



The Autism Connection



ISSUE XVIII

Northwestern Counseling & Support Services' Autism Awareness Newsletter

Winter 2015

**NORTHWESTERN
COUNSELING**
& SUPPORT SERVICES



Developmental pediatrician Paul Wang is Autism Speaks senior vice president and head of medical research.

1 in 68: What Do Autism's Rising Numbers Mean for Our Families?

We asked Dr. Wang to address how the continued rise in prevalence will affect the autism community.

Two years ago, the CDC updated its estimate of autism's prevalence from 1 in 110 to 1 in 88. Now we're up to 1 in 68. What do these new numbers mean for individuals on the spectrum and their families?

Compared to the last update two years ago, I believe these newest numbers show that we're getting better at detecting autism spectrum disorder (ASD). That's good news because diagnosis is the first step to getting the services that can improve a child's development and function. Unfortunately, our capacity to deliver high-quality, effective therapy is not keeping pace with the number of children – and adults – who need services. We have to redouble our efforts to improve the availability of highly effective and evidence-based treatments and support services.

The CDC report also helps us focus our nation's attention on the huge number of Americans affected by ASD. With prevalence at these

levels, the inadequacy of services will affect our entire country and economy. More than 50,000 children with autism reach adulthood each year. Research tells us that they're less likely than any other disability group to be employed or pursue postsecondary education. Yet we know that autism brings strengths and talents as well as challenges. We have to ensure that all those on the autism spectrum have the opportunity to become valued and fulfilled members of our society. This just isn't happening now.

We have to help our children and teens with autism become as capable as possible now, so they'll need less support in the future. Our researchers, legislators, educators and health insurers have to work together to make this happen.

Will rising prevalence mean longer waits for therapy, specialized medical treatment and other services?

These numbers remind us that we face a dire shortage of autism expertise and resources in our medical and educational systems. Many children and families affected by autism already face long waits for evaluation and treatment. This is unacceptable. Research shows that high-quality early intervention improves both brain and behavioral development – and with them, a child's long-term outcomes.

Federal law requires that the educational system respond in a timely way to requests for evaluation and services. But we have to do more to ensure that this happens, and to ensure that our school and medical systems have the capacity to meet our children's needs for behavioral therapies and specialized medical services. We must continue to advocate for health insurance coverage for proven therapies.

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CDC Publishes 2014 Community Report on Autism

Report to autism community summarizes scientific findings behind new 1 in 68 estimate of autism prevalence in the United States

April 22, 2014 - The Centers for Disease Control and Prevention (CDC) has published its 2014 Community Report on Autism. Written for a lay audience, the report summarizes the technical study behind the CDC's new estimate of autism prevalence in the United States: 1 in 68 children.

The Community Report provides background on how the CDC conducted the surveillance study, the results of which were published last month. In state-by-state sections, the report also provides key findings on autism in the 11 communities involved in the research.

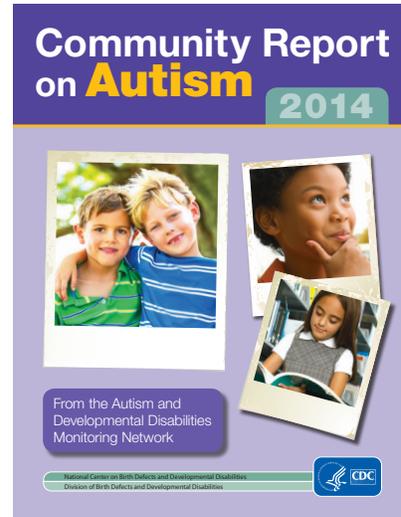
Autism Speaks President Liz Feld was among the national autism advocates invited to provide perspective in the Community Report. Feld writes:

The numbers in the CDC's report represent real children in every neighborhood across the country. They need access to proven behavioral therapies. They need educational support. Many need better medicines to manage their most disabling symptoms. And we need far more research to improve our understanding and treatment of autism and its complexity of related medical conditions.

We know that the earlier we diagnose autism and intervene with effective therapies, the better the outcomes. But while autism can be reliably identified by age 2, the average age of diagnosis in our country lags behind. For minority populations, the delay is even greater. Even after a parent, teacher, or physician raises concerns about autism, many of our children must wait months for a full evaluation and diagnosis. And even then, high-quality services remain out of reach for far too many families.

Download the CDC's 2014 Community Report on Autism here. Read Autism Speaks' complete coverage and perspective on this year's prevalence update here.

<http://www.autismspeaks.org/science/science-news/cdc-publishes-2014-community-report-autism>



Continued from cover

How can we increase access to high-quality medical, behavioral and educational services?

Federal and state governments and public health agencies must do more. In addition, we need to increase our investment in the research and training that will bring greater autism expertise to our medical and educational systems.



The Autism Speaks Autism Treatment Network (AS-ATN) continues to train doctors on the best approaches for whole-person care of individuals with ASD. Through its role as the federally funded Autism Intervention Research Network for Physical Health,

the AS-ATN is also developing and disseminating best-practice guidelines to physicians around the country and the world.

We desperately need more funding for research that can deliver better medicines, behavioral therapies, educational strategies and lifetime supports for children and adults with autism. At the same time, we need to ensure that schools, medical centers and communities have the resources they need to serve and support individuals with ASD.

Importantly, this support can't end abruptly when our children reach adulthood. We have to advocate for transition-support services beginning in high school, if not before. We likewise need services in our colleges and in our communities to help young adults with autism find a productive and fulfilling place in society. Autism Speaks also

supports passage of the ABLE Act, which will allow families to set aside funds to help address these lifelong issues.

How is Autism Speaks prioritizing research funding to address these needs?

Autism Speaks is funding a wide range of research, because the needs of those with autism are diverse. We know that early intervention improves brain development, function and outcomes. So we fund a large number of projects on earlier identification of autism. Other funded research focuses on treatment, language and communication support services or the use of technology to provide support in daily life as well as improve research.



But Autism Speaks can't do this alone. We need our national and state governments to invest far more in autism research and services – an investment in line with the number of American families that autism touches.

Concerned about autism prevalence? Join people around the world to Light It Up Blue for autism awareness. <http://www.autismspeaks.org/blog/2014/03/28/1-68-what-do-autism%E2%80%99s-rising-numbers-mean-our-families>



Facts about Autism

Did you know ...

- Autism now affects 1 in 68 children and 1 in 42 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
- Boys are nearly five times more likely than girls to have autism
- There is no medical detection or cure for autism

National Institutes of Health Funds Allocation

- Total 2012 NIH budget: \$30.86 billion
- Of this, only \$169 million goes directly to autism research. This represents 0.55% of total NIH funding

Recognition and Management of Gastrointestinal (GI) and Nutritional Issues in Children with Autism Spectrum Disorder (ASD)

Please join speaker Dr. Timothy Buie, Director of Pediatric Gastroenterology and Nutrition, Lurie Center for Autism; Massachusetts General Hospital for Children and Harvard Medical School for a free one hour presentation on the recognition and management of GI and nutritional issues in children with ASD.

- Recognize the prevalence of GI issues in children with ASD and how these issues may be identified.
- Describe the most commonly occurring GI symptoms and potential nutritional deficits in children with ASD.
- Discuss assessment needs and management strategies for children with ASD and GI and/or nutrition issues.
- Identify 2 ways in which amino acid-based formula/semi-solid food may be indicated for children with ASD with GI and/or nutrition issues.

See more at: <http://www.nutricialearningcenter.com/en/gi-allergy/webinar/recognition-management-of-gi-nutritional-issues-in-children-with-autism-spectrum-disorder-asd/#sthash.Aw2Q7mK8.dpuf>

Watch this webinar at your own leisure at: <http://www.nutricialearningcenter.com/en/gi-allergy/webinar/recognition-management-of-gi-nutritional-issues-in-children-with-autism-spectrum-disorder-asd/>

Recipe Corner

Cinnamon Bun Cheesecake Pops

Adapted from Sticky, Chewy, Messy Gooney by Jill O'Connor



Ingredients:

- 2 1/2 (8 oz.) packages cream cheese, brought to room temperature
- 1 cup sugar
- 2 tablespoons sweet rice flour
- 1/4 teaspoon salt
- 3 large eggs
- 1 egg yolk
- 1 tablespoon vanilla extract (yes, a tablespoon!)
- 2 tablespoons evaporated milk or heavy cream
- Boiling water as needed
- toothpicks or 20 lollipop sticks
- 1 (12 oz.) package of Hershey's Cinnamon Chips
- 1 tablespoon Spectrum Palm Shortening

Directions:

1. Preheat to 325 degrees. Set some water to boil.
2. At low speed, beat together cream cheese, sugar, sweet rice flour, and salt until smooth.
3. Add eggs, beat well after each addition. Beat in vanilla and evaporated milk or cream.
4. Grease an 8" cake pan (not springform), pour batter into the cake pan. Place the pan in a larger roasting pan. Fill roasting pan with boiling water until it reaches halfway up the sides of the cake pan. Bake 35-55 minutes, until the cheesecake is firm and slightly golden on top. (Cheesecake will not "jiggle" when it is done, it should look and feel set if you gently touch the top!).
5. Remove the cheesecake from the water bath and cool to room temperature. Cover the cheesecake with plastic wrap and refrigerate until very cold, at least 3 hours or overnight.
6. When the cheesecake is cold and very firm, scoop cheesecake into 2oz balls and place them onto a parchment or foil-lined baking sheet. Carefully insert a lollipop stick or toothpick into each cheesecake ball. Freeze the cheesecake pops uncovered, until they are very hard, 1-2 hours or overnight.
7. When cheesecake pops are frozen and ready for dipping, melt cinnamon chips over a double broiler, or if you are lazy like me, you can simply put them in a glass bowl along with the tablespoon of palm shortening and microwave them for 1 minute. Stir the melted chips and shortening until they are smooth and liquid.
8. Quickly dip the cheesecake pops one at a time in the melted cinnamon chips, swirling quickly to coat.
9. Place pops on a clean cookie sheet lined with parchment paper or foil. Refrigerate pops for up to 24 hours, or until ready to serve.

<http://gingerlemongirl.blogspot.com/2008/04/daring-bakers-challenge-3-cheesecake.html>

Frequently Asked Questions

How Common is Autism?

Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 68 American children as on the autism spectrum—a ten-fold increase in prevalence over the last 40 years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls. An estimated 1 out of 42 boys and 1 in 189 girls are diagnosed with autism in the United States.

ASD is estimated to affect more than 2 million individuals in the U.S. and tens of millions worldwide. Moreover, government autism statistics suggest that prevalence rates have increased 10 to 17 percent annually in recent years. There is no established explanation for this continuing increase, although improved diagnosis and environmental influences are two reasons often considered. Learn more ...

What Causes Autism?

Not long ago, the answer to this question would have been “we have no idea.” Research is now delivering the answers. First and foremost, we now know that there is no one cause of autism just as there is no one type of autism. Over the last five years, scientists have identified a number of

rare gene changes, or mutations, associated with autism. Research has identified more than a hundred autism risk genes. In around 15 percent of cases, a specific genetic cause of a person’s autism can be identified. However, most cases involve a complex and variable combination of genetic risk and environmental factors that influence early brain development.

In other words, in the presence of a genetic predisposition to autism, a number of nongenetic, or environmental, influence further increase a child’s risk. The clearest

evidence of these environmental risk factors involves events before and during birth. They include advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy, extreme prematurity and very low birth weight and certain difficulties during birth, particularly those involving periods of oxygen deprivation to the baby’s brain. Mothers exposed to high levels of pesticides and air pollution may also be at higher risk of having a child with ASD. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk.

A small but growing body of research suggests that autism risk is less among children whose mothers took prenatal vitamins (containing folic acid) in the months before and after conception.

Increasingly, researchers are looking at the role of the immune system in autism. Autism Speaks is working to increase awareness and investigation of these and other issues, where further research has the potential to improve the lives of those who struggle with autism. Learn more ...

What Does it Mean to Be “On the Spectrum”?

Each individual with autism is unique. Many of those on the autism spectrum have exceptional abilities in visual skills, music and academic skills. About 40 percent have intellectual disability (IQ less than 70), and many have normal to above average intelligence. Indeed, many persons on the spectrum take deserved pride in their distinctive abilities and

“atypical” ways of viewing the world. Others with autism have significant disability and are unable to live independently. About 25 percent of individuals with ASD are nonverbal but can learn to communicate using other means. Autism Speaks’ mission is to improve the lives of all those on the autism spectrum. For some, this means the development and delivery of more effective treatments that can address significant challenges in communication and physical health. For others, it means increasing acceptance, respect and support.

How Did My Child Develop Autism?

Research suggests that the development of autism is rooted in very early brain development. However, in most cases, no one cause can be identified.



Research has identified several genes that can cause autism in and of themselves. These account for about 15 percent of cases of autism spectrum disorders. Research has identified more than 100 genes or gene changes (mutations) that increase the risk that a child will develop autism. In most cases, genetics alone can’t distinguish why one person has autism and another does not.

Gene-environment interactions appear to be at play. When scientists use the term “environment,” they are referring to a wide range of nongenetic factors. Those most associated with increased autism risk include advanced parental age at time of conception and prematurity with very low birth weight. Other possible environmental risk factors include maternal diabetes or infection during pregnancy and certain birth complications, particularly those that may involve oxygen deprivation to a baby’s brain. Autism Speaks continues to fund a wealth of studies on the causes of autism, including research on gene-environment interactions that may increase autism risk. You can explore these and other studies using our Grant Search.

Are Vaccines to Blame?

Many studies have been conducted to determine if a link exists between immunization and increased prevalence of autism, with particular attention to the measles-mumps-rubella (MMR) vaccine and vaccines containing the preservative thimerosal. These studies have found no link between vaccines and autism. We strongly encourage parents to have their children vaccinated, because this will protect them against serious diseases. It remains possible that, in rare cases, immunization might trigger the onset of autism symptoms in a child with an underlying medical or genetic condition. Autism Speaks is funding studies on the underlying biology of autism, including studies to better understand medical and genetic conditions associated with autism.

We recognize that some parents may still have concerns about vaccines, especially those parents who already have a child or relative with an autism spectrum disorder. Because parents and guardians differ in their sensitivity and concern about this issue, we urge them to find a pediatrician or other health practitioner who will partner with them to consider their concerns and help them ensure the optimal well-being of their child. Establishing open communication and trust with a physician who understands each child and his or her family is the best strategy for keeping a child healthy.



How Can I Tell if My Child has Autism?

Though autism cannot be definitively diagnosed until around 18 to 24 months, research shows that children as young as 8 to 12 months may exhibit early signs. Parents should look for symptoms such as no back-and-forth sharing of sounds, smiles or other facial expressions by 9 months; no babbling or back-and-forth gestures (e.g. pointing) by 12 months; or any loss of babbling, speech or social skills at any age. For more information, please see our Learn the Signs page and the “Developmental Milestones” section of our Video Glossary.

What Should I Do if I Suspect Something is Wrong with My Child?

Don't wait. Talk to your doctor or contact your state's Early Intervention Services department about getting your child screened for autism. (For more information, about your child's rights and public resources, see the Early Intervention section of our 100 Day Tool Kit.) Research has consistently shown that early diagnosis and intervention offer the best chance for improving function and maximizing a child's progress and outcomes.

How Do I Get My Child the Help He or She Needs?

In addition to the Early Intervention Services mentioned above, it's important to make sure your child has a knowledgeable and reputable healthcare team. This means finding doctors, therapists, psychologists and teachers who understand and have experience with autism and can respond to his shifting needs appropriately.

The Autism Speaks Autism Treatment Network (ATN) is a groundbreaking network of hospitals, physicians, researchers and families at 17 locations across the United States and Canada. ATN clinicians work together to develop the most effective approach to medical care for children and adolescents affected by autism. The ATN's aim is to provide comprehensive, high-quality care by teams of healthcare professionals who understand autism spectrum disorders and excel at treating associated medical conditions including the sleep disturbances and gastrointestinal problems that can vex children with ASD and their families. You can locate your nearest ATN center here.



What if I Suspect that I Have Autism?

Many persons with Asperger syndrome or other high-functioning forms of autism never received a diagnosis as a child. They may be diagnosed as adults when seeking help for related problems at work or in their social lives. Consider asking your physician for a referral to an appropriate

specialist. Professionals qualified to make an adult autism diagnosis include licensed clinical psychologists, neurologists and psychiatrists. Some nurse practitioners, social workers and master's level psychologists likewise have the expertise to diagnose autism in adults.

How Do I Deal with this Diagnosis?

For adults, an autism diagnosis may bring relief in terms of an explanation for their lifelong struggles. For parents, the first months after learning that their child has a developmental disorder can be emotional, confusing and challenging. For this reason, Autism Speaks has developed the 100 Day Tool Kit, to help families navigate the oft-tumultuous first 100 days after a child's diagnosis. You can download a free copy here.

It's particularly important that parents not blame themselves. The next step is to educate yourself. Knowledge is power, and the more you know, the more capable you'll feel about helping your child.

However, it's also important for parents to give themselves a “break” from autism when you are tired or overwhelmed. And if you find that you're unable to get past the emotional upheaval of your child's diagnosis, consider talking with a counselor or therapist. You can't — and aren't expected to — weather this alone.



Will My Child Be Able to Attend School?

Absolutely. In fact, it's a child's right: According to the Individuals with Disabilities Act of 1990, your child deserves access to a “free and appropriate” education funded by the government, whether it be in a mainstream or special education classroom. More information here.

Resources: We are pleased to offer many resource-packed tool kits for free download (here and here), including the 100 Day Kit for families who have a child recently diagnosed with autism. For still more information and resources please see our Video Glossary and FAQs and special sections on Diagnosis, Symptoms, Learn the Signs, Treatment, Your Child's Rights, Asperger Syndrome and PDD-NOS. These resources are made possible through the generous support of our families, volunteers and other donors.

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



Autism Walk

of Northwestern Vermont



Sunday, May 17, 2015

Registration begins at 12:30 pm
Walk begins at 1:00 pm

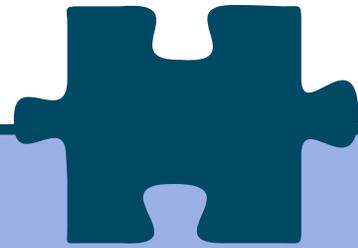
Collins Perley Sports & Fitness Center
St. Albans, Vermont

Registration and Pledge Forms
are available on our website at
www.ncssinc.org/about-us/calendar/event
AutismWalk or by calling: **(802) 393-6406**

Organized by

**NORTHWESTERN
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**In the event of unfavorable weather, this event
will be moved indoors.*



April is Autism Awareness Month



- Autism now affects 1 in 68 children and 1 in 42 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.

Link up your autism posts at
www.singingthroughtherain.net



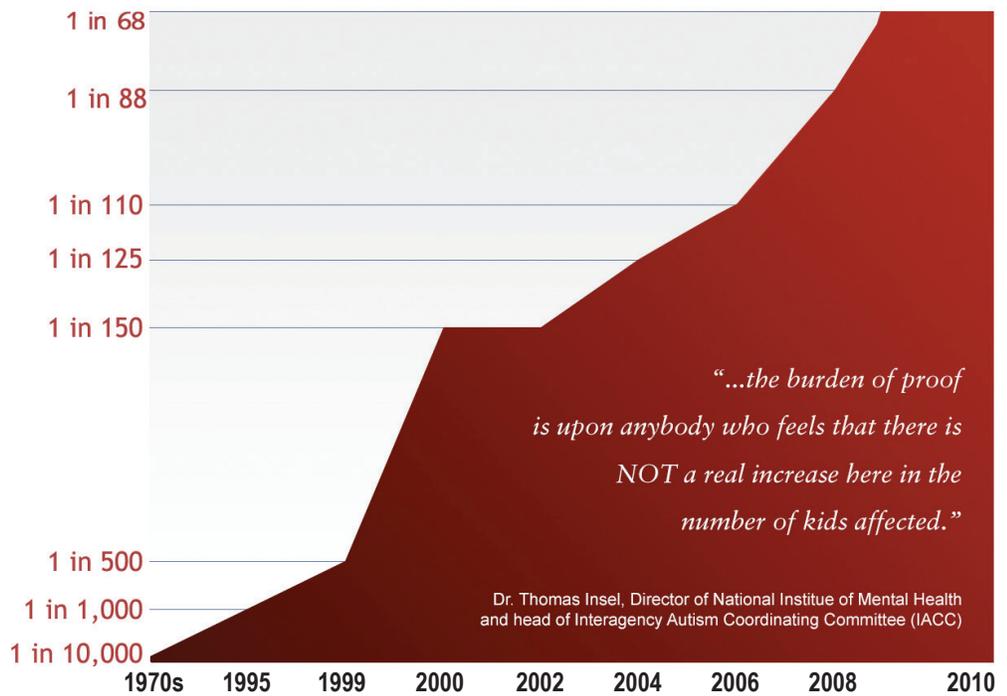
Autism Occurrence

- Autism now affects 1 in 68 children and 1 in 42 boys (updated in a study posted March 2014 from data starting in 2010 from 2010)
- 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
- Boys are nearly five times more likely than girls to have autism
- There is no medical detection or cure for autism

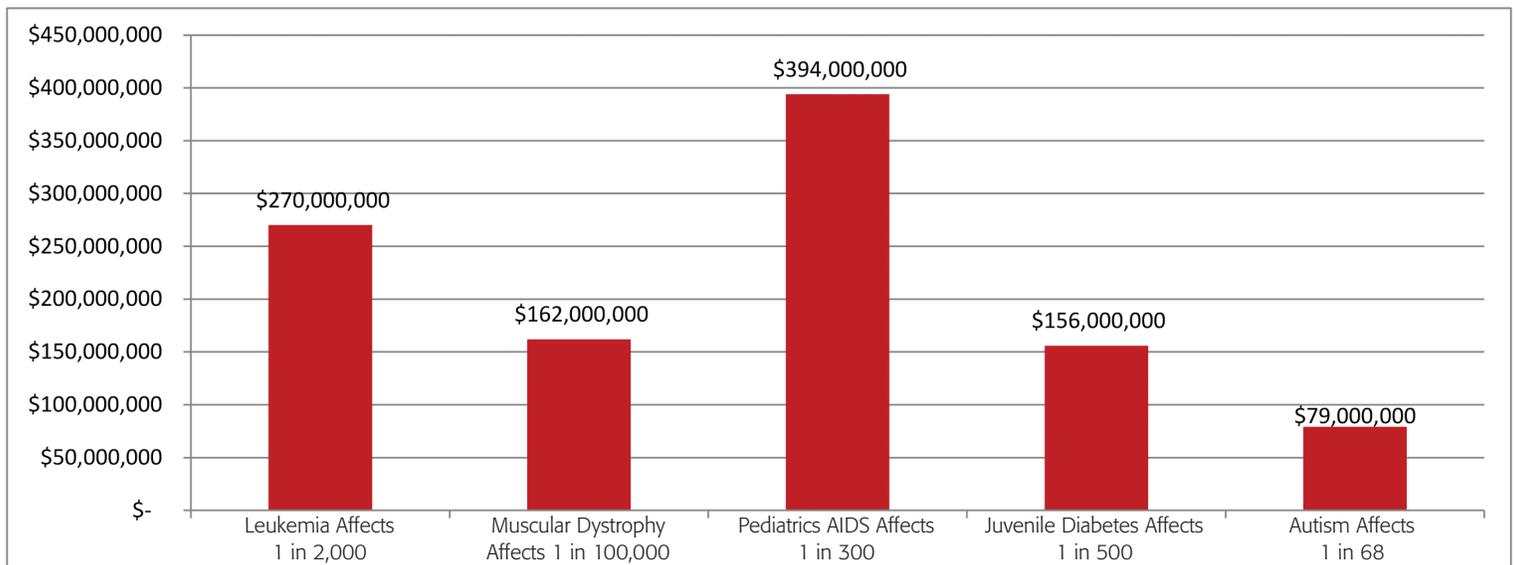
National Institutes of Health Funds Allocation

- Total 2012 NIH budget: \$30.86 billion
- Of this, only \$169 million goes directly to autism research. This represents 0.55% of total NIH funding

Autism Occurrence Statistics



Funding for Urgent Issues Affecting U.S. Children



Autism Diagnostic circumstances in USA

Out of 1,300 families surveyed the statistics are the following:

- The average age of diagnosis of autism was 6 years of age, despite the fact that most parents felt something was wrong by 18 months of age
- Less than 10% of children with autism were diagnosed at initial presentation
- 10% were either told to return if their worries persisted, or that their child “would grow out of it”

- The rest were referred to another professional (at a mean age of 40 months); of which:
 - 40% were given a formal diagnosis
 - 25% were told “not to worry”
 - 25% were referred to a third or fourth professional

<http://brighttots.com/Autism/Statistics.html>

<http://www.tacanow.org/family-resources/latest-autism-statistics-2/>

Support Where You Need It



Given the sharp increase in autism spectrum disorders and increased need in the community, NCSS has created wrap around services to accommodate the entire spectrum.

Early Intervention Services (Birth - 3 Years Old)

This program brings together families and service providers from many aspects of the community, including public and private agencies, parent child centers, local school districts, and private providers. Supports and services come together to meet each child's unique needs and the needs of their family in their home and community.

School Based Services (3 - 21 Years Old)

Training and support services will be provided in all settings, as determined by each child's team.

Family Support Program (Lifetime)

The Family Support Program provides support in the home and community for families raising children with ASD.

Program for Adaptive & Expressive Arts (Lifetime)

Communication, physical, social and emotional skills building program.

**For more information about the services above,
please call 802-524-6554**



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Inside the next issue:

- Autism in the News
- More from Recipe Corner
- NCSS Services

NORTHWESTERN COUNSELING & SUPPORT SERVICES

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NCSS is recognized with the highest level of accreditation from the Commission on Accreditation of Rehabilitation Facilities

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