



Autism 101: Understanding and Communicating about Autism



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It can be frustrating to still be talking about autism and vaccines when as medical and public health professionals we know all these points are true...

1. There are dozens of studies looking at the relationship between autism and vaccines, and none indicate an association, even in genetically susceptible subgroups like younger siblings. You can read the studies for yourself here:
www.autismsciencefoundation.org/autismandvaccines.html
2. The study that originally connected autism and the MMR vaccine, conducted by Andrew Wakefield, was retracted in early 2010.¹
3. Andrew Wakefield was stripped of his medical license² and his report was deemed “an elaborate fraud”.³
4. The Vaccine Court has denied all claims in the Autism Omnibus Hearings,⁴ writing “this case is not a close case...the overall weight of the evidence is overwhelmingly contrary to the petitioners’ causation theories.”
5. More and more children are getting sick from vaccine preventable diseases like measles⁵ and pertussis.⁶



Even with all these facts, some parents may **still** question the safety and efficacy of vaccines. Some parents are also still unsure of the connection between autism and vaccines. According to a [Harris Interactive/HealthDay](#) poll published in January 2011⁷:

- **18%** of Americans say vaccines cause autism
- **30%** of Americans aren't sure

¹ ABC News. “Lancet Retracts Controversial Autism Paper.” February 2, 2010. <http://abcnews.go.com/Health/AutismNews/autism-vaccines-lancet-retracts-controversial-autism-paper/story?id=9730805>

² New York Times. “British Medical Council Bars Doctor Who Linked Vaccine with Autism.” May 25, 2010. www.nytimes.com/2010/05/25/health/policy/25autism.html

³ CNN. “Retracted autism study an 'elaborate fraud,' British journal finds.” January 5, 2011. www.cnn.com/2011/HEALTH/01/05/autism.vaccines/index.html

⁴ U.S. Department of Health and Human Services Health Resources and Services Administration. “About the Omnibus Autism Proceeding.” Last updated August 19, 2010. www.hrsa.gov/vaccinecompensation/omnibusautism.html.

⁵ CDC. “Measles --- United States, January--May 20, 2011.” May 27, 2011. www.cdc.gov/mmwr/preview/mmwrhtml/mm6020a7.htm?s_cid=mm6020a7_w

⁶ CDC. “Pertussis – Outbreaks.” Last reviewed August 20, 2010. www.cdc.gov/pertussis/outbreaks.html

⁷ Harris Interactive. “Vaccine-Autism Link: Sound Science or Fraud?” January 20, 2011. www.harrisinteractive.com/newsroom/pressreleases/tabid/446/mid/1506/articleid/674/ctl/readcustom%20default/default.aspx

Physicians are feeling the effects, according to a *Pediatrics* study published in March 2015⁸:

- **93% of physicians** reported some parents of children <2 years requested to spread out vaccines.
- **21% reported ≥10% of parents** made this request.
- **40% of physicians** reported this issue had decreased their job satisfaction.



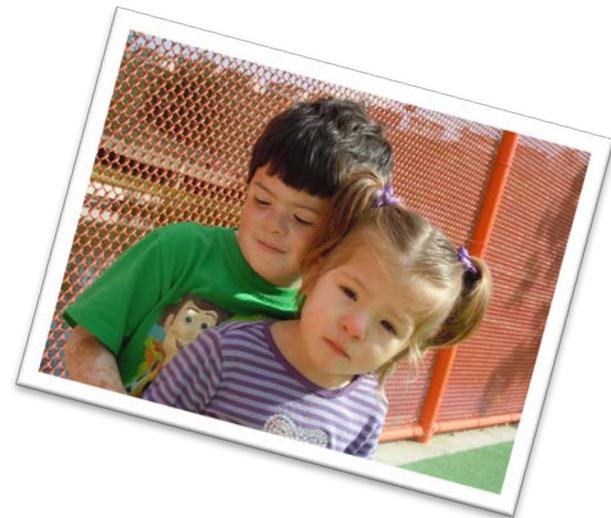
The science on autism and vaccines is clear, but still some parents are not getting the message. Better communication with parents about vaccines is necessary. Our traditional frameworks for communicating science are no longer adequate. We need a new way of talking to parents and we need to understand what does cause autism so we can better explain what doesn't.

Autism 101

For many years, we thought once the studies exonerating vaccines as a cause of autism were published that parents' concerns would be allayed. But this has not been the case. The good news is there are new studies helping us start to understand what **does** cause autism. By sharing some of this information with parents we may further be able to calm their fears regarding vaccines.

The Types of Autism

Autism is a group of brain-based disorders that is characterized by impairment in social communication and the presence of repetitive or stereotyped behavior. These symptoms can range from subtle to debilitating. Some people with autism have above average IQ, while others have intellectual disability. Some are nonverbal while others have an abundance of language. Some experience severe aggressive outbursts and can be self-injurious, while others need support in social situations.



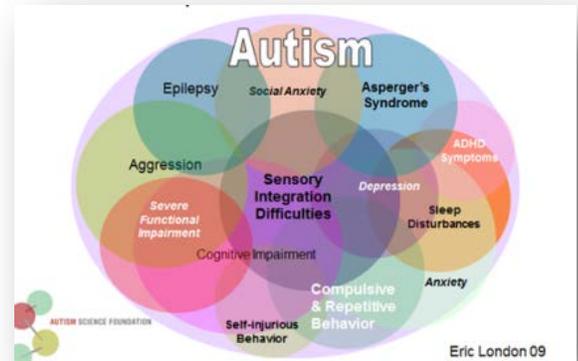
⁸ Kempe, A. et al. "Physician Response to Parental Requests to Spread Out the Recommended Vaccine Schedule." *Pediatrics* Vol 135, Issue 4 (2015). <http://pediatrics.aappublications.org/content/135/4/666.abstract?sid=e1dd4520-cbec-4708-b0f9-4c2c44130ca8>.

What is Autism?

Regardless of the classification of autism, every person diagnosed with autism has some level of impairment in two areas:

- **Social and Communication** - problems with communication in a social context, and difficulties in social interaction in different settings and contexts. This can include both language and non-verbal communication such as gestures.
- **Behavior** - repetitive behaviors, spinning, flapping, self injury, tantrums, aggression

The connection of social, language and behavior is a very simplified view of what autism means for a family. When a child has autism families are most often dealing with a wide-range of medical conditions and behaviors. There are many more associated symptoms and syndromes, like anxiety, depression and aggression, and co-morbidities like sleep disturbance and epilepsy.



What Causes Autism?

We can't pinpoint an exact cause of autism yet, but scientists have been hard at work looking for the causes of autism and also developing new treatments for autism. Many scientists are testing theories that autism results from a combination of genetic and environmental factors. What we do know is that the brain's development is off course.

We know that about **15-40%** of autism is attributable to specific genetic causes, meaning in that in about **1 in 3 children** with autism we can identify a genetic abnormality that explains their autism.



We are discovering that the genes that are linked to autism are involved in the formation and function of neural synapses,⁹ which are the spaces between neurons that enable communications signals to be transmitted through the brain.

⁹ Brose, N et al. (2010) "Synaptopathy: dysfunction of synaptic function?" *Biochemical Society Transactions*. 38 volume 2 (2010). www.ncbi.nlm.nih.gov/pubmed/20298199

Recently, scientists have discovered that differences in brain structure of an Autism Spectrum Disorder (ASD) child can be seen prenatally, as early as in the second trimester¹⁰. What they have found is that an overproduction of brain cells in the frontal lobes of the brain creates patches of functional abnormality. Too many cells are created, and the genes responsible for sorting and differentiating the needed cells from the unneeded cells are compromised. This relatively new knowledge will be essential to developing early biomarkers for autism.

Several studies have shown that specific drugs are successful in reversing the deficits associated with autism, at least in mice.¹¹ By creating mouse models that mimic the genetic anomalies found in autism, we are able to test new drugs and see if they help to correct the problems we see. FDA clinical trials of these drugs in humans are currently underway.

While there are some environmental factors that have been ruled out, like ultrasounds and vaccines, there are several environmental factors that have been implicated as a cause of autism. Valproic acid taken during pregnancy and rubella exposure during pregnancy have both been shown to increase the chance of ASDs. An infection during pregnancy, such as the flu, can increase the risk of autism. Studies are underway to determine how certain chemicals like air pollution or pesticides work on the developing brain and if they also increase the risk of ASD. Some research has shown an increased risk of ASD following environmental exposures, but scientists agree that it is a combination of genetic and environmental factors that produce the largest risk.



¹⁰ Courchesne, E. "The Development Neurobiology of Autism: The First Steps and the Road Ahead." Speech presented at the IMFAR 2011, San Diego, CA. May, 2011.

¹¹Silverman JL, Pride MC, Hayes JE, Puhger KR, Butler-Struben HM, Baker S, Crawley JN. [GABA_B Receptor Agonist R-Baclofen Reverses Social Deficits and Reduces Repetitive Behavior in Two Mouse Models of Autism.](http://www.ncbi.nlm.nih.gov/pubmed/?term=silverman+autism) (2015)



How is Autism Diagnosed?

The number of children being diagnosed with autism is now **1 in 68**, a large increase over past decades. It is still unclear whether this rise is a true increase in incidence or the result of better diagnosis. Diagnostic criteria for autism has been expanded over the past years, and better awareness of autism has meant increased availability of services.

The good news is that we are able to diagnosis children younger and younger. In some studies, children as young as 6 weeks old are able to be reliably diagnosed (this is well before the infant has received most vaccines).¹² There is also a new, simple screening tool for pediatricians to use on all 12-month-old babies.¹³

The CDC lists these **Red Flags** for Autism¹⁴

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not respond to name by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his or her own by 24 months (not repeating)
- Has any loss of any language or social skill at any age



Why is Early Diagnosis Important?

Early intervention works. Children with autism in a good early intervention program **can** make meaningful gains in skills. In fact with early treatment, **30-50%** make enough gains to be mainstreamed by kindergarten. Gains made through the interventions have been shown to be maintained 2 years after intervention is discontinued.¹⁵ Scientists can effectively screen children as early as 12 months,¹⁶ and recent studies have even found that some diagnoses can be made as at 6 to 8 weeks.¹⁷ It's important to note that early Intervention programs vary by state, so check with your local organizations.

¹² Margolis, A., Jones, A., Trubanova, W., Jones, K., Chawarska and Klin, A. "Childhood Vaccinations and ASD: No Relationship Between Number or Schedule of Vaccinations and Diagnostic Outcome or Severity." Speech presented at the IMFAR 2011, San Diego, CA. May, 2011. <http://imfar.confex.com/imfar/2011/webprogram/Paper9380.html>

¹³ Pierce, K. et al. "Detecting, Studying, and Treating Autism Early: The One-Year Well-Baby Check-Up Approach." *Journal of Pediatrics*. Vol. 159, Issue 3 (2011). www.jpeds.com/article/S0022-3476%2811%2900240-X/abstract

¹⁴ CDC. "Act Early." Last reviewed December 10, 2010. www.cdc.gov/ncbddd/actearly/index.html

¹⁵ Estes, A. et al "Long-Term Outcomes of Early Intervention in 6-Year-Old Children with Autism Spectrum Disorders." *Journal of the American Academy of Child & Adolescent Psychiatry*. Vol 54, Issue 7 (2015). [www.jaacap.com/article/S0890-8567\(15\)00256-7/abstract](http://www.jaacap.com/article/S0890-8567(15)00256-7/abstract)

¹⁶ Pierce, K et al. "Detecting, studying and treating autism early: the one-year well- baby check-up approach." *Journal of Pediatrics*. Vol. 159, Issue 3 (2011). www.jpeds.com/article/S0022-3476%2811%2900240-X/abstract.

¹⁷ Klin, A. "Diagnostic Indicators of Autism Spectrum Disorders in the First Six Months of Life." Speech presented at the IMFAR 2011, San Diego, CA. May, 2011.

What Do We Know About Risk?

Recent science has made great strides into determining risk factors for ASD diagnoses. The following have been found to be proven risks for an autism diagnosis:

- Genetics - Identical twins, who share all their DNA, show a higher autism concordance rate than fraternal twins, further validating that autism is a genetically based disorder.
- Male children - Boys are diagnosed **four times** more frequently than girls.¹⁸
- Siblings - Studies have shown that there is a **20%** chance that a younger sibling of a child with autism will also be diagnosed with autism.¹⁹
- “Older” parents - Higher maternal and paternal age at conception adds to risk of ASD diagnosis.²⁰
- Premature infants – those babies born before 28 weeks of age have an 8% chance of being diagnosed with autism.
- Prenatal Exposures - Exposure to maternal infection, including rubella virus (but not rubella vaccine) or valproic acid during pregnancy increases risk that the child will be diagnosed with autism.

Autism Treatments

There have been major advances in evidence-based treatments. These are just some that have been shown to be effective in clinical trials. Usually people with autism need a combination of these therapies to succeed:

- Applied Behavior Analysis Therapy - Several ABA models have good evidence behind them, including discrete trial training, relationship development intervention, pivotal response training
- Naturalistic Behavioral Interventions – many early interventions are rooted in ABA but have been adapted to fit different settings appropriate for toddlers. This includes the “Early Start Denver Model” and “Early Social Interaction”^{21,22}
- Speech, Occupational and Physical Therapy
- Pharmacological Interventions - The FDA has approved Risperdal²³ and Abilify²⁴ for symptoms associated with autism. Other drugs are currently undergoing FDA clinical trials in humans.



¹⁸ Sarachana T. et al. “Sex Hormones in Autism.” *PLoS One*. February 16, 2011. www.ncbi.nlm.nih.gov/pubmed/21359227

¹⁹ Ozonoff, S. et al. “Recurrence Risk for Autism Spectrum Disorders: A Baby Siblings Research Consortium Study.” *Pediatrics*. August 15, 2011. Doi: 10.1542/peds.2010-2825.

²⁰ Croen, E. et al. “Maternal and Paternal Age and Risk of Autism Spectrum Disorders.” *Archives of Pediatric Adolescent Medicine*. April, 2007. <http://archpedi.ama-assn.org/cgi/reprint/161/4/334.pdf>.

²¹ University of California at Davis. “Early Start Denver Model.” Last accessed on September 7, 2011. <http://www.ucdmc.ucdavis.edu/mindinstitute/research/esdm/>

²² Wetherby et al. “Parent-implemented social intervention for toddlers with autism: an RCT.” *Pediatrics* 134(6):1084-93

²³ PubMed Health. “Risperidone.” Last revised June 15, 2011. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000944/>

²⁴ PubMed Health. “Aripiprazole.” Last revised May 16, 2011. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0000221/>

Children with autism are often being treated with several concurrent treatments. According to a report from the Interactive Autism Network (IAN), on average, children with autism are receiving five simultaneous treatments.²⁵ About 5% of children currently receive no treatment at all, while others receive dozens. One child in the survey was receiving 56 concurrent treatments.

Unfortunately, parents of children with autism are often lured with promises of improvement by charlatans or quacks looking to make a quick buck. Here are some treatments for which there is little or no evidence of efficacy:

- Music Therapy (AIT)
- Horseback Riding or Dolphin Swimming Therapy
- Medical Marijuana
- Special Diet (Gluten and Casein Free)
- Vitamin Supplements, including Omega 3 fatty acid supplements
- Secretin Injections
- Hyperbaric Oxygen Therapy
- Chelation
- Nicotine Patch
- Giant electromagnets
- Ecstasy



Parents of Autistic Children

Parents of children with autism often have more stress than typical parents or even parents of children with other disabilities. They often experience stress related to their child's poor social relatedness and behavioral problems, their child's sleep problems, and from lack of resolution with diagnosis. This stress, combined with fierce love for their children, may lead parents to use non evidence-based interventions. You may hear anecdotal reports from parents or the media that certain treatments work. In fact, parents are often so eager for new treatments to work that they report tremendous improvements even for children on placebo.

²⁵ IAN & Kennedy Krieger Institute. 2008

Additional Resources

IACC

Every year, the federal Interagency Autism Coordinating Committee (IACC) writes a strategic plan to guide federal and private spending on autism research²⁶. This document is a blueprint for the most pressing issues in autism science and is a great resource for the public health community. The IACC also publishes an annual Summary of Advances in Autism Spectrum Disorder Research,²⁷ which reports on new findings that have made the most impact on the field.

Government Pages

- **National Institute of Health (NIH)** - <http://health.nih.gov/topic/Autism>
- **CDC** - www.cdc.gov/ncbddd/autism/index.html
- **Health Resources and Services Administration (HRSA)** - <http://mchb.hrsa.gov/programs/autism/>



Autism Science Foundation

The Autism Science Foundation (ASF) is a nonprofit organization dedicated to science and evidence. ASF funds autism research directly, and supports families by reinforcing the message that no science currently exists to indicate that vaccines cause autism.

- **Website:** www.autismsciencefoundation.org
- **Blog:** www.autismsciencefoundation.wordpress.com
- **Facebook:** www.facebook.com/autismsciencefd
- **Twitter:** www.twitter.com/autismsciencefd
- **YouTube/Weekly podcast:** www.youtube.com/users/autismsciencefdn

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²⁶ IACC. "The 2010 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research" January 19, 2010. <http://iacc.hhs.gov/strategic-plan/2010/index.shtml>

²⁷ IACC. "Summary of Advances in Autism Spectrum Disorder Research." Last accessed on September 7, 2011. <http://iacc.hhs.gov/summary-advances/2009/index.shtml>