction develops later)
 4. Appearance of poorly coordinated gait or trunk movements
 5. Severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic Criteria for 299.10 Childhood Disintegrative Disorder

1. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
1. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
 1. Expressive or receptive language
 2. Social skills or adaptive behavior
 3. Bowel or bladder control
 4. Play
 5. Motor skills
1. Abnormalities of functioning in at least two of the following areas:
 1. Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
 2. Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
 3. Restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, including motor stereotypes and mannerisms
1. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia

Autism spectrum disorder is a new DSM-5 name that reflects a scientific consensus that four previously separate disorders are actually a single condition with different levels of symptom severity in two core domains. ASD now encompasses the previous DSM-IV autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. ASD is characterized by 1) deficits in social communication and social interaction and 2) restricted repetitive behaviors, interests, and activities (RRBs). Because both components are required for diagnosis of ASD, social communication disorder is diagnosed if no RRBs are present.

<http://www.dsm5.org/Documents/changes%20from%20dsm-iv-tr%20to%20dsm-5.pdf>

Causes

We do not know all of the causes of ASDs. However, we have learned that there are likely many causes for multiple types of ASDs. There may be many different factors that make a child more likely to have an ASD, including environmental, biologic and genetic factors.

- Most scientists agree that **genes** are one of the risk factors that can make a person more likely to develop an ASD.
- Children who have a sibling or parent with an ASD are at a higher risk of also having an ASD.
- ASDs tend to occur more often in people who have certain genetic or chromosomal conditions. About 10% of children with ASDs also have been identified as having Down

syndrome, fragile X syndrome, [tuberous sclerosis](#), or other genetic and chromosomal disorders.

- When taken during pregnancy, the prescription drugs valproic acid and [thalidomide](#) have been linked with a higher risk of ASDs.
- We know that the once common belief that poor parenting practices cause ASDs is not true.
- There is some evidence that the critical period for developing ASDs occurs before birth. However, concerns about vaccines and infections have led researchers to consider risk factors before and after birth.
- A small percentage of children who are born prematurely or with low birth weight are at greater risk for having ASDs.

ASDs continue to be an important public health concern. Like the many families living with ASDs, CDC wants to find out what causes the disorder. Understanding the risk factors that make a person more likely to develop an ASD will help us learn more about the causes. We are currently working on one of the largest U.S. studies to date, called [Study to Explore Early Development \(SEED\)](#). SEED is looking at many possible risk factors for ASDs, including genetic, environmental, pregnancy, and behavioral factors. <http://www.cdc.gov/ncbddd/autism/facts.html>

Symptoms

ASDs begin before the age of 3 and last throughout a person's life, although symptoms may improve over time. Some children with an ASD show hints of future problems within the first few months of life. In others, symptoms might not show up until 24 months or later. Some children with an ASD seem to develop normally until around 18 to 24 months of age and then they stop gaining new skills, or they lose the skills they once had.

A person with an ASD might:

- Not respond to their name by 12 months
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes

- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

Diagnosing ASDs can be difficult since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child's behavior and development to make a diagnosis.

ASDs can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable.⁴ However, many children do not receive a final diagnosis until much older. This delay means that children with an ASD might not get the help they need

There is currently no cure for ASDs. However, research shows that early intervention treatment services can greatly improve a child's development.^{2,3} Early intervention services help children from birth to 3 years old (36 months) learn important skills. Services can include therapy to help the child talk, walk, and interact with others. Therefore, it is important to talk to your child's doctor as soon as possible if you think your child has an ASD or other developmental problem.

Even if your child has not been diagnosed with an ASD, he or she may be eligible for early intervention treatment services. The [Individuals with Disabilities Education Act \(IDEA\)](#) ☐ says that children under the age of 3 years (36 months) who are at risk of having developmental delays may be eligible for services. These services are provided through an early intervention system in your state. Through this system, you can ask for an evaluation.

In addition, treatment for particular symptoms, such as speech therapy for language delays, often does not need to wait for a formal ASD diagnosis.

Do Children or Adults Diagnosed with Autism Ever Move Off "the Spectrum"?

Growing evidence suggests that a small minority of persons with autism progress to the point where they no longer meet the criteria for a diagnosis of autism spectrum disorder (ASD). Various theories exist as to why this happens. They include the possibility of an initial misdiagnosis, the possibility that some children mature out of certain forms of autism and the possibility that successful treatment can, in some instances, produce outcomes that no longer meet the criteria for an autism diagnosis.

You may also hear about children diagnosed with autism who reach "best outcome" status. This means they have scored within normal ranges on tests for IQ, language, adaptive functioning, school placement and personality, but still have mild symptoms on some personality and diagnostic tests.

Some children who no longer meet the criteria for a diagnosis of autism spectrum disorder are later diagnosed with attention deficit and hyperactivity disorder (ADHD), anxiety disorder or a relatively high-functioning form of autism such as Asperger Syndrome.

Currently, we don't know what percentage of persons with autism will progress to the point where they

“lose their diagnosis.” We likewise need further research to determine what genetic, physiological or developmental factors might predict who will achieve such outcomes.

We do know that significant improvement in autism symptoms is most often reported in connection with intensive early intervention—though at present, we cannot predict which children will have such responses to therapy.

We also know that many people with autism go on to live independent and fulfilling lives, and that *all* deserve the opportunity to work productively, develop meaningful and fulfilling relationships and enjoy life. With better interventions and supports available, those affected by autism are having better outcomes in all spheres of life.

<http://www.autismspeaks.org/what-autism/treatment>

Autism

Autism is one of a group of serious developmental problems called autism spectrum disorders that appear in early childhood — usually before age 3. Though symptoms and severity vary, all autism spectrum disorders affect a child's ability to communicate and interact with others.

The number of children diagnosed with autism appears to be rising. It's not clear whether this is due to better detection and reporting of autism or a real increase in the number of cases or both.

While there is no cure for autism, intensive, early treatment can make a big difference in the lives of many children with the disorder.

<http://www.mayoclinic.com/health/autism/DS00348>

Diagnostic Criteria for 299.00 Autistic Disorder

2. Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 2. Failure to develop peer relationships appropriate to developmental level
 3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 4. Lack of social or emotional reciprocity
 2. Qualitative impairments in communication as manifested by at least one of the following:
 1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. Stereotyped and repetitive use of language or idiosyncratic language
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
2. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
 3. Stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 4. Persistent preoccupation with parts of objects
2. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
2. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Aspergers

Asperger's syndrome is a developmental disorder that affects a person's ability to socialize and communicate effectively with others. Children with Asperger's syndrome typically exhibit social awkwardness and an all-absorbing interest in specific topics.

Doctors group Asperger's syndrome with other conditions that are called autistic spectrum disorders or pervasive developmental disorders. These disorders all involve problems with social skills and communication. Asperger's syndrome is generally thought to be at the milder end of this spectrum.

While there's no cure for Asperger's syndrome, if your child has the condition treatment can help him or her learn how to interact more successfully in social situations.

<http://www.mayoclinic.com/health/aspergers-syndrome/DS00551>

Diagnostic Criteria for 299.80 Asperger's Disorder

2. Qualitative impairment in social interaction, as manifested by at least two of the following:
 2. Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction
 2. Failure to develop peer relationships appropriate to developmental level
 2. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

2. Lack of social or emotional reciprocity
2. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
 3. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
 4. Apparently inflexible adherence to specific, nonfunctional routines or rituals
 2. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 2. Persistent preoccupation with parts of objects
 2. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
 2. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
 2. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
 2. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Childhood Degenerative Disorder

Childhood disintegrative disorder is also known as Heller's syndrome. It's a very rare condition in which children develop normally until at least two years of age, but then demonstrate a severe loss of social, communication and other skills.

Childhood disintegrative disorder is part of a larger category called autism spectrum disorder. However, unlike autism, someone with childhood disintegrative disorder shows severe regression after several years of normal development and a more dramatic loss of skills than a child with autism does. In addition, childhood disintegrative disorder can develop later than autism does.

Treatment for childhood disintegrative disorder involves a combination of medications, behavior therapy and other approaches.

<http://www.mayoclinic.com/health/childhood-disintegrative-disorder/DS00801>

Diagnostic Criteria for 299.10 Childhood Disintegrative Disorder

2. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
2. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
 6. Expressive or receptive language
 7. Social skills or adaptive behavior
 8. Bowel or bladder control
 9. Play

10. Motor skills
2. Abnormalities of functioning in at least two of the following areas:
4. Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
5. Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
6. Restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, including motor stereotypes and mannerisms
2. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia

Pervasive Developmental Disorder

The term "pervasive developmental disorders," also called PDDs, refers to a group of conditions that involve delays in the development of many basic skills. Most notable among them are the ability to socialize with others, to communicate, and to use imagination. Children with these conditions often are confused in their thinking and generally have problems understanding the world around them.

Because these conditions typically are identified in children around 3 years of age -- a critical period in a child's development -- they are called developmental disorders. The condition actually starts far earlier than age 3, but parents often do not notice a problem until the child is a [toddler](#) who is still not walking, talking, or developing in the ways other children of the same age are.

Pervasive development disorder, not otherwise specified (PDD-NOS): This category is used to refer to children who have significant problems with communication and play, and some difficulty interacting with others, but are too social to be considered autistic. It's sometimes referred to as a milder form of autism.

<http://www.webmd.com/brain/autism/development-disorder>

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" - presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Rett Disorder

[Rett syndrome](#) is a rare, severe, "girls only" form of [autism](#). It's usually discovered in the first two years of life, and a child's diagnosis with Rett syndrome can feel overwhelming. Although there's no cure, early identification and treatment may help girls and families who are affected by Rett syndrome.

<http://www.webmd.com/brain/autism/rett-syndrome>

Rett syndrome is a rare genetic disorder that affects the way the brain develops. It occurs almost exclusively in girls.

Most babies with Rett syndrome seem to develop normally at first, but symptoms surface after 6 months of age. Over time, children with Rett syndrome have increasing problems with movement, coordination and communication that may affect their ability to use their hands, communicate and walk.

Although there's no cure for Rett syndrome, potential treatments are being studied. Current Rett syndrome treatment focuses on improving movement and communication and providing care and support for affected children and their families.

<http://www.mayoclinic.com/health/rett-syndrome/DS00716>

Diagnostic Criteria for 299.80 Rett's Disorder

2. All of the following:
 1. apparently normal prenatal and perinatal development
 2. apparently normal psychomotor development through the first 5 months after birth
 3. normal head circumference at birth
2. Onset of all of the following after the period of normal development:
 1. deceleration of head growth between ages 5 and 48 months
 2. loss of previously acquired purposeful hand skills between 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
 3. loss of social engagement early in the course (although often social interaction develops later)
 4. appearance of poorly coordinated gait or trunk movements
 5. severely impaired expressive and receptive language development with severe psychomotor retardation

What is an Intellectual Disability?

-Intellectual disability (ID), once called mental retardation, is characterized by below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with intellectual disabilities can and do learn new skills, but they learn them more slowly. There are varying degrees of intellectual

disability, from mild to profound

-Someone with intellectual disability has limitations in two areas. These areas are:

- **Intellectual functioning.** Also known as IQ, this refers to a person's ability to learn, reason, make decisions, and solve problems.
- **Adaptive behaviors.** These are skills necessary for day-to-day life, such as being able to communicate effectively, interact with others, and take care of oneself.

IQ (intelligence quotient) is measured by an IQ test. The average IQ is 100. A person is considered intellectually disabled if he or she has an IQ of less than 70 to 75.

To measure a child's adaptive behaviors, a specialist will observe the child's skills and compare them to other children of the same age. Things that may be observed include how well the child can feed or dress him or herself; how well the child is able to communicate with and understand others; and how the child interacts with family, friends, and other children of the same age.

Intellectual disability is thought to affect about 1% of the population. Of those affected, 85% have mild intellectual disability. This means they are just a little slower than average to learn new information or skills. With the right support, most will be able to live independently as adults.

<http://children.webmd.com/intellectual-disability-mental-retardation>

Causes of an Intellectual Disability

-Anytime something interferes with normal **brain** development, intellectual disability can result. However, a specific cause for intellectual disability can only be pinpointed about a third of the time.

The most common causes of intellectual disability are:

- **Genetic conditions.** These include things like **Down syndrome** and **fragile X syndrome**.
- **Problems during pregnancy.** Things that can interfere with fetal brain development include alcohol or drug use, malnutrition, certain infections, or preeclampsia.
- **Problems during childbirth.** Intellectual disability may result if a **baby** is deprived of oxygen during childbirth or born extremely premature.
- **Illness or injury.** Infections like **meningitis**, **whooping cough**, or the **measles** can lead to intellectual disability. Severe **head injury**, near-drowning, extreme malnutrition, exposure to toxic substances such as lead, and severe neglect or abuse can also cause it.
- <http://children.webmd.com/intellectual-disability-mental-retardation>

Symptoms of an Intellectual Disability

-There are many different signs of intellectual disability in children. Signs may appear during infancy, or they may not be noticeable until a child reaches school age. It often depends on the severity of the disability. Some of the most common signs of intellectual disability are:

- Rolling over, sitting up, crawling, or walking late
- Talking late or having trouble with talking
- Slow to master things like potty training, dressing, and feeding himself or herself
- Difficulty remembering things
- Inability to connect actions with consequences
- Behavior problems such as explosive tantrums
- Difficulty with problem-solving or logical thinking

In children with severe or profound intellectual disability, there may be other health problems as well. These problems may include seizures, mental disorders, motor handicaps, [vision](#) problems, or hearing problems.

<http://children.webmd.com/intellectual-disability-mental-retardation>

Treatment

Each child or adult is unique and, so, each intervention plan should be tailored to address specific needs.

Intervention can involve behavioral treatments, medicines or both. Many persons with autism have additional medical conditions such as sleep disturbance, seizures and gastrointestinal (GI) distress. Addressing these conditions can improve attention, learning and related behaviors.

Early intensive behavioral intervention involves a child's entire family, working closely with a team of professionals. In some early intervention programs, therapists come into the home to deliver services. This can include parent training with the parent leading therapy sessions under the supervision of the therapist. Other programs deliver therapy in a specialized center, classroom or preschool.

Typically, different interventions and supports become appropriate as a child develops and acquires social and learning skills. As children with autism enter school, for example, they may benefit from targeted social skills training and specialized approaches to teaching.

Adolescents with autism can benefit from transition services that promote a successful maturation into independence and employment opportunities of adulthood.

What Early Intervention Therapies Are Currently Available?

Objective scientific studies have confirmed the benefits of two methods of comprehensive behavioral early intervention. They are the Lovaas Model based on Applied Behavior Analysis (ABA) and the Early Start Denver Model. Parents and therapists also report success with other commonly used behavioral

therapies, including Floortime, Pivotal Response Therapy and Verbal Behavior Therapy. For still more information, also see the “Treatment and Therapies” chapter of our 100 Day Kit.

Treatment Options for Toddlers and Preschool Children

Scientific studies have demonstrated that early intensive behavioral intervention improves learning, communication and social skills in young children. While the outcomes of early intervention vary, all children benefit. Researchers have developed a number of effective early intervention models. They vary in details, but all good early intervention programs share certain features. They include:

- √ The child receives structured, therapeutic activities for at least 25 hours per week.
- √ Highly trained therapists and/or teachers deliver the intervention. Well-trained paraprofessionals may assist with the intervention under the supervision of an experienced professional with expertise in autism therapy.
- √ The therapy is guided by specific and well-defined learning objectives, and the child’s progress in meeting these objectives is regularly evaluated and recorded.
- √ The intervention focuses on the core areas affected by autism. These include social skills, language and communication, imitation, play skills, daily living and motor skills.
- √ The program provides the child with opportunities to interact with typically developing peers.
- √ The program actively engages parents in the intervention, both in decision making and the delivery of treatment.
- √ The therapists make clear their respect for the unique needs, values and perspectives of the child and his or her family.
- √ The program involves a multidisciplinary team that includes, as needed, a physician, speech-language pathologist and occupational therapist.

<http://www.autismspeaks.org/what-autism/treatment>

Treatments can be divided into [Nonmedical Interventions](#), which include behavioral and educational approaches as well as sensory, [communication](#) and other interventions, and [Biomedical Treatments](#), which include modifications in diet, addition of vitamins and minerals, gut treatments, immune system regulations and others.

Nonmedical Interventions

The dramatic increase in the number of individuals identified with ASD has focused increased attention on the types of interventions that can lead to opportunities for a high quality of life.

"The best measure of effectiveness of an intervention is whether it is effective for a particular individual.

It is of utmost importance to collect and analyze data when using interventions with a student with autism. If an intervention results in positive change for a particular student and you, as an educational professional, have data to support that, then the intervention is evidence-based for that student."

Approaches to Improve Communication

Communication – an essential ability in all stages of life, necessary for addressing concerns, meeting goals, and otherwise pursuing success and happiness. Unfortunately, many individuals on the autism spectrum struggle to communicate with others. Stress, unfamiliarity with social conventions or an inability to share ideas verbally can dissuade someone with autism from conversing, with the result being social isolation, lost opportunity or the persistence of dissatisfying or even dangerous circumstances. In light of this challenge, speech-language pathologists, behavior analysts and other professionals have developed many methods of promoting effective communication in individuals with ASD.

The first step in improving communication skills is identification of areas of difficulty. Communication is a dynamic convention, with a conversation between adults sounding very different from children's chatter, so the "red flags" of communication deficits vary according to age. A speech-language pathologist (SLP), who specializes in the improvement of communication skills, can diagnose issues and provide family members or caregivers with suggestions for intervention and therapy.

The behavioral approach to communication instruction encompasses four categories of verbal response: the mind, or request; the tact, or reaction to a sensation; the echoic, or repetition (which is useful in learning new words); and the intraverbal, or answer to a spoken question. Individuals with ASD often have difficulty with one or more of these categories – for example, a child may know what ice cream is and be able to describe it, but not know how to ask for it. With instruction, however, he/she can learn to communicate spontaneously and effectively.

Because children rely on others to provide them with things they want and need, the mand is an especially significant communication skill from an early age. Children with ASD sometimes have difficulty asking questions (What? When? Who? Where?), and as a result express desires through ineffective and/or inappropriate means. In a public environment, such as a classroom, this can have negative social consequences for the child; therefore, it is imperative that parents and educators instruct and encourage the use of "wh-" questions in students with ASD.

As the individual with ASD grows up, he/she will be prompted more often to participate in conversation – that is, lengthier communication between two or more people. Being able to hold a conversation is an important social skill, but a difficult one for many people with ASD because it requires knowledge of complicated but unspoken verbal etiquette

While communication can be quite a challenge for someone on the spectrum, it is a surmountable one. With adequate instruction and encouragement, the individual with ASD can achieve personal expression and enjoy others' understanding and respect

Biomedical Treatments

There are many established and new autism treatments and interventions in the domains of medicine, education and behavior. Biomedical interventions are those that focus on the physical needs of the person as a biomedical organism, addressing deficits or encouraging weaker pathways by medical or chemical means.

[This summary](#) covers some of the common biomedical interventions in current autism treatment, such as the gluten-free/casein-free diet, addressing food sensitivities, use of supplements, gut treatments, sulfation and immune system regulation. These treatments are summarized by an engineering scientist who volunteers his time to several autism research and affiliate activities, and who is also an experienced parent of a young adult with autism. Again, it is important to keep in mind that each person with autism is unique and may respond better to some treatments than others

Summary of Biomedical Treatments for Autism

By James B. Adams, Ph.D.

To access the full article, visit <http://autism.asu.edu> or www.autism.com.

Overview

This document is intended to provide a simple summary of the major biomedical treatments available to help children and adults with autism/Asperger's. Biomedical treatments will not help every child, but they have helped thousands of children improve, sometimes dramatically. This summary is primarily based on the excellent book "Autism: Effective Biomedical Treatments" by Jon Pangborn, Ph.D., and Sidney Baker, MD,. Published by the Autism Research Institute. That book provides much more depth on the testing and treatments, which are briefly summarized in this document. Another good source of information is "Children with Starving Brains," by Jaquelyn McCandless, MD. After reading this document, it is highly recommended that you go to those sources for more information.

This Summary includes the following sections:

- Improve Diet
- Food Sensitivities
- GFCF Diet
- Vitamin/Mineral Supplements
- High-Dose Vitamin B6 and Magnesium
- Essential Fatty Acids
- Gut Treatments
 - Antifungals
 - Probiotics
 - Digestive Enzymes
- Amino Acids
- Melatonin
- Thyroid Supplements
- Sulfation
- Glutathione

- Chelation
- Immune System Regulation

Note: This summary is not intended as individual medical advice, and people should consult their physician for how to best treat their individual child. Autism is a spectrum disorder, and a treatment that helps one child may not help others.

Improving Diet

Rationale: Humans need certain essential nutrients for their bodies to function, including vitamins, minerals, essential fatty acids, and amino acids (from protein). A balanced diet rich in vegetables, fruits, and protein is important to help provide those key nutrients.

Explanation of Diet:

- Consume 3-4 servings of nutritious vegetables and 1-2 servings of fruit each day. (Corn is not a vegetable, it is a grain; potatoes have only limited nutritional value, especially if fried). Fruit juice is less healthy than eating the whole fruit, but better than soda.
- Consume at least 1-2 servings/day of protein (meat, chicken, eggs, nuts, beans). If child shows periods of irritability between protein meals, consider smaller protein snacks given more frequently.
- Greatly reduce or avoid added sugar (soda, candy, etc.).
- Avoid “junk food” – cookies, fried chips, etc. – they contain empty calories.
- Greatly reduce or avoid fried foods or foods containing trans fats.
- Avoid artificial colors, artificial flavors, and preservatives.
- If possible, eat organic foods as they do not contain pesticides, and have more nutrients (vitamins and minerals). If eating non-organic food, wash fruit and vegetables well if eating the outside.

Benefits:

- Vegetables and fruits contain essential vitamins, minerals, and phytonutrients to improve and maintain mental and physical health.
- Protein is needed to provide amino acids, which are the building blocks for neurotransmitters and many other key amino acids and proteins in the body.
- Reduction in sugar intake can prevent rapid rises and falls in blood sugar, which can cause irritability and difficulty concentrating.
- Artificial colors and flavors can irritate some sensitive individuals, causing behavioral and other problems.
- Pesticides often contain toxic metals, and are suspected as a possible cause of some cases of autism.

Duration: Lifelong

Food Sensitivities

Rationale: Many children with autism have food sensitivities, due to abnormalities in their digestive and/or immune systems. If food is not fully-digested into individual sugars, amino acids, etc., then the

partly digested food can pass from the gastrointestinal tract into the bloodstream, especially if the child has a “leaky gut” due to inflammation. The immune system recognizes those foods as foreign, and may launch an immune response to those foods, resulting in an allergic response.

Explanation of treatment:

- Avoid allergic foods.
- Consider digestive enzymes to more fully digest foods.
- Consider other methods to heal the gut – many food allergies will disappear when gut inflammation is healed.
- Consider using a 4-day diet rotation, in which a given food is only eaten 1 day every four days, so that there is less likelihood of developing an allergy to it.

Testing:

Some allergic reactions are immediate, and some are delayed by hours or days; the latter are much harder to detect. Some responses are very strong, such as rashes or even anaphylactic shock, whereas other reactions are milder such as headaches or stomachaches. Testing can include observations, diet log, skin testing, and blood testing.

Observations: Look for red cheeks, red ears, and dark circles under eyes, which may indicate allergies. Also look for changes in behavior.

Diet Log: Keep a diet log, and look for a pattern between symptoms and foods eaten in the last 1-3 days.

Blood testing: IgE and IgG testing is offered by many commercial labs. IgE related to an immediate immune response, and IgG relates to a delayed immune response.

Skin testing: less useful than blood testing, as it only checks for immediate response.

All allergy testing is limited, in that IgE tests can be negative even if there are clinical symptoms of food allergy. IgG and IgE tests can be positive but not correlate to a clinical symptom. Use allergy testing to suggest foods to avoid, and then observe the effects.

If you cannot afford or do not wish to do the testing, another option is to try an elimination diet of the most common reactive foods which include gluten (in wheat, rye, barley, possibly oats), dairy, cane sugar, corn, soy, yeast, peanuts, egg, artificial colors and preservatives. If there is improvement, then try challenging the children with one pure food every 4 days, to see if any can be added back in. Gluten and dairy are the last challenged.

Benefits:

Removing allergic foods can result in a wide range of improvements in some children, especially improvements in behavior and attention.

Duration: Some food allergies (like peanuts) seem to be lifelong, whereas others can disappear when gut inflammation is healed and/or the immune system is normalized.

Gluten-Free, Casein-Free Diet (and often corn-free and soy-free)

Rationale: Human digestive systems have not evolved on a diet containing high amounts of wheat and dairy products. Humans are the only animal who drink milk as adults, and the only animal to drink the milk of another animal. Cows milk is a perfect food for baby cows, but not for humans, especially past age of nursing.

Over the last several hundred years, wheat has been bred to greatly increase its gluten content, and a typical US diet contains far higher amounts of wheat than humans were eating 1000-10,000 years ago. Gluten (in wheat, rye, barley, and possibly oats) and casein (in all dairy products, including milk, yogurt, cheese, ice cream, caseinate) can cause two problems:

- They are common food allergens (see previous section), especially in children and adults with autism.
- Certain peptides from gluten and casein can bind to opioid-receptors in the brain, and can have a potent effect on behavior (like heroin or morphine), causing problems including sleepiness, giddiness, inattention/"zoning out", and aggressive and self-abusive behavior. Like opioids, they can be highly addictive, and a lack of them can cause severe behaviors.

These problems appear to be due to:

- A failure of the digestive tract to fully digest the gluten and casein peptides into single amino acids
- Inflammation of the gut, allowing the gluten and casein peptides to enter the bloodstream and reach opioid receptors in the brain.

Explanation of Treatment:

- Total, 100% avoidance of all gluten products and all dairy products. Even small amounts, like a bite of a cookie, can cause allergic and/or opioid problems. Many foods have trace contamination with gluten, such as dusting French fries and raisins with wheat powder to keep them from sticking, so it can be very difficult to avoid all foods and contaminated foods.
- Digestive enzymes can also be helpful, especially if there is an accidental exposure, but they are probably not as helpful as a total avoidance of casein and gluten.
- Many children with autism also benefit by removing corn and/or soy products.

Benefits:

Children who most crave dairy and/or wheat, and who eat a lot of it, are most likely to benefit.

Casein-free diets usually produce benefits within a month, and sometimes within a week. Gluten free diets usually take 1-3 months to produce benefits. In some children there is a worsening of symptoms for a few days (similar to a drug withdrawal) followed by improvement.

Duration: At least until problems in the gut are addressed, and possibly lifelong.

Safety Note: It is important that a calcium supplement be taken while on a dairy-free diet unless a child has an exceptionally nutritious diet rich in calcium.

Testing: There are tests available for allergies to wheat and dairy. However, a negative allergy test does not mean that dairy and wheat are ok, as they can also cause problems due to opioid action. A trial of avoiding the foods is the best test.

Other Diets:

Several other diets are being investigated currently. One alternative diet is the Specific Carbohydrate Diet (SCD), which involves avoiding all carbohydrates and most sugars (except monosaccharides in fruit). For more information on this diet, see www.pecanbread.com

For more information, go to: Autism Network for Dietary Intervention: www.autismndi.com

Vitamin/Mineral Supplements

Rationale: In order to be classified as a “vitamin” or “essential mineral”, many studies were conducted that showed that the lack of that vitamin or mineral resulted in disease or even death. The RDA is the minimum amount required to prevent disease, but may be less than the amount needed for optimal mental and physical health. Most people in the US consume less than the Required Daily Allowance (RDA) of one or more vitamins and minerals. For example, many women lack enough calcium and iron, leading to osteoporosis and anemia, respectively.

Explanation of Treatment:

Vitamins and minerals are available in vegetables, fruits, meat, and other sources. However, the typical U.S. diet is lacking in key vitamins and minerals, so many people need to take a supplement.

Juicing: One option is to use a juicer to make fresh vegetable/fruit juice, and storing it for up to a few days in an airtight glass container. Fresh vegetable/fruit juice is a rich source of vitamins, minerals, and other nutrients. Commercial juices are “pasteurized” or heated to destroy bacteria, which also causes a loss of some nutrients. Grinding vegetables/fruit one time provides only about half of the original vitamins/minerals, so after the first juicing it is useful to soak the pulp for about 15 minutes in a small amount of pure water (about 10% of the amount of liquid initially squeezed out), and then grind the pulp again – this will yield most of the remaining vitamins/minerals. The only small disadvantage to juicing is a loss of insoluble fiber, but the soluble fiber remains, and that is the most important fiber. However, the advantage of juicing is that it is often a very easy and tasteful way to get healthy nutrients into children who don’t eat fruits/vegetables. Some of the healthiest vegetables to use include cabbage, spinach, carrots, broccoli, parsley, oregano, mixed with a small amount of fresh fruit for flavor and other nutrients. Organic vegetables and fruits are preferred, as they have a higher amount of vitamins and minerals and less toxic pesticides. 8 ounces/day should be enough for most children and adults, depending on their intake of other vegetables and fruits.

Supplements: Vitamin/mineral supplements are largely unregulated, and some supplements do not contain what they claim, or use forms that are poorly absorbed. Some companies choose to participate in the Dietary Supplement Verification Program (DSVP) of the United States Pharmacopeia (USP) - that program verifies that the contents of the supplement match the label.

- Also, most supplements do not contain all the essential vitamins and minerals, or do not

contain enough of them.

- Several good choices for broad-spectrum vitamin/mineral supplements include Kirkman's Super Nu Thera (very high in vitamin B6), Kirkman's Spectrum Complete, Brainchild's Spectrum Support, and Awaken Nutrition. However, most of those supplements do not contain enough calcium, which is also very important to supplement, and they do not contain iron, which some children may need.
- Calcium supplements are especially important if a person is on a dairy-free diet.
- Iron supplements are needed by some typical children as well as children with autism, but should only be given if a test indicates a need, as too much iron can also be a problem.
- In general, nutritional supplements are a good way to boost key nutrients lacking in the diet.

Testing:

Most vitamin and mineral levels can be tested using blood samples taken while fasting. Vitamin Diagnostics is one of very few companies that can measure the level of all vitamins. Several commercial labs can measure the level of most minerals, most of which can be measured reliably in Red Blood Cells (RBC). Calcium is best measured in the urine, preferably with a 24-hour urine collection. Some laboratories also offer functional assessments of the need for vitamins and minerals based on blood and/or urine testing. Measure iron with serum ferritin.

Recommended Dosages:

We recommend the following dosages for people with autism as a reasonable level to start with. However, some individuals may need more or less depending on their diet and metabolic needs, and testing can help determine optimal supplement levels. Note that vitamin and minerals can have a potent effect on body function and behavior, and so start at a low dose (1/10 of that below) and then gradually increasing over 3-4 weeks.

Iron should be added only if a test indicates a need for iron – this is common, and worth testing for. Low iron is a leading cause of mental retardation in the US, and 40% of infants under the age of 2 have low iron (and so do 40% of women of child-bearing age).

The dosage below should be adjusted up or down by bodyweight; ie, half for a 30 lb child, and for 90 pounds and above give 50% more.

Duration: Lifelong, although improving diet and healing gut may reduce the need for supplementation.

Safety Note: Most vitamins are water soluble, and excess amounts of them will be safely excreted in the urine. Some vitamins (vitamins A, D, E, K) are fat soluble, and excess amounts of those can build up in the body and cause toxicity if taken at high levels (above what we recommend) for a long time.

Research:

One small double-blind, placebo-controlled study published by Adams et al. found that a strong, balanced multi-vitamin/mineral supplement resulted in improvements in children with autism in sleep and gut function, and possibly in other areas. Adams JB et al., Pilot study of a moderate dose multivitamin-mineral supplement for children with autistic spectrum disorder. J Altern Complement Med.

2004 Dec;10(6):1033-9.

One study found that high-dose vitamin C (1.1 g per 10 kg bodyweight) helped children with autism. Dolske MC et al., A preliminary trial of ascorbic acid as supplemental therapy for autism. *Prog Neuropsychopharmacol Biol Psychiatry* 1993 Sep;17(5):765-74.

Several studies have demonstrated that children with autism have substantial oxidative stress, suggesting either a low level of key antioxidants or an increased need for them. For more information, go to: <http://autism.asu.edu> .

High-Dose Vitamin B6 and Magnesium

Rationale There are over 20 studies of vitamin B6 with Magnesium for autism, including 12 double-blind, placebo-controlled studies, making it one of most studied treatments for autism. Almost all of these studies found that 45-50% of children and adults with autism benefited from high-dose supplementation of vitamin B6 with magnesium. Vitamin B6 is required for over 100 enzymatic reactions, including the production of major neurotransmitters (serotonin, dopamine, and others) and glutathione (needed for detoxification). Magnesium is used to prevent the possibility of hyperactivity, which can occur if the vitamin B6 is taken by itself.

Most of the studies used dosages of about 8-15 mg/pound of B6 (maximum of 1000 mg). Only 1 study used a lower dosage (1.3 mg/pound), and that is one of the few studies that found no benefit.

A dosage study by T. Audhya steadily increased the dosage of vitamin B6 from 1 to 10 mg/pound. They found that at least 3 mg/pound was needed to begin to see benefits, and 6 mg/pound was enough for most children to see benefit.

The reason why many children and adults benefit from high-dose vitamin B6 is still unclear, but a possible explanation is that many children and adults with autism have both 1) a decreased ability to convert vitamin B6 to its active form, and 2) defective enzymes for making key neurotransmitters that require an unusually high amount of the active form of vitamin B6. (For more explanation see Adams et al, Abnormally high plasma levels of vitamin B6 in children with autism not taking supplements compared to controls not taking supplements. *J Altern Complement Med.* 2006 Jan-Feb;12(1):59-63).

Treatment: Based on a review of all the research, Dr. Bernard Rimland has recommended a dosage of about 8 mg/pound of vitamin B6 (maximum of 1000 mg) and half as much magnesium. However, he emphasized that some individuals with autism need somewhat more or less.

It should be noted that all the treatment studies involved children and adults who were generally not following DAN! Interventions, and it is possible that the other DAN! Interventions may reduce the need for high-dose vitamin B6 in some children and adults.

Test: There is not yet a lab test to determine who will benefit from high-dose vitamin B6, although measurements of low neurotransmitters might be a possible clue. The best test is simply a 2-month trial, slowly increasing the dose from 1 mg/pound bodyweight to 8 mg/pound bodyweight of B6, and half as

much magnesium.

Safety: High dose supplementation of vitamin B6 in children and adults with autism appears to be very safe. One study by Audhya compared 6 months of treatment with high-dose vitamin B6 in two forms (P5P or pyridoxine HCl) in 184 children with autism, and found adverse side-effects (worsening of behaviors) in 10% of those children receiving P5P (half the group) vs. none in those receiving pyridoxine HCl. However, a few children can do better on P5P. So, we suggest first starting with pyridoxine HCL, and then consider adding some P5P (5-25 mg) to see if further improvement occurs.

There is a small possibility that high dose vitamin B6 could cause temporary peripheral neuropathy (loss of feeling in fingers and toes), but this is extremely rare, and stopping supplementation generally results in full recovery.

For more info: A summary of vitamin B6 studies in autism is available at <http://www.autismwebsite.com/ari/treatment/b6studies.htm> .

Essential Fatty Acids

Rationale: Essential fatty acids are critical nutrients for humans. They exist in the cell membrane of every cell, and roughly 20% of an infant's brain is composed of essential fatty acids. Mother's milk is very rich in essential fatty acids, but some infant formulas lack this key ingredient needed for brain development.

Two general categories of essential fatty acids are omega-3 and omega-6. Omega-3 fatty acids have relatively short shelf-lives, so commercial food processing often hydrogenates or partially hydrogenates them, which provides long shelf life but eliminates their nutritional value. Thus, over 80% of the US population has low levels of omega 3 fatty acids – this is one of the most widespread nutritional problems in the US.

Low levels of essential fatty acids are associated with a wide range of psychological disorders, including depression, post-partum depression, bipolar (manic/depression) and Rett's syndrome (similar to autism). Most importantly, two published studies have found that children with autism have lower levels of omega –3 fatty acids than the general population.

Explanation of Treatment:

One of the best sources of omega 3 fatty acids are fish, who obtain them from algae and plankton in the sea. Unfortunately, many fish are high in mercury and other toxins, especially the large predators (shark, swordfish, and tuna). Small fish, such as salmon and shrimp, tend to have lower levels of mercury, but it depends where they come from. So, it is generally safer for children to obtain essential fatty acids from fish oil, since little mercury is stored in the oil. Because fish oil (and fish) spoil readily, it is important to obtain a high-quality oil that does not smell or taste rancid, and it should be kept refrigerated.

Two of the major omega 3 fatty acids are EPA and DHA. DHA is critical for early brain development, and EPA is useful for later development.

Recommended dosages: (based on the amount of omega 3's, not the total amount of oil which will contain

other oils) are:

Omega 3: 20-60 mg/kg (600-1800 mg for a 30 kg, or 60 lb, child). For younger children, use a supplement richer in DHA, and for older children and adults, use a supplement richer in EPA.

Omega 6: $\frac{1}{4}$ as much omega 6 as omega 3; so, if taking 1000 mg of omega 3's, then 250 mg of omega 6. It is important to maintain a balance of omega 3 and omega 6, so although most people in the US have enough omega 6, those taking an omega 3 supplement usually should take more.

Flax seed oil is also a source of omega 3 fatty acids, but the form it provides (alpha linolenic acid) must be converted by the body to the active form (EPA and DHA). There have been some reports that children with autism respond poorly to flax seed oil, so we generally recommend fish oil instead.

Cod liver oil (or other fish liver oil) is a good source of omega 3 fatty acids, and also provides good amounts of vitamin A and vitamin D. However, vitamin A intake from all supplements should not greatly exceed the RDA intake (see vitamin/mineral section) for extended periods, since excess amounts will be stored in the liver and could affect liver function. (Carotenes are pre-vitamin A and are not a problem).

Testing:

The level of essential fatty acids can be measured in the red blood cell membrane. However, because most people in the US have low levels of omega 3's, it is desirable to reach levels at the top of the "normal" range for omega 3's. Also, it is better to measure the absolute amount of each fatty acid, rather than just the percentage of each.

Research:

There is a huge number of scientific studies showing that humans need essential fatty acids, and that most people in the US do not consume enough. As mentioned above, 2 studies found that children with autism have lower levels of omega 3 fatty acids than do typical children. There have been four treatment studies for children/adults with autism.

A 90-day open trial of essential fatty acids in 18 children with autism found significant increases in language and learning skills. Patrick L and Salik R, The Effect of Essential Fatty Acid Supplementation on Language Development and Learning Skills in Autism and Asperger's syndrome. Autism/Asperger's Digest: Research Article – Jan/Feb 2005.

One small double-blind, placebo-controlled treatment study by Amminger et al. found that fish oil might have some benefit in reducing hyperactivity, but the numbers were too small to be statistically significant.

One study by Adams et al. found that 2 months supplementation of fish oil (rich in DHA) led to significant improvements in sociability and other areas, especially in children and adults who consumed 0-1 servings of fish/month.

One open study by Audhya et al. was a 9-month treatment study. They found little improvement by 6 months, but substantial improvements by 9 months. The largest improvement was in gut function

(verified by pre and post endoscopies in many cases), but also improvements in other areas.

For more info: see www.nordicnaturals.com

Digestive Enzymes

Rationale: The body normally produces a variety of digestive enzymes to break large food molecules into smaller ones which can be absorbed. Different enzymes are needed for different types of protein, carbohydrates, and fats. Children with autism sometimes have low levels of certain enzymes, or less active enzymes, or both – enzyme problems are especially common in children with gut problems (chronic constipation or diarrhea).

One digestive enzyme, DPP4, is easily deactivated by small amounts of toxins including mercury and organophosphates (pesticide sprays). DPP4 is needed to digest some peptides from casein and other substances that can have an opioid-like effect.

Treatment: Take a digestive enzyme with each meal, usually at the start of the meal. Use enzymes that are as complete as possible. Proteases are needed for protein, lipases for fats, and disaccharidases and other enzymes for carbohydrates.

Note that we recommend digestive enzymes in addition to special diets, and should not be used instead of special diets. If a child has a problem digesting wheat or dairy products, it is best to just avoid them, and use the digestive enzymes as a precaution against unknown exposures.

Sometimes during detoxification treatments, toxic elements such as mercury are freed from sequestration inside cells and they are "removed" via bile. However, once in the small intestine, these toxics (mercury) can bind to and inactivate digestive enzymes such as peptidases (DPP4) and disaccharidases which are needed to break down complex sugars. There are reports of "no evidence of need" for digestive enzymes until detoxification was started. The message is that there can be several reasons for use of digestive aids and that "things change".

Testing: A Comprehensive Digestive Stool Analysis can reveal if some types of foods are not being digested well, suggesting a problem with specific digestive enzymes.

Gut Treatments: Anti-fungals and Probiotics

Rationale: The human gut contains a large number of bacteria (10x more gut bacteria than cells in the entire body). Most of these gut bacteria are beneficial, and help with food digestion, water balance, and limiting the growth of harmful bacteria and yeast.

Some children with autism have low levels of beneficial bacterial, and high levels of harmful bacteria and yeast. The harmful bacteria and yeast produce toxins that can severely affect mental functioning and behavior; alcohol is just one of many toxins that yeast can produce, and is a good example of a yeast toxin that can severely affect behavior. It seems that the best way to treat these problems is with a combination of antifungal diet, antifungal medications (if yeast are present) and probiotics (beneficial bacteria). These

can help restore normal gut function.

Treatment:

Anti-fungal Diet: Yeast feed on sugar and simple carbohydrates, so reducing or avoiding those foods is important. Also, it can be helpful to avoid foods containing yeast or yeast products, including fruit juice, vinegar (in ketchup and other foods), leavened foods (bread, pizza, bagels, rolls), cheese, and mushrooms (a type of yeast/fungus).

Duration: Dr. Sidney Baker recommends a trial for 5-14 days, followed by a high exposure to see if the diet makes a difference. If so, continue long-term.

Anti-fungal Medications: There are several prescription and non-prescription anti-fungal treatments, and sometimes several need to be tried before finding an effective one for a given strain of yeast. Nystatin is the safest because it is not absorbed, but many yeast are now resistant to it. Diflucan, Sporanox, Lamisil, and Nizoral are alternatives which yeast are less likely to be resistant to, but since they are absorbed into the body they have a very small chance of overtaxing the liver, so liver enzymes should be checked every few months if they are used long-term. Some non-prescription antifungal treatments include caprylic acid, oregano concentrate, citrus seed extract, undecylenic acid, and pau d'arco. An unusual treatment is *saccharomyces boulardii*, a harmless yeast that will kill off other yeast and promote beneficial bacteria, but will disappear within a few weeks when you stop taking it, often leaving behind a now healthy gut.

Duration: Dr. Sidney Baker recommends a series of high-dose trials of 2-3 weeks for each antifungal, followed by the next one until you find one that works.

Die-off reaction: When yeast are killed, they can release all their toxins at once. This can cause a temporary “die-off” reaction lasting a few days, followed by good improvement when the toxins leave the body. Activated charcoal can be taken to absorb these toxins and reduce side-effects.

Probiotics: Probiotics are mixtures of one or more beneficial bacteria which are normally present in the gut. Many probiotics contain only a few billion or less Colony Forming Units (CFU's), but some strong probiotics contain 30-75 billion CFU's, and some prescription probiotics contain up to 500 billion CFU's. The higher-dose products are more likely to be able to reach the gut and recolonize it with good bacteria. If high-dose probiotics continue to be needed, this may suggest pancreatitis or other serious dysfunction may be present.

Duration: Use a high dose initially, and then consider a lower maintenance dose.

Testing: One simple and very useful test is to look at the stool, since half of the stool is bacteria. The stool should be a medium/dark brown and well-formed, with 1-3 bowel movements/day.

Use Antibiotics only with great caution: One round of oral antibiotics typically kills off over 99% of beneficial gut bacteria, but has little or no effect on yeast or many types of bad bacteria, which then thrive due to lack of competition from beneficial bacteria. Oral antibiotics often cause overgrowths of bad bacteria and yeast, and are suspected as the cause of many of the gut problems in autism. Several studies have shown that children with autism had, on average, a much higher usage of oral antibiotics than typical

children in their first few years of life.

Lab Testing: A Comprehensive Digestive Stool Analysis (available from Great Smokies or Doctor's Data) will reveal the amount of some types of normal and abnormal bacteria and yeast. A sensitivity analysis can suggest which anti-fungals are most likely to be beneficial, but often just a series of trials of different antifungals is the best approach.

Urinary organic acid testing can be done to check for abnormally high levels of metabolites from yeast, although the reliability of this test is somewhat unclear.

Research:

A large study by Rosseneau et al. found that 95% of 80 children with regressive autism and chronic constipation had roughly 10,000x the normal amount of E. Coli, and many also had similarly high levels of other types of Aerobic Gram Negative Bacilli (AGNB). A 3-month treatment study of 11 children found that a potent antibiotic (not available in the US) resulted in complete elimination of the bacteria and a great improvement or total cure of the gut problems, and a large improvement in behavior. However, when the antibiotics were stopped, the AGNB returned within a month, and the improvements in gut function and behavior were lost. A similar small treatment study by Sandler et al with another potent antibiotic (Vancomycin) again found temporary improvement in gut function and behavior, but again the gains were lost when the treatment was stopped. Sander et al, Short-term benefit from oral vancomycin treatment of regressive-onset autism. J Child Neurol. 2000 Jul;15(7):429-35..

Amino Acids

Rationale: Protein is made of long strands of individual amino acids. When protein is digested properly, digestive enzymes split the long protein molecule into small peptides and individual amino acids, which the body can absorb. Those amino acids can then be reassembled to make a wide array of critical substances, such as neurotransmitters, hormones, enzymes, antibodies, immunoglobulins, glutathione, and many other substances. Amino acids are the “building blocks” of life.

Some children with autism have self-limited diets that are low in protein, and some have digestive problems that limit their ability to digest protein into individual amino acids. Either of these problems can lead to insufficient amino acids.

Treatments:

- Ensure diet contains sufficient protein (two 4-oz servings/day).
- Consider digestive enzymes to more completely digest the protein into individual amino acids
- Give “free-form” amino acids; “free-form” means that the amino acids exist as individual molecules, rather than part of a large protein molecule that needs to be digested. General amino acid supplements are available, and they can also be customized by a compounding pharmacy.

Testing:

Amino acids can be tested either from blood (when fasting for 10 hours) or from a urine sample (24 hour is best). Fasting blood plasma reveals circulating levels of amino acids related more to metabolism than to

diet/digestion. 24-hour urine amino acid analysis shows what's in excess or not usable and what's deficient, if kidney transport is normal. Urine has to be interpreted carefully, as high levels in the urine can indicate "wasting" or excessive excretion, resulting in a low body level.

It may also be useful to measure levels of neurotransmitters in platelets (blood), as low levels of neurotransmitters can be treated by supplementing with amino acids, allowing the body to build their own.

Research:

One study by Aldred et al. found that patients with autism or Asperger syndrome and their siblings and parents all had raised glutamic acid, phenylalanine, asparagine, tyrosine, alanine, and lysine ($p < .05$) than age-matched controls, with reduced plasma glutamine. Other amino acids were at normal levels. This suggests a general disorder of amino acid metabolism in their families. Aldred S, Moore KM, Fitzgerald M, Waring RH. Plasma amino acid levels in children with autism and their families. *J Autism Dev Disord*. 2003 Feb;33(1):93-7.

Melatonin

Rationale: Many children and adults with autism have sleep problems, including falling asleep, nighttime waking, and early waking. These sleep problems have a strong correlation with gut problems, and healing the gut seems to reduce many of those sleep problems. However, if sleep problems continue, supplementation with melatonin can help. Melatonin is the hormone the body naturally produces at nighttime to regulate sleep. It is formed from the neurotransmitter serotonin, so low serotonin levels can cause low melatonin levels.

Testing: The best test for melatonin is simply a trial of it if a person has continuing sleep problems not due to other causes (see below).

Treatment: Melatonin production is greatly reduced by light, and even a simple nightlight can greatly decrease melatonin production. So, first try eliminating all sources of light.

For problems falling asleep, first try a behavioral approach of a regular nighttime routine (at a fixed time, begin bath/shower, brush teeth, story, etc.). Also, be sure to eliminate caffeine and reduce sugar intake at nighttime.

If sleep problems persist, start with 1 mg of melatonin (0.5 mg for children), and increase up to 2-5 mg if necessary (1-3 mg for children). If waking occurs during the night, then try a time-release form rather than increasing the dose. 2 mg time-release can be better than 5 mg all at once.

Safety: Melatonin seems to be exceptionally safe, and high dosages in animals produce no toxicity, and a study of 1400 women taking 75 mg/day for up to 4 years with no adverse effects. In fact, animal studies suggest that long-term use of melatonin can increase lifespan 20%, presumably due to its strong antioxidant effect.

Thyroid Supplementation

Rationale: About 5-10% of the general population has a thyroid disorder requiring supplementation, and that percentage may be higher in autism. Poor thyroid function due to lack of iodine is the major cause of mental retardation in the world, resulting in over 80 million cases of mental retardation. Poor thyroid function can be caused by other factors as well.

Testing:

A simple initial assessment can be done by measuring body temperature before waking. A low body temperature is a good indicator of too low a level of thyroid function. Overall low energy/activity level can also be a possible indicator of a thyroid problem, but could be caused by other factors also.

A blood thyroid test can also be done. However, some laboratory reference ranges may be too broad, and should be interpreted carefully. A very sensitive urinary thyroid test is available from Vitamin Diagnostics.

Treatment:

If iodine levels are low, then one can begin with iodine supplementation. If that does not normalize thyroid levels, then one can consider thyroid supplements. We recommend natural thyroid supplements derived from animals, as they will provide a complete thyroid source. Synthetic thyroid supplements are NOT recommended, as they are incomplete.

Duration:

Usually 1-2 months of supplementation is needed to observe an increase in energy level and body temperature. Supplementation may be needed long-term unless the problem with thyroid development is resolved.

CAUTION:

Too much thyroid hormone can cause weight loss and other problems, so thyroid levels should be monitored regularly if taking a supplement.

Research:

One study by Adams et al found that many children with autism have unusually low levels of iodine in their hair, which possibly suggests a low level in their body and need for more. Adams JB et al., Analyses of toxic metals and essential minerals in the hair of Arizona children with autism and associated conditions, and their mothers. Biol Trace Elem Res. 2006 Jun;110(3):193-209.

Glutathione Therapy

Rationale: Many children with autism have low levels of active glutathione, which is needed to protect the body from many toxins including toxic metals.

Treatment: There are many ways to increase active glutathione levels. They include:

- Oral glutathione: Only about 10% of oral glutathione is absorbed, so this method is not

very effective at raising body levels, but it may improve levels in the gut.

- IV glutathione: The IV form is highly effective, but temporary, and it can be difficult to administer regularly to the child.
- Vitamin C: 500 mg of vitamin C was found to raise RBC glutathione levels 50% in college students.
- Johnston et al, Vitamin C elevates red blood cell glutathione in healthy adults. Am J Clin Nutr. 1993 Jul;58(1):103-5.
- TMG/Folinic Acid/methyl-B12: A study by James et al. found that 800 mcg of folinic acid and 1000 mg of TMG somewhat improved plasma glutathione levels in children with autism. Adding subcutaneous injections of methyl-Vitamin B12 (methyl-cobalamin) resulted in normalization of plasma glutathione levels.
- James et al, Metabolic endophenotype and related genotypes are associated with oxidative stress in children with autism. Am J Med Genet B Neuropsychiatr Genet. 2006 Dec 5;141(8):947-56.
- DMSA (chelation): Toxic metals such as mercury can greatly decrease the body's ability to make glutathione, so removing toxic metals by chelation seems to greatly help glutathione production.

Research:

A large study by James et al confirmed her original finding of low glutathione in children with autism due to abnormalities in their methionine pathway. She also found that children with autism were more likely to have genetic polytypes associated with abnormalities in the methionine pathway. James et al. Metabolic endophenotype and related genotypes are associated with oxidative stress in children with autism. Am J Med Genet B Neuropsychiatr Genet. 2006 Dec 5;141(8):947-56.

A study by Adams et al. found that DMSA (chelation) resulted in a great improvement or normalization of RBC (red blood cell) levels of glutathione after just 1 round (3 days) of DMSA treatment, with benefits lasting at least 1-2 months. Adams et al, Preliminary results of DMSA treatment study, presentation at Fall DAN! Conference 2006.

Chelation: Removal of Toxic Metals

Rationale: Many children with autism have a low amount of active glutathione, and a higher fraction of their glutathione is oxidized (inactive). Glutathione is the body's primary defense against mercury, toxic metals, and many toxic chemicals, so a low level of glutathione results in a higher body burden of toxins. Also, many children with autism had increased use of oral antibiotics in infancy, which alter gut flora and thereby almost completely stop the body's ability to excrete mercury. Normalizing glutathione, restoring gut flora, and removing toxic metals often results in reduction of the symptoms of autism.

Preparation for Treatment: Prior to beginning chelation, it is important to first prepare the body for it. This includes:

- Reducing exposure to toxins (organic food, reverse osmosis water, no mercury fillings, avoiding pesticides, etc.).

- Improving levels of essential vitamins and minerals – see section on vitamins and minerals.
- Improving glutathione levels - see section on glutathione.
- Treating gut dysbiosis – see sections on gut treatments.

Testing:

There are several good ways to test for heavy metal toxicity. They include:

- Urinary porphyrins: This test checks for abnormal levels of porphyrins in the urine, where different porphyrin levels appear to correlate with body burden of mercury, lead, or other toxic metals. See <http://www.labbio.net>
- Challenge dose: Give a trial of DMSA or DMPS, and measure the level of toxic metals in the urine before and after taking it. A large increase indicates that the metals are present, and that the medication is helpful in removing them.

Hair, blood, and unprovoked urine testing only indicate recent exposure to toxic metals, and are NOT useful in determining past exposure. Children may have a high body burden but a low level in their current hair, blood, or urine.

Treatment: The chelation treatments recommended by DAN! include DMSA, DMPS, and TTFD.

DMSA: Oral DMSA is approved by the FDA for treating lead poisoning in children. Some of the compounded rectal suppositories also appear to increase excretion of toxic metals, but the transdermal forms do not measurably increase excretion of toxic metals.

Safety: DMSA only slightly affects excretion of most essential minerals, so a basic mineral supplement can compensate for this. The exception is that the first dose of DMSA removes a significant amount of potassium (equivalent to that in a banana), and that is not included in mineral supplements, so 1-2 servings of fresh fruit or vegetables should be consumed to restore potassium levels. DMSA also significantly increases excretion of cysteine, so that should be supplemented before and/or during therapy.

DMSA has a small chance of increasing liver enzymes or decreasing blood cell count, so those should be monitored during treatment.

DMPS: DMPS is not approved by the FDA, but a physician may have it legally compounded for IV, oral, and rectal use, all of which increase excretion of toxic metals. The transdermal form does NOT appear to increase excretion of toxic metals.

Safety: DMPS slightly increases the excretion of some essential minerals, so a basic mineral supplement is recommended to compensate for this loss. It is unknown if it causes a loss of potassium. DMPS has a small chance of increasing liver enzymes or decreasing blood cell count, so those should be monitored during treatment.

TTFD: A small pilot study of TTFD (used as a rectal suppository) resulted in some increase in excretion of arsenic and possibly other metals, and also significant reduction of autistic symptoms. The transdermal

form may also work, although more study is needed.

Safety: TTFD appears to be very safe, with animal studies at high doses finding no evidence of toxicity.

More info: Anyone considering chelation therapy is urged to read the DAN! Consensus Report on Treating Mercury Toxicity in Children with Autism, available at www.autismresearchinstitute.com. This report provides more detailed advice on pre-treatments, treatments, dosages, and safety.

Research:

There is substantial evidence to suggest that many children with autism suffer from exposure to mercury, and probably other toxic metals and toxic chemicals. The data includes:

- A literature review by Bernard et al showing that the symptoms of autism were very similar to those of people suffering from infantile exposure to mercury poisoning.
- Bernard S et al, Autism: a novel form of mercury poisoning. *Med Hypotheses*. 2001 Apr;56(4):462-71.
- A study by James et al. found that children with autism had low levels of glutathione, which is the body's primary defense against mercury. James et al, Metabolic endophenotype and related genotypes are associated with oxidative stress in children with autism. *Am J Med Genet B Neuropsychiatr Genet*. 2006 Dec 5;141(8):947-56.
- A large study by Nataf et al. found that over half of children with autism had abnormal levels of a porphyrin in their urine that highly correlates with a high body burden of mercury. Nataf R et al., Porphyrinuria in childhood autistic disorder: implications for environmental toxicity. *Toxicol Appl Pharmacol*. 2006 Jul 15;214(2):99-108
- A study by Bradstreet et al. found that children with autism excreted 3-6x as much mercury as did typical children when both were given DMSA. Bradstreet J., Geier DA, Kartzinell JJ, Adams JB, Geier MR, A Case-Control Study of Mercury Burden in Children with Autistic Spectrum Disorders, *J. Am. Phys. Surg* 8(3) 2003 76-79.
- A baby hair study by Holmes et al. found that children with autism had unusually low levels of mercury in their baby hair (1/8 normal), suggesting a decreased ability to excrete mercury. A replication study by Adams et al. found similar, although less dramatic, differences. The Adams et al study also found that children with autism had much higher usage of oral antibiotics than did typical children, which is important because usage of oral antibiotics almost completely stops the body's ability to excrete mercury. Holmes AS, Blaxill MF, Haley BE. Reduced levels of mercury in first baby haircuts of autistic children. *Int J Toxicol*. 2003 Jul-Aug;22(4):277-85.
- A small pilot study by Adams et al found that children with autism had 2x more mercury in their baby teeth than did typical children, suggesting that they had a higher body burden of mercury during their infancy when the teeth formed. That study also found that children with autism had a much higher usage of oral antibiotics during their infancy, similar to their baby hair study.
- Two studies of airborne mercury, in Texas and in the San Francisco Bay area, found that the amount of mercury in the air correlated with the incidence of autism. Windham et al, Autism spectrum disorders in relation to distribution of hazardous air pollutants in the San

Francisco bay area. Environ Health Perspect. 2006 Sep;114(9):1438-44. Palmer RF et al., Environmental mercury release, special education rates, and autism disorder: an ecological study of Texas. Health Place. 2006 Jun;12(2):203-9.

· There have been nine epidemiological studies of the link between thimerosal in vaccines and autism. Four published studies by the Geiers have consistently found that children who received thimerosal in their vaccines had a 2-6x higher chance of developing autism than those who received thimerosal-free vaccines. Four published studies by groups affiliated with vaccine manufacturers have failed to find a link, and one was inconclusive. Three of the studies were conducted in other countries where the usage of thimerosal is much less and the incidence of autism is much lower, so those results have limited relevance to the US.

Immune System Regulation

Rationale: Several studies have found abnormal immune systems in autism, generally with shift to Th-2, and some evidence for auto-immunity. Molloy et al., Elevated cytokine levels in children with autism spectrum disorder, J. Neuroimmunol 172 (2006) 198-205.

Treatments: More research on effective treatments for normalizing the immune system in children with autism are needed. If lab testing reveals abnormal immune system, current possible treatments include Actos (pioglitazone), intra-venous immunoglobulins (IVIG), and low-dose naltrexone.

Research:

IVIG: Gupta et al., found IVIG benefited 4 of 10 children, with 1 case of marked improvement. This is an expensive treatment, as the immunoglobulins need to be collected from hundreds or thousands of human donors. Gupta et al., Treatment of children with autism with intravenous immunoglobulin. J Child Neurol. 1999 Mar;14(3):203-5. No abstract available.

Twenty six autistic children received intravenous gamma globulin (IVIG) every 4 weeks for 6 months at a dose of 400mg/Kg. Aberrant behaviors, speech, hyperactivity, inappropriate stims and social interactions significantly improved. However 22 of the 26 children regressed within 4 months after discontinuing IVIG. Boris m, Goldblatt A, Edelson SM; Improvement in children with autism treated with intravenous gamma globulin. Journal of Nutritional & Environmental Medicine, Dec 2005; 15(4): 169-176.

ACTOS: (pioglitazone) has multiple effects, including the ability to decrease inflammation. An open study of ACTOS in 25 children with autism for 3-4 months found substantial improvements in irritability, lethargy, stereotypy, and hyperactivity, with greater benefits in the younger children.

Doses were 30 mg (younger children) and 60 mg (older children) Boris et al., Effect of pioglitazone treatment on behavioral symptoms in autistic children, accepted in J. Neuroinflammation 2007.

Low-dose naltrexone:

There have been 14 clinical trials of naltrexone for children with autism. A review paper by Elchaar et al. reported "Naltrexone has been used most commonly at doses ranging from 0.5 to 2 mg/kg/day and found to be predominantly effective in decreasing self-injurious behavior. Naltrexone may also attenuate hyperactivity, agitation, irritability, temper tantrums, social withdrawal, and stereotyped behaviors.

Patients may also exhibit improved attention and eye contact. Transient sedation was the most commonly reported adverse event.” Elchaar et al., Efficacy and safety of naltrexone use in pediatric patients with autistic disorder. *Ann Pharmacother*. 2006 Jun;40(6):1086-95. Epub 2006 May 30. Review.

It has been suggested that low-dose naltrexone, at about 3-5 mg/day (much lower than the doses mentioned above) may be beneficial to children with autism and may improve the regulation of their immune system. More research is needed.

Summary

Autism is a very complex disorder, and we do not fully understand it. However, there are many biomedical abnormalities that have been identified, and most can be treated to some degree. By following the testing and treatments outlined above, many children will improve to some degree, and some will improve dramatically. Sometimes one treatment shows great benefit, but it is more common that each treatment helps a small amount. However, the cumulative effect of multiple treatments can be substantial. Younger children are the ones most likely to benefit, especially those who had a period of normal development followed by regression, but older children and adults can often benefit from the same treatments outlined here.

Much more research is needed to improve on these treatments and to determine who is most likely to improve, and to discover new treatments.

<http://www.autism-society.org/living-with-autism/treatment-options/summary-of-biomedical.html>

Facts and Stats

Autism now affects 1 in 88 children and 1 in 54 boys

- Autism prevalence figures are growing
- Autism is the fastest-growing serious developmental disability in the U.S.
- Autism costs a family \$60,000 a year on average
- Autism receives less than 5% of the research funding of many less prevalent childhood diseases
- Boys are nearly five times more likely than girls to have autism
- There is no medical detection or cure for autism
- 1 percent of the population of children in the U.S. ages 3-17 have an autism spectrum disorder.¹
- Prevalence is estimated at 1 in 88 births.²
- 1 to 1.5 million Americans live with an autism spectrum disorder.³

- Fastest-growing developmental disability; 1,148% growth rate.⁴
- 10 - 17 % annual growth.⁵
- \$60 billion annual cost.⁶
- 60% of costs are in adult services.⁷
- Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention.⁸
- In 10 years, the annual cost will be \$200-400 billion.⁹
- 1 percent of the adult population of the United Kingdom have an autism spectrum disorder.¹⁰
- The cost of autism over the lifespan is 3.2 million dollars per person.¹¹
- Only 56% of students with autism finish high school.¹²
- The average per-pupil expenditure for educating a child with autism was estimated by SEEP to be over \$18,000 in the 1999-2000 school year. This estimate was nearly three times the expenditure for a typical regular education student who did not receive special education services.¹³
- The unemployment rate for people with disabilities was at 14%, compared with 9% for people without a disability. Additionally, during the same period, only 21% of all adults with disabilities participated in the labor force as compared with 69% of the non-disabled population.¹⁴

<http://www.autism-society.org/about-autism/facts-and-statistics.html>

- Autism Spectrum Disorders (ASD) are a complex set of neurological disorders that severely impair social, communicative and cognitive functions.
- Individuals with ASD suffer from cognitive impairments, though some have typical or above average IQs.
- Typical ASD behaviors include stereotyped actions (hand flapping, body rocking), insistence on sameness, resistance to change and, in some cases, aggression or self-injury.
- Between 30-50% of people with autism have seizures.
- Autism was originally believed to be a form of schizophrenia brought on by a traumatic experience or bad parenting. This is not the case.
- In 2012, the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network determined that approximately 1 in 88 children (1 in 54 for boys, and 1 in 252 for girls) is diagnosed with an autism spectrum disorder in the United States.
 - Autism was first described by Dr. Leo Kanner in 1943. He reported on eleven children who showed a marked lack of interest in other people, but a highly unusual interest in the inanimate environment.
 - <http://www.autismsciencefoundation.org/quick-facts-about-autism>

- About 1 in 88 children has been identified with an autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.
- ASDs are reported to occur in all racial, ethnic, and socioeconomic groups.
- ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252).
- Studies in Asia, Europe, and North America have identified individuals with an ASD with an average prevalence of about 1%. A recent study in South Korea reported a prevalence of 2.6%.
- About 1 in 6 children in the U.S. had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.
- Studies have shown that among identical twins, if one child has an ASD, then the other will be affected about 36-95% of the time. In non-identical twins, if one child has an ASD, then the other is affected about 0-31% of the time. [\[1-4\]](#)
- Parents who have a child with an ASD have a 2%–18% chance of having a second child who is also affected. [\[5,6\]](#)
- ASDs tend to occur more often in people who have certain genetic or chromosomal conditions. About 10% of children with autism are also identified as having Down syndrome, fragile X syndrome, tuberous sclerosis, and other genetic and chromosomal disorders. [\[7-10\]](#)
- The majority (62%) of children the ADDM Network identified as having ASDs did not have intellectual disability (intelligence quotient ≤ 70)
- Children born to older parents are at a higher risk for ASDs.
- A small percentage of children who are born prematurely or with low birth weight are at greater risk for having ASDs.
- ASD commonly co-occurs with other developmental, psychiatric, neurologic, chromosomal, and genetic diagnoses. The co-occurrence of one or more non-ASD developmental diagnoses is 83%. The co-occurrence of one or more psychiatric diagnoses is 10%.
- Research has shown that a diagnosis of autism at age 2 can be reliable, valid, and stable.
- More children are being diagnosed at earlier ages—a growing number (18%) of them by age 3. Still, most children are not diagnosed until after they reach age 4. Diagnosis is a bit earlier for children with autistic disorder (4 years) than for children with the more broadly-defined autism spectrum diagnoses (4 years, 5 months), and diagnosis is much later for children with Asperger Disorder (6 years, 3 months).
- Studies have shown that parents of children with ASDs notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills were evident from 6 months of age.
- Individuals with an ASD had average medical expenditures that exceeded those without an ASD by \$4,110–\$6,200 per year. On average, medical expenditures for individuals with an ASD were 4.1–6.2 times greater than for those without an ASD. Differences in median expenditures ranged from \$2,240 to \$3,360 per year with median expenditures 8.4–9.5 times greater.
- In 2005, the average annual medical costs for Medicaid-enrolled children with an ASD were \$10,709 per child, which was about six times higher than costs for children without an ASD (\$1,812).
- In addition to medical costs, intensive behavioral interventions for children with ASDs cost

\$40,000 to \$60,000 per child per year.^[11]

<http://www.cdc.gov/ncbddd/autism/data.html>

- Intellectual disability is the most common developmental disability.
- Approximately 6.5 million people in the United States have an intellectual disability.
- More than 545,000 children (ages 6-21) have some level of intellectual disability and receive special education services in public school under this category in IDEA, the nation's special education law.
- In fact, 1 in every 10 children who need special education have some form of intellectual disability.

<http://nichcy.org/disability/specific/intellectual#def>

TR Implications

Autism has numerous treatment implications for recreational therapy because of the significant impact on an individual's lifestyle. The main features of Autism include severe delays in language development, inconsistent pattern of sensory responses, uneven patterns of intellectual functioning with peak skills in some areas and significant deficits in others, and marked restriction of activity and interests. Beyond the public perception of Dustin Hoffman's performance in the movie Rain man, most people understand very little about this complex disorder that affects every aspect of an individual's life.

Socially, children with Autism may lack awareness of others, have severe anxiety around others, experience difficulties with reciprocity, and significant difficulties with socialization. A child with Autism will usually lack any kind of a social smile or eye contact. They lack 'normal' responses to people, they may laugh and giggle inappropriately or cry and tantrum easily. They usually have poor play skills, and spend time alone rather than with others. They show little interest in making friends and usually lack the ability to form personal attachments. Often children with Autism lack spontaneous or imaginative play. They do not imitate others' actions and they don't initiate pretend games like other children.

Autism involves many cognitive consequences including; problems with verbal commands, problems with verbal concepts and explanations, literal and concrete understanding, delayed processing, and problems with communicating. Children with Autism often focus on detail and have trouble with choices. They are unable to distinguish relevant from irrelevant information, which results in significant difficulty making decisions. They have trouble understanding cause and effect relationships and are usually not able to understand the concept of time.

Children with Autism have a strong need for sameness and they usually have a very hard time with any changes or transitions. These children have a strong need for rituals and routine and free time is very difficult for them to manage.

Children with Autism often have low muscle tone, self-injurious behavior, and unusual sleeping patterns. Autism is associated with various kinds of neurobiological symptoms, which may include unusual

reflexes and high rates of seizure disorder. Children with Autism have significant sensory and perceptual problems, including inconsistent response to sounds. They are very distractible and will over or under react to stimuli. They usually dislike certain textures. They may have a strong sensory need to smell or lick and they have a great deal of trouble screening sounds and processing words.

The lifestyle of children with Autism includes many challenges due to their organizational and sequencing problems. These children don't know where to start, what comes next, or when a task is finished. This creates significant difficulties with organizing their day or their activity involvements.

Recreational therapy interventions can help address many of these affected life areas. Recreational therapy can play a primary role in enhancing the quality of life and productivity of a child with Autism. According to the American Therapeutic Recreation Association, Recreational therapists offer individuals with disabilities the opportunity to resume normal life activities and to establish/re-establish skills for successful social integration.

<http://www.recreationtherapy.com/articles/autismandquatictherapy.htm>

Resources

-Welcome to the Autism NOW Center. The nation's source for resources and information on community-based solutions for individuals with autism, other developmental disabilities, and their families. A national initiative of The Arc. - See more at: <http://autismnow.org>

-<http://www.autismspeaks.org/family-services/resource-library>

-<http://www.nationalautismresources.com>

-<http://www.autism-resources.com/links/index.html>

<ul style="list-style-type: none">• <u>Accounts of Autistic People (31 links)</u>• <u>Asperger's Syndrome (13 links)</u>• <u>Charities & Foundations (9 links)</u>• <u>Sites with Definitions of Autism (13 links)</u>• <u>For Sale & Services (40 links)</u>• <u>Online Discussion: mailing lists, etc (27 links)</u>• <u>Sites with General Information on Autism (18 links)</u>• <u>Specific Issues (17 links)</u>• <u>Libraries (8 links)</u>• <u>Other Indexes of Links (16 links)</u>	<ul style="list-style-type: none">• <u>Methods, Treatments, Programs (98 links)</u>• <u>More Links (49 links)</u>• <u>News (11 links)</u>• <u>Non English-Language Resources (53 links)</u>• <u>Online Papers (21 links)</u>• <u>Organizations (124 links)</u>• <u>Regional Interest (6 links)</u>• <u>Not dedicated to autism but related (253 links)</u>• <u>Academic and Research Programs (21 links)</u>
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| | <ul style="list-style-type: none"> • <u>Bibliography: Books and Articles (37 links)</u> |
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Autism Society Affiliates

Autism Society affiliates (formerly referred to as chapters) are your best source of information and support. Many affiliates are volunteer-led by parents, care providers, and other professionals. The Autism Society has affiliates in 39 states reaching out to individuals with autism and their families with information, support, and encouragement. [Click here](#) to find an Autism Society affiliate in your area.

Autism Source™

The [Autism Source](#) database features thousands of resources with listings in all 50 states. The Autism Society continues to add programs, and users can recommend resources to be added through the site. Listings include physicians; psychologists; speech, occupational and behavioral therapists; schools; camps; training programs; government agencies; and much more.

Resource Materials

The Autism Society offers several [resource materials](#) with practical information on a wide range of topics. These can be downloaded using Adobe Reader.

Journal Resources

- [*American Journal on Intellectual and Developmental Disabilities*](#)
- [*Autism*](#)
- [*Clinical Neuropsychiatry*](#)
- [*Developmental Medicine and Child Neurology*](#)
- [*Education and Training in Autism and Developmental Disabilities*](#)
- [*Exceptional Children*](#)
- [*Focus on Autism and Other Developmental Disabilities*](#)
- [*Journal of Attention Disorders*](#)
- [*Journal of Autism and Developmental Disorders*](#)
- [*Journal of Child Neurology*](#)
- [*Journal of Child Psychology and Psychiatry*](#)

- *Journal of Developmental and Learning Disorders*
- *Journal of the American Academy of Child & Adolescent Psychiatry*
- *Social Neuroscience*

Online Communities/Blogs

Autism Society Blog: the Autism Society's blog

WrongPlanet.net: a web community designed for individuals (and parents/professionals of those) with autism, Asperger's Syndrome, ADHD, PDDs, and other neurological differences

Autism Blogger: online support group that allows people who have been affected by autism to share their stories, provide support and help others

Drive Mom Crazy: a young man with Asperger's Syndrome shares experiences about his world

Aspie Teacher: a former teacher diagnosed with Asperger's Syndrome writes about the struggles people on the spectrum face in education, employment and personal life

The Autism Hub: a central point for blogs about autism from autistic people, family members and students/professionals

Estée Klar: a blog by autism mom and author, curator and founder of The Autism Acceptance Project

Adventures in Autism: a mother shares about her young son's trials with autism

<http://www.autism-society.org/living-with-autism/how-we-can-help/resources.html>