Frequently Asked Questions About Autism

What causes autism?

Genetic inheritance is involved in the development of autism spectrum disorders (ASD). Genetic factors likely interact with environmental variables to result in the expression of autism. Neurobiological research indicates that autism is likely the result of genetically determined abnormalities in brain development. This abnormal brain development may start before the child is born. It has been difficult for genetics researchers to locate a specific chromosome(s) involved in autism but recent studies have identified several genetic mechanisms that each lead to autism.

How many people have autism?

The original estimates of the prevalence of autism indicated that it occurred in around 2 per 10,000 people. However, recent estimates place the prevalence as high as or higher than 1 per 68 for all autism spectrum disorders combined according to The Centers for Disease Control and Prevention (CDC). It is likely that the increased prevalence of autism is due to increased awareness of the disorder by the population at large as well as by physicians and other providers of service to children and better diagnostic tools that more accurately covers the entire autism spectrum. There is some evidence that suggests that mental retardation is being given as a primary diagnosis less often than in the past. The increased prevalence of autism coincides with this decrease. However, a true increase in the prevalence of autism across time is certainly possible.

What are some of the behaviors exhibited by a child who may have an autism spectrum disorder?

Though the presentation of symptoms with autism can vary quite a bit, there are specific behaviors necessary for diagnosing it. Impairment in reciprocal social interaction must be present. We often envision a child with autism as avoiding eye contact or perhaps as using people as they would inanimate objects. Communicative deficits also must be present for an ASD to be diagnosed. There are well-documented specific problems in communication such as incorrect usage of pronouns, but the range of impairment in this area is great and can include the absence of any functional communication skill. Repetitive behaviors and/or marked adherence to specific routines also must be present for an ASD to be diagnosed. Stereotypic behavior is quite prevalent in persons with autism and recent research indicates that though these repetitive behaviors occur during typical development, they tend to persist in children with autism beyond the developmental stages at which they are usually replaced by more functional behavior. Symbolic play deficits have also been noted to be common in children with autism.

My child is 3 and not talking yet, does this mean he has autism?

No. There are a variety of disorders that are related to limited speech development but any child that is not talking by the age of 3 should have a developmental assessment immediately. Most children are babbling before they reach their first birthday and use single words to communicate by 18 months. Any child that does not display these behaviors or who has and subsequently loses a communicative or social skill should be screened for an autism spectrum disorder as soon as possible.

What kinds of tests need to be done to diagnose autism?

There are no definitive diagnostic tests for autism. The soundest means of determining diagnosis is a thorough review of the child's developmental history and observation of their behavior in structured and unstructured situations. The diagnostic tools most often turned to by pediatricians, who are the front line of noting developmental problems, are the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD). When a pediatrician suspects autism or another developmental disorder, they should refer the child's family to a specialist in childhood development. When a child is referred to a specialist for formal testing, a caregiver interview instrument is often the first diagnostic tool used. Two tools require clinicians to receive competency-based training to implement them. One is the Autism Diagnostic Interview (ADI), developed by a panel of autism experts headed by Catherine Lord in 1994, and the other is the Diagnostic Interview for Social and Communication Disorders (DISCO), developed by Lorna Wing and colleagues in the UK. A structured observation of the child should also be conducted and the currently accepted gold standard for this is the Autism Observation Diagnostic Schedule (ADOS). Clinicians are also required to pass competency-based trainings to administer this tool.

What treatment has been proven effective for treating autism?

A recent study by Sallows and Graupner (2005) has replicated the results of Lovaas and colleagues. They indicated that a positive treatment outcome was best predicted by a child's pre-intervention language, imitation, and social skills. Another study by Howard, Sparkman, Cohen, Green, and Stanislaw (2005), compared intensive behavior analytic intervention to standard early intervention services provided to children with developmental impairment and to "eclectic" treatment. It was found that, after over a year of service delivery, children in the intensive behavioral treatment group had gained substantially more skills than either of the two comparison groups. It can be concluded from this study that ABA services alone are superior to eclectic intervention that combines ABA with unproven treatments.

What is Applied Behavior Analysis?

Applied Behavior Analysis or ABA is the application of the empirically validated principles of behavior to build skills through directed instruction and to treat problem behaviors by determining the function of them and arranging for effective intervention that addresses the behavior's function. ABA is an approach to analyzing each individual's skill deficits and problem behaviors. Though autism is a disorder that involves specific general impairments, each child brings with them a distinct set of difficulties. No single treatment package can be used for all children and ABA is a method for examining the needs of each person. Specific instruction can then be tailored to a child's unique situation.

Why ABA?

No single "treatment package" will serve every child's needs and no individual can claim to own ABA. ABA, for the treatment of autism, is the application of the principles of learning to 1) build skills and 2) treat problem behavior. It works because each person's behavior is assessed to determine what skills they have not mastered and what types of problem behavior interfere with learning and social functioning. For skill deficits, direct instruction is provided until the skill is mastered. For problem behavior, specific analysis of why the behavior occurs is used to develop treatment to eliminate the behavior or teach the person to use other more appropriate behavior to serve the same function.

Who is qualified to provide ABA services?

The person who supervises the implementation of an ABA program should be a "behavior analyst." There is a Behavior Analyst Certification Board[®] (BACB[®]) and the criteria for becoming a Board Certified Behavior Analyst[®] or BCBA[®] are listed at <u>www.bacb.com</u> (see the consumer information section, click on "Standards for becoming a BCBA or BCABA[®]"). This certification process is relatively new and if a person were to meet the academic and experiential

requirements to sit for the BACB's certification exam then such persons might be seen as having the appropriate background for supervising a program in Applied Behavior Analysis. In brief, a professional would need a Master's or PhD in a human service discipline such as psychology, education, or special education and they should have a number of graduate courses specifically in behavior analysis. Another necessary qualification is substantial relevant supervised experience in working with persons with autism. Beyond that, a BCBA or BCABA must remain abreast of developments in the field by obtaining a minimum of 36 hours of continuing education across every 3 years.

Does ABA always work?

This is a difficult question to answer. Though ABA has been shown to be effective, many of the aspects of applying the principles of behavior analysis in the treatment of autism have not been investigated thoroughly. For example, how many hours per week are necessary to produce a change is not known. Additionally, some skills are very difficult to teach and the best instructional strategies are not known. It is, however, quite likely that the proficiency of the providers of service, both direct care therapists or teachers and their supervisors will play a significant role in the progress that any child makes.

Does the MMR vaccine cause autism?

Scientific evidence indicates that there is no correlation between autism and vaccines though millions of dollars, which might otherwise have gone to funding important research, have been spent investigating this notion. Andrew Wakefield and 12 colleagues published a study in The Lancet tentatively suggesting a link. However, it was discovered that Wakefield was paid over \$100,000 by a group of lawyers and parents seeking to sue vaccine manufacturers for damages caused by the MMR injection prior to conducting his research. Additionally, participants were deliberately rather than randomly selected for the study. It is likely they were chosen to suggest a link because they had autism and gastrointestinal difficulties. This link has not been supported by subsequent scientific investigation. Madsen and colleagues (2002) conducted a large scale study in Denmark in which over half a million children born between 1991 and 1998 were studied. Nearly 100,000 were not vaccinated with the MMR vaccine. The prevalence of autism in this group was compared to that observed in the over 400,000 children who did receive the MMR vaccine. If the vaccine was related to autism a difference in prevalence would be apparent, however, prevalence was identical across the groups. This study provides overwhelming evidence against the hypothesis that MMR vaccination causes autism. The CDC, the American Academy of Pediatrics, the National Academy of Sciences Institute of Medicine, the World Health Organization, and the UK's Medical Research Council have all concluded that there is no evidence that the MMR is related to autism.

Does mercury used in vaccines cause autism?

Thimerosal is a preservative that has been used in some vaccines since the 1930s (CDC, retrieved June 2005). Thimerosal consists of 49% ethylmercury and some have suggested, partly because of the known effects of methylmercury (an environmental contaminant often found in fish) as a toxic substance, that thimerosal delivered in vaccines causes autism to develop in some children. Much is known about the effects of the more dangerous methylmercury. Massive systemic damage can occur through excessive methylmercury exposure. The Food and Drug Administration (EPA, retrieved June 2005) has advised pregnant women, nursing mothers, and young children limit their intake of certain types of fish, like tuna, that tend to contain high levels of methylmercury in order to prevent excessive methylmercury consumption.

Much less is known about ethylmercury, however, the CDC reports that the cumulative exposure to ethylmercury that occurred when thimerosal was used as a preservative in vaccines was less than the FDA and World Health Organization recommended maximum safe exposure to methylmercury. However, the EPA's more stringent guideline

for methylmercury exposure was exceeded. Therefore, given the heightened concern over mercury exposure, the suggested link between thimerosal and autism, and technology that exists for eliminating ethylmercury from vaccines, thimerosal has been removed from all vaccines in the U.S. with the exception of certain flu vaccines. Research into this putative link to autism was, and still is, clearly warranted.

But is there evidence for thimerosal causing autism? The most definitive study to date was conducted by Danish researchers (Hviid et al., 2003). It looked at thousands of children who received either vaccines containing thimerosal or vaccines without this preservative and found that the rates of autism were identical in the two groups. If thimerosal was causing autism, a difference should have been found. Thimerosal had been removed from the vaccines of other developed countries such as Canada and Denmark prior to it being removed from vaccines in the U.S., however, no decrease in the prevalence of autism has been detected in these countries (NYTimes, retrieved 06/25/05). In 2003 the American Academy of Pediatrics, an organization that called for the removal of thimerosal from vaccines in July 1999, summarizes the evidence of harm from it as follows, "No scientific data link thimerosal used as a preservative in vaccines with any pediatric neurologic disorder, including autism. Despite this, the Centers for Disease Control and Prevention, American Academy of Pediatrics, National Institutes of Health, and US Public Health Service have continued to investigate this issue to put theoretic concerns about this mercury-containing compound to rest."

Why do concerns about mercury in vaccines persist?

Concerns about the thimerosal-autism link persist for a number of reasons. Methylmercury is unquestionably a toxic substance and there is warranted concern about exposure to many toxins present in the environment. Known links between toxin exposure and disease such as cancer should prompt close scrutiny by our government and the scientific community. On the other hand, reports in popular media also propagate the putative link and often present anecdotal information as just as valid as scientific evidence. Moreover, inaccuracies in reporting are often overlooked or viewed as insignificant. For example, Rolling Stone magazine recently published an article written by Robert F. Kennedy Jr. accusing the U.S. government of concealing evidence linking thimerosal-containing vaccines to autism. Particularly concerning is the lack of accuracy in his presented evidence. The following disclaimer was posted on June 20, 2005 on the Rolling Stone website acknowledging some of these inaccuracies:

"NOTE: This story has been updated to correct several inaccuracies in the original, published version. As originally reported, American preschoolers received only three vaccinations before 1989, but the article failed to note that they were innoculated a total of eleven times with those vaccines, including boosters. The article also misstated the level of ethylmercury received by infants injected with all their shots by the age of 6 months. It was 187 micrograms - an amount 40 percent, not 187 times, greater than the EPA's limit for daily exposure to methylmercury. Finally, because of an editing error, the article misstated the contents of the rotavirus vaccine approved by the CDC. It did not contain thimerosal. Salon and Rolling Stone regret the errors.

An earlier version of this story stated that the Institute of Medicine convened a second panel to review the work of the Immunization Safety Review Committee that had found no evidence of a link between thimerosal and autism. In fact, the IOM convened the second panel to address continuing concerns about the Vaccine Safety Datalink Data Sharing program, including those raised by critics of the IOM's earlier work. But the panel was not charged with reviewing the committee's findings. The story also inadvertently omitted a word and transposed two sentences in a quote by Dr. John Clements, and incorrectly stated that Dr. Sam Katz held a patent with Merck on the measles vaccine. In fact, Dr. Katz was part of a team that developed the vaccine and brought it to licensure, but he never held the patent. Salon and Rolling Stone regret the errors."

Will there be any resolution?

Because thimerosal was removed from vaccines several years ago and the prevalence of autism has continued to increase, then thimerosal in vaccines was not a cause of autism.

American Academy of Pediatrics (September 13, 2010, retrieved November 3, 2011). Study fails to show a connection between thimerosal and autism. <u>More Info</u> >>

Centers for Disease Control (retrieved November 2011). Mercury and Vaccines (Thimerosal). <u>More Info</u>>>

Environmental Protection Agency (retrieved November 2011). What you need to know about mercury in fish and shellfish. <u>More Info</u>>>

Howard, J.S., Sparkman, C.R., Cohen, H.G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. Research in Developmental Disabilities, 26, 359-383.

Hviid, A., Stellfeld, M., Wohlfahrt, J., & Melbye, M. (2003). Association between thimerosal-containing vaccine and autism. Journal of the American Medical Association, 290, 1763-1766.

New York Times - Harris, G., & O'Connor, A. (June 25, 2005). On autism's cause, it's parents vs. research. <u>More Info</u> >>

Sallows, G.O., & Graupner, T.D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. AJMR, 110, 417-438.

Shattuck, P. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. Pediatrics, 117, 1028-1037.

Wing, L. & Potter, D. (2002). The epidemiology of autistic spectrum disorders: Is the prevalence rising? Mental Retardation and Developmental Disabilities Research Reviews, 8(3), 151-161.