

QUESTIONS AND ANSWERS
from the
Community Forum on Developmental Delays
and Autism in the Minnesota Somali Community

THE DIAGNOSIS OF AUTISM

Is autism a pre-existing condition or is it acquired after birth?

Autism is believed to be present before a child is born and typically symptoms are evident before 3 years of age.

Do we know if autism is caused by parenting styles or bad parenting?

Autism is a neurologically based developmental disorder and is not something that is caused by parenting style or bad parenting. Children with autism are not intentionally choosing to behave badly or in unusual ways. Autism cannot be cured through rituals or punishment.

There are statements that autism is present at birth, how do you explain regressive autism where children suddenly lose acquired skills?

There are a number of other health conditions that can impact development in such a way that children lose skills. For example, Sanfilippo syndrome, Spinal Muscular Atrophy and certain types of muscular dystrophy result in lost skills. It is extremely important that a child be evaluated by a physician if he or she experiences any loss of acquired skills.

When a physician is doing the physical check up for a child, doesn't he notice that a child may have autism?

There are no obvious physical characteristics or laboratory tests for diagnosing autism. A physician might not always identify if a child has autism, especially if the presentation of autism is mild. As someone who knows your child the best, it is important that you bring to your health care provider's attention any concerns you have about how your child interacts with others or if your child is not growing and learning like other children you know.

What is autism, a mental or behavior problem?

Autism is not a mental illness nor is it a behavior problem, though children with autism can have challenging behaviors. Autism is a neurologically based developmental disorder.

Can you tell us levels/degrees of autism or how it could harm the person's life in the future?

The symptoms of Autism and disorders on the autism spectrum can range from mild to severe. Autism is a condition that affects a child's overall development in 3 primary areas:

- 1) it affects the way a child communicates, understands and uses language;
- 2) it affects how the child interacts socially with others; and
- 3) it affects how the child understands and responds to his environment and the world around him or her.

How a child might function as an adult is difficult to predict because the variability in this disorder is so vast. Children with a mild to moderate type of autism and normal or superior intelligence may not be recognizable as having autism as an adult. Children with autism who have a severe or profound intellectual disability are more likely to need additional support throughout their lives.

Can a child pick up or learn autistic behaviors by living with someone that has autism?

Young children frequently imitate the behaviors of the people around them. The difference between children with autism and those without, is that the behavior of children without autism can be easily redirected by their parents or other adults.

Has anyone seen someone with autism that spoke or regained the ability to speak?

Yes, therapies directed at learning to speak or regaining speech may be successful with some children.

In the future, how can you help us and how can we prevent autism?

This is a very important question and until there is an understanding of the causes of autism, steps can not be taken to prevent it. However, it is important that early intervention occur for children who have autism or an Autism Spectrum Disorder. The Minnesota Department of Health can assist families in finding resources.

What causes autism?

Researchers have not found a specific cause for autism. About 25% of cases of autism are attributable to an underlying disorder. Evidence indicates that there are genetic factors involved and that there are biological and/or neurological differences in the brains of children with autism.

INTERVENTIONS FOR CHILDREN WITH AUTISM

How can I determine which therapy is best for my child?

The Developmental Psychology Professor who is the Chief Science Officer of Autism Speaks, Dr. Geraldine Dawson, and Clinical Psychologist Dr. Julie Osterling reviewed eight model early intervention programs for children with autism and described the following six elements that seemed to be common in effective intervention programs.

- 1) A curriculum content emphasizing five basic skills: to attend to elements of the environment that are essential for learning; to imitate others; to understand and use language; to play appropriately with toys; and to interact socially.
- 2) A supportive and structured environment that includes strategies for generalization to more complex, natural environments.
- 3) Predictability and routine to assist the child with transitions from one activity to another.
- 4) A functional approach to problem behaviors that includes recording the behavior, developing a hypothesis about the function of the behavior for the child, changing the environment to support appropriate behavior, and teaching appropriate behaviors to replace problem behaviors.
- 5) Plans for transition from preschool classroom by teaching “survival” skills that children will need later.
- 6) Family involvement as a critical component in the overall program.

The Autism Society of America's Panel of Professional Advisors has developed guidelines to help parents evaluate therapies related to autism. Here are some things to think about as you consider treatment options for your child:

- Will the treatment result in harm to my child?
- If this treatment fails, how will that failure affect my child and family?
- Has this treatment been recommended by experts and scientists who study autism?
- Is it clear how I will know my child is improving with this therapy?
- How will the treatment be integrated into my child's current program?

Make sure all your child's needs are being met by whatever therapy or program you choose for your child. Be concerned about a treatment that focuses too narrowly on one aspect of your child's needs and ignores others (for example focusing solely on speech and ignoring vocational life and social skills).

Are there other things to consider when choosing a therapy?

Consider the following questions (compiled by the National Institute of Mental Health) when you are considering a program or specific therapy for you child:

- How successful has the program been for other children?
- How many children who have received this treatment have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured?
- Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

Alternative Therapies

There were several questions posed at the forum about a variety of biologic and non-biologic treatments, therapies and providers for autism.

It is recommended that careful consideration be given to the use of alternative therapies to treat autism. Some have proven to be ineffective and others have not been sufficiently evaluated to determine if effective or if there are risks involved in their use.

ROLES OF PROFESSIONALS

What is the role of Early Childhood Educators?

Early Childhood Educators evaluate the developmental strengths and needs of each child. They develop and implement specific strategies designed to enhance each child's development. Early childhood educators also provide guidance to families so they can maximize their child's development.

Most of the Somali children have a primary care clinic. Why didn't the health care providers consult with parents about autism? Why is the school the primary alarm of autism in Somali kids?

While the Minnesota Department of Health cannot speak for private primary care providers or the schools, health care providers routinely screen for developmental delays and refer to early childhood programs for early intervention. Schools are responsible for assuring that children with developmental delays, including children with suspected autism, get the services they need as quickly as possible.

As a Somali community we feel when it comes to autism that we are very much forgotten. What will you do about that to make us feel that we are part of this State?

Minnesota works hard to help diverse communities from around the world feel welcomed in our state. Families of children with disabilities - any disabilities from any community whether foreign born or native - face many challenges and often feel isolated. Engaging with other parents of children with special needs can be particularly helpful in coping with the feelings of isolation. Organizations such as The Arc of Minnesota and The Autism Society of Minnesota work to link families. Early Childhood Programs such as Early Childhood Family Education often provide opportunities for parents of children with special needs to meet together, learn from each other and to socialize. The Minnesota Department of Health can help families find available community resources.

AUTISM OVER THE LIFE SPAN

If a child has autism, is it possible for them to become normal after a couple of years? Does autism have a cure?

There is no known cure for autism, but the symptoms associated with autism can improve over time. With therapy, educational intervention and with parents who provide a consistent, supportive environment, children can learn to communicate, have social relationships and have fewer or less intense behavior problems. Progress can sometimes be slow, so patience is needed.

INCIDENCE OF AUTISM

Where will the Minnesota Department of Health report on the incidence of autism be posted or available? Any knowledge of when?

The Minnesota Department of Health will complete the report on autism occurrence and Minneapolis Schools Early Childhood Special Education program participation by April 1, 2009 and will post it on our website.

How common is it to have multiple children in one family with autism?

Families who have one child with autism have an increased risk of having another child with autism.

GENERAL

How could you help and what would you advise in the case of the child who is not eating or is having difficulty eating? Also how could you help a child with sleeping difficulties or problems? Please advise on a child that is upset, breaking things and has little sleep?

Parents should discuss these issues with their child's physicians, therapists, and/or early childhood intervention team.

Have any of you read the book "Changing the Course of Autism" by Dr. Bryan Jepson?

There are a number of books authored by parents of children with autism or written by medical professionals that have contributed to the discussion on the causes and treatments of autism. Dr. Jepson is both a parent and a physician. It is important that accepted scientific standards be applied to any new theories in order for them to be accepted or promoted by the public health or medical community.

IMMUNIZATION QUESTIONS

Does immunizing children cause autism?

To date there have been multiple, reliable, and scientifically valid studies that have not found an association between vaccines and autism.

If parents say that their child regressed after vaccination is that being studied with lab tests?

Experts have looked at thimerosal exposure in vaccinated versus unvaccinated children and did not find a concern. They have also looked at groups of children who received MMR vaccine and those who did not, and they did not see an increase in autism if a child received an MMR vaccine.

The Somali community is concerned about children who are double immunized – once in Africa and again in the U.S. Can you comment on the safety of that and indications of damage?

Information on the safety of receiving extra vaccine doses can be found in the General Recommendations on Immunizations by the national Advisory Committee on Immunization

Practices (CDC). General Recommendations on Immunizations: Recommendations of the Advisory Committee on Immunization Practices. MMWR. 2006;Vol.55:No.RR-15:33-35.
www.cdc.gov/mmwr/preview/mmwrhtml/rr5515a1.htm

Vaccines are not the causes of autism but a carrier, just as a mosquito is not the cause but the carrier of malaria. What do you think?

Again, there have been multiple, reliable, and scientifically valid studies that have not found an association between vaccines and autism.

It is possible that a small subset of children could have a genetic predisposition, and then different environmental triggers (e.g., chemicals, pesticides, heavy metals - such as lead and mercury, poor nutrition, processed foods, possibly a very high number of immunizations given in a short period of time, possibly some fungal infections viruses or bacteria that we don't know of definitely yet, and other things not yet known), set off conditions in the body and brain that manifests itself in autistic behaviors. Can research be done in this area?

This is a very good question but a very difficult one to study because everyone is exposed to so many of these environmental factors. It is hard to separate each one out and test them.

Researchers at the Centers for Disease Control and Prevention (CDC) are trying to figure out the way to best tackle such a study project. They have studied MMR and thimerosal in vaccines and found that they were not triggers for autism.

Is there any way to convince parents that autism is not caused by the vaccine and, if so, is there something conclusive to show us?

There are many studies that have looked at vaccines and autism. No study has shown an association between vaccine and autism. Here is a listing of some of the studies so that parents can read the studies themselves if they would like.

Measles Vaccination and Antibody Response in Autism Spectrum Disorders

Authors: Baird G, Pickles A, Simonoff E, Charman T
 Source: Arch Dis Child, October 2008, Vol. 93(10):832-7

Lack of Association between Measles Virus Vaccine and Autism with Enteropathy: A Case-Control Study

Authors: Hornig M, Brieese T, Buie T, et al.
 Source: PLoS ONE, September 4, 2008, Vol. 3(9):e3140

Mercury Levels in Newborns and Infants after Receipt of Thimerosal-Containing Vaccines

Authors: Pichichero ME, Gentile A, Giglio N, et al
 Source: Pediatrics, February 2008; 121(2) e208-214

Association between Microdeletion and Microduplication at 16p11.2 and Autism

Authors: Weiss LA, Shen Y, Korn JM, et al
 Source: N Engl J Med, January 9, 2008 [Epub ahead of print]

Continuing Increases in Autism Reported to California's Developmental Services System: Mercury in Retrograde

Authors: Schechter R, Grether JK
 Source: Arch Gen Psychiatry, January 2008, Vol. 65(1):19-24

Lack of Association between Rh Status, Rh Immune Globulin in Pregnancy and Autism

Authors: Miles JH, Takahashi TN
 Source: Am J Med Genet, May 16, 2007 [Epub ahead of print]

MMR-Vaccine and Regression in Autism Spectrum Disorders: Negative Results Presented from Japan

Authors: Uchiyama T, Kurosawa M, Inaba Y
 Source: J Autism Dev Disord, February 2007; 37(2):210-217

Mutations in the Gene Encoding the Synaptic Scaffolding Protein SHANK3 are associated with Autism Spectrum Disorders

Authors: Durand CM, Betancur C, Boeckers TM, et al
Source: Nat Genet, January 2007; 39(1):25-27

A Genetic Variant that Disrupts MET Transcription is Associated with Autism

Authors: Campbell DB, Sutcliffe JS, Ebert PJ, et al
Source: Proc Natl Acad Sci USA, October 19, 2006 [Epub ahead of print]

No Evidence of Persisting Measles Virus in Peripheral Blood Mononuclear Cells from Children with Autism Spectrum Disorder

Authors: D'Souza Y, Fombonne E, Ward BJ
Source: Pediatrics, October 2006, Vol. 118(4):1664-1675

Advancing Paternal Age and Autism

Authors: Reichenberg A, Gross R, Weiser M, et al
Source: Arch Gen Psychiatry, September 2006, Vol. 63(9):1026-1032

Pervasive Developmental Disorders in Montreal, Quebec, Canada: Prevalence and Links with Immunizations

Authors: Fombonne E, Zakarian R, Bennett A, Meng L, McLean-Heywood D
Source: Pediatrics, July 2006, Vol. 118(1):e139-e150

Autism and Family Home Movies: A Comprehensive Review

Authors: Palomo R, Belinchon M, Ozonoff S
Source: J Dev Behav Pediatr, April 2006, Vol. 27(2 Suppl):S59-S68

Risk Factors for Autism: Perinatal Factors, Parental Psychiatric History, and Socioeconomic Status

Authors: Larsson HJ, Easton WW, Madsen KM, et al.
Source: American Journal of Epidemiology, May 15, 2005, Vol. 161(10):916-925

No Effect of MMR Withdrawal on the Incidence of Autism: A Total Population Study

Authors: Honda H, Shimizu Y, Rutter M
Source: Journal of Child Psychology & Psychiatry, Online Early Release

MMR Vaccination and Pervasive Developmental Disorders: A Case-Control Study

Authors: Smeeth L, Cook C, Fombonne E, Heavey L, Rodrigues LC, Smith PG, Hall AJ
Source: Lancet, September 11, 2004, Vol. 364(9438):963-9

Age at First Measles-Mumps-Rubella Vaccination in Children with Autism and School-Matched Control Subjects: A Population-Based Study in Metropolitan Atlanta

Authors: DeStefano F, Bhasin TK, Thompson WW, Yeargin-Allsopp M, Boyle C
Source: Pediatrics, February 2004, Vol. 113(2):259-266

Association Between Thimerosal-Containing Vaccine and Autism

Authors: Hviid A, Stellfeld M, Wohlfahrt J, Melbye M
Source: Journal of the American Medical Association, October 1, 2003, Vol. 290(13):1763-6

Thimerosal and the Occurrence of Autism: Negative Ecological Evidence from Danish Population-Based Data

Authors: Madsen KM, Lauritsen MB, Pedersen CB, et al
Source: Pediatrics, Sept. 2003, Vol. 112(3 Pt 1):604-606

Autism and Thimerosal-Containing Vaccines. Lack of Consistent Evidence for an Association

Authors: Stehr-Green P, Tull P, Stellfeld M, Mortenson PB, Simpson D
Source: American Journal of Preventive Medicine, August 2003, Vol. 25(2):101-6

Mercury Concentrations and Metabolism in Infants Receiving Vaccines Containing Thimerosal: A Descriptive Study

Authors: Pichichero ME, Cernichiari E, Lopreiato J, Treanor J
Source: The Lancet, November 30, 2002, Vol. 360:1737-1741

A Population-Based Study of Measles, Mumps, and Rubella Vaccination and Autism

Authors: Madsen KM, Hviid A, Vestergaard M, et al
Source: New England Journal of Medicine, November 7, 2002, Vol. 347(19):1477-1482

Relation of Childhood Gastrointestinal Disorders to Autism: Nested Case-Control Study Using Data from the UK General Practice Research Database

Authors: Black C, Kaye JA, Jick H
Source: British Medical Journal, August 2002, Vol. 325:419-421

No Evidence for a New Variant of Measles-Mumps-Rubella-Induced Autism

Authors: Fombonne E, Chakrabarti S
Source: Pediatrics, October 2001, Vol. 108(4):E58

Time Trends in Autism and in MMR Immunization Coverage in California

Authors: Dales L, Hammer SJ, Smith NJ
Source: JAMA, March 7, 2001, Vol. 285(9):1183-5

Mumps, Measles, and Rubella Vaccine and the Incidence of Autism Recorded by General Practitioners: A Time Trend Analysis

Authors: Kaye JA, Melero-Montes M, Jick H

Source: British Medical Journal, February 24, 2001, Vol. 322:460-463

No Evidence for Measles, Mumps, and Rubella Vaccine-Associated Inflammatory Bowel Disease or Autism in a 14-year Prospective Study

Source: The Lancet, May 2, 1998, Vol. 351:1327-8