

AUTISM AWARENESS



*"The moment you think
you can't, you discover you can.
We are not superparents;
we are just parents.
ASI brings us together."*

SPREAD THE WORD • YOUR SUPPORT IS NEEDED



Rising autism rates

By Janice Youngwith

The numbers are staggering. New research indicates that as many as one in every 45 children in the U.S. display signs of autism. That's the finding of the Centers for Disease Control & Prevention (CDC) 2014 National Health Interview Survey released in November.

Historically, in the 1970s and '80s, it was reported that one out of every 2,000 children had autism. Prevalence spiked to one in 80 between 2011-2013.

Behind the numbers

So what's behind the spike in autism rates, and does this mean they will continue to rise?

"The biggest reason for the change in rates has been in a change in how autism is diagnosed and defined," explains Dr. Peter J. Smith, a University of Chicago developmental pediatrician who collaborates with a multidisciplinary autism medical diagnostic evaluation team at Easter Seals DuPage & Fox Valley, Villa Park.

"Systems of care now are actively looking for autism. In the past, systems were not looking at all, or even actively looking away from children who had signs of an autism spectrum disorder. As part of this change, the actual definitions of who meets criteria for an autism spectrum disorder have changed."

As part of these changes, the subgroups within autism have been eliminated and former diagnosis/labels, such as Asperger disorder, have been removed from formal diagnostic criteria used by professionals.

"The reason for their elimination is simple," explains Dr. Smith, who says the prior system divided children and



PHOTO COURTESY OF VERN PECHTA
Everett Mazzie is served by Easter Seals DuPage & Fox Valley.

adults in ways that proved inaccurate. "The subgroups were misleading, and ultimately were not easily applied in clinical settings, especially over time."

He concludes that instead of diagnosing — and increasing the risk of perhaps misdiagnosing — very specific disorders, autism spectrum disorder now includes pervasive developmental disorders, including classic autism and Asperger syndrome.

Experts conclude there is no doubt the rates of children identified with an autism spectrum disorder have risen. They point to changes in the system of classification as a major part of the change, as well as improved systems of screening and diagnosis.

"The primary reason that the systems of finding children with an autism spectrum disorder have improved is because professionals now recognize that there are effective therapies for autism spectrum



PHOTO COURTESY OF RICH HOWE
Andrea Sagel, occupational therapist, works with client Caleb Kapsalis at Easter Seals DuPage & Fox Valley.

disorders," Dr. Smith notes.

"Children who are now described as meeting criteria for an autism spectrum disorder are eligible for therapies and services that would not have been offered in the past. Therefore, the outcomes of children today will most likely be much better than previous generations."

This increase, he concluded, shows just how important it is to detect these issues in children early.

"The sooner you can determine whether or not your child has autism, the sooner you can go about finding the best ways to enhance and encourage their mental development," Dr. Smith states.

Service needs soar

Hand-in-hand with the rising numbers is the growing need for autism-specific services. That need is evidenced by the growing number of area educational, therapeutic and recreational providers, in addition to specialized career centers focusing on serving those with autism, their families and loved ones.

On the local front, a new 12,000-square-foot, two-story Ann Haskins Center at Marklund Day School officially opened Nov. 12, 2015, in West suburban Bloomingdale.

Designed from the ground up to meet the needs of students on the autism spectrum, the new building contains six classrooms, each with private observation areas, a Snoezelen therapy room, model apartment, offices, conference room, and multipurpose/lunchroom. Special

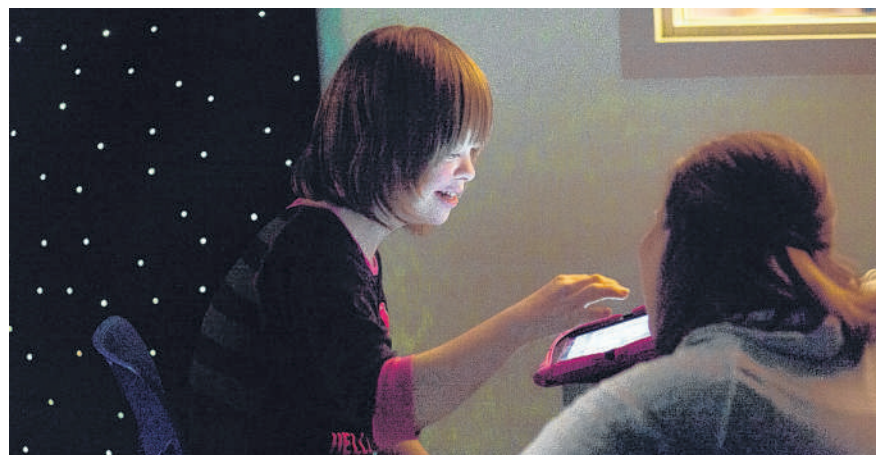
observation rooms are beneficial for college students focusing on careers in special education, as well as parents and school district officials wanting unobtrusively to observe students.

"I have a saying hanging on my wall that says, 'There are no easy roads to any place worth going.' This was worth the effort," says Marklund President/CEO Gil Fonger.

Explaining that the project began with the launching of the strategic plan in August 2012 that identified expansion of the school as a key goal, he noted that it really was a dream that started in 1986 by St. Charles resident Mary Haskins. Having a daughter with mild developmental disabilities that required her to need special education, Mary created a trust in her daughter's name that eventually would be used to build a laboratory school that would provide special education to children with disabilities in Kane and DuPage counties. With a \$3.5 million bequest from that trust, Marklund was able to construct the Ann Haskins Center at the Marklund Day School in Bloomingdale and ultimately serve 42 students with autism each year whose needs cannot be met in their home school districts.

For information, visit www.marklund.org/school. To meet with the Director of Education Paula Bodzioch or to schedule a tour, call (630) 307-1882.

For information on autism, resources and support, contact the Autism Society of Illinois at 2200 S. Main St., Suite 203, Lombard, IL 60148; call (630) 691-1270; or email info@autismillinois.org.



Marklund Day School recently opened a 12,000-square-foot Ann Haskins Center in Bloomingdale to meet the needs of students on the autism spectrum.

Help with Change For Autism 2016

YOU CAN MAKE A DIFFERENCE

5

By Janice Youngwith

Today one in 45 children will be diagnosed on the autism spectrum. According to the Autism Society of Illinois, the numbers are staggering and so are the challenges faced by individuals, families and local communities.

April marks the observance of National Autism Awareness Month and a chance to learn more about this lifelong developmental disability with no single known cause.

The first National Autism Awareness Month was declared by the Autism Society of America in April 1970, and since that time the organization and its local affiliates have been educating, advocating, providing resources, referrals, and helping support families touched by autism.

"Autism has profound impact on individuals, families and society," says Matt Ackerman, Autism Society of Illinois executive director. "With greater numbers of families learning of a child's autism diagnosis, the need for information, resources, and services is on the rise."

Autism and its many-faceted symptoms can be present from birth or diagnosed during early childhood.



The Autism Society of Illinois

2200 S. Main St., Suite 203
Lombard, IL 60148-5366
(630) 691-1270

Or request a packet by email:

info@autismillinois.org

Use subject line: Change For Autism

Autism is a developmental disorder that impairs the functioning of the brain. It includes having challenges in social interaction, delayed and deviant communication development, difficulty with a range of motor skills, and various repetitive behaviors. A wide spectrum disorder, people with autism have symptoms unique to themselves.

While no two people with autism will have the same set of symptoms or challenges, common characteristics can include unpredictable learning rates, challenges with social skills and

interactions, difficulty recognizing and understanding the feelings of others, aversion to physical contact, inability to adapt to sudden physical changes in environment including loud noises, lighting intensity and smell, obsessions, speech difficulties, repetition or monotones, behavioral changes and the inability to adapt to reordering of routines.

"In addition to individual challenges, the impact of an autism diagnosis affects families, education and health care systems, government funding and even the nation as a whole," says Ackerman. "As the numbers rise, so too does the need for information and the quest for quality programs and services, both in the community and at home."

With early detection and intervention, the Autism Society of Illinois and its members say they hope to help families and communities build strong foundations and offer lifelong support.

This April, make Change For Autism

The Autism Society of Illinois invites elementary, middle school and high

school students across the state to help Change For Autism in April. For information on autism, support and details on how your school can help make the Change For Autism, contact the Autism Society of Illinois at (630) 691-1270 or email info@autismillinois.org.

How can schools help

How can your school support autism awareness, education and outreach in your community? By participating in ASI's "Change for Autism!"

- Pick a week or weeks in April that your school or district will be collecting change. (Any amount will be great.)

- Educate and make people aware of autism.

- Start gathering containers for each classroom. (Milk jugs with handles are easy to carry.) ASI will provide labels for classroom containers.

- Let ASI know how many fliers and labels you will need.

- Spread the word! Start collecting!

Wrap the campaign up by the end of April. Report your results and your school will be recognized with a certificate. Your top class will receive "Change For Autism" bracelets.



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Ages & Stages: Parental Action Plan

Navigating the physical, development and social milestones of childhood can be tough, especially for parents who have a child with a developmental disability like an autism spectrum disorder or special needs.

"It's important for families to know help is available," says Andrea Sagel, licensed occupational therapist and autism services coordinator at Easter Seals DuPage and the Fox Valley Region, an accredited outpatient pediatric rehabilitation center in Villa Park. "Timing is critical and for those children with an autism spectrum disorder, receiving treatment at the earliest stages is vital."



PHOTO COURTESY OF HELENA JOER-GENRUD

Emma LaMorte is served by Easter Seals DuPage & Fox Valley.

Prioritization of Urgency of Need for Services (PUNS) database functions as a waiting list for services. If your child has the diagnosis of a developmental disability or an autism spectrum disorder, register now. Call your Independent Service Coordination Agency (ISC) at (800) 588-7002 or (888) DDPLANS. You may request funding for services such as respite, the children's waiver, a home-based services waiver, job coaches, and group homes.

• Learn all you can and start now planning for your child's future.

For support, information and resources, contact the Autism Society of Illinois, 2200 S. Main St., Suite 203, Lombard, or call (630) 691-1270, or email info@autismillinois.org.

Check out school presentations or visit The ARC of Illinois online at www.thearcofil.org for a listing of many educational offerings and service providers.

Parental peer support is available from the Illinois Statewide Advisory Council on Developmental Disabilities and online at www.iacdd.org.

Area wide work groups also are a good source of information and support.

High school & beyond:

• **Begin transition planning by age 14½.** At school, ensure your child's individualized education plan reflects realistic goals: whether college bound in a two-year or four-year program, planning for work, living arrangements and more. Understand the differences of an IEP and a 504 plan if attending college or university.

Preparing for adulthood at age 18:

• **Apply for SSI benefits and Medicaid.** Consider also the need for guardianship versus powers of attorney for your child. Have a school power of attorney form executed and given to the school.

• **Obtain an Illinois identification card** and check out the RTA reduced fare permit and/or ADA Para Transit Service.

• **Males register for Selective Service.**

• **Register to vote** — if applicable.

• **Establish and update a letter of intent** and keep it updated.

Saying goodbye to school:

In Illinois, the day before your child turns 22 is the day school-based services and support end. At least one year or more before this date, search for and evaluate day and residential programs as well as community-based services your child may need when school ends.

Make the first five count Screening tool helps parents stay on top of child's development

Concerned about your child's development? Not certain if they are on track to meet developmental milestones?

In addition to asking your pediatrician, a new online screening tool, Make the First Five Count, is available for families to begin assessing their infant, toddler or young child's development.

"The screening tool (available online at www.EasterSealsDFVR.org/ASQ) allows families to start evaluating a child's motor, communication, personal-social and problem-solving skills," explains Andrea Sagel, a licensed occupational therapist and autism services coordinator at Easter Seals DuPage & Fox Valley, an accredited outpatient pediatric therapy and rehabilitation center in Villa Park. "If delays are identified, we offer the support needed to help young children be school-ready and build a foundation for a lifetime of learning."

Developmental experts say receiving the right support at the earliest stage of life can help a child gain the skills he or she needs to be school-ready, and are especially vital for children with an autism spectrum disorder. Research indicates that, when children receive the right treatment and therapy they need before age 5, they are more prepared to learn alongside their peers, build lifelong skills, and achieve their dreams.

Sagel also notes a special medical diagnostic clinic at the Villa Park Center is for families who are seeking a multidisciplinary medical diagnostic evaluation for their child.

Through a partnership with the University of Chicago, this evaluation is conducted by an experienced team of professionals including Dr. Peter J. Smith, a developmental-behavioral pediatrician, and highly trained specialists including an occupational therapist, speech and language pathologist, developmental therapist, audiologist, and parent liaison from Easter Seals DuPage & Fox Valley.

"This partnership provides a strong, cohesive team specializing in early diagnosis of the young child," explains Sagel, who notes that many families who have come through the specialized medical diagnostic clinic find their concerns are validated and learn of autism spectrum involvement.

According to Sagel, the diagnostic clinic partnership is unique since there are few trained developmental pediatricians. Dr. Smith is available every Friday for consultation.

For additional information on the program, visit online at <https://eastersealsdfvr.org/pages/3.-services---programs/medical-diagnostic-clinic>.



PHOTO COURTESY OF RICH HOWE

Andrea Sagel, a licensed occupational therapist and autism services coordinator at Easter Seals DuPage & Fox Valley, pictured with Caleb Kapsalis, says that early intervention helps build a foundation for learning.