AUTISM SUPPORT OF WEST SHORE

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by Mandy Anderson

My son Jaden is 15 and heading into his second year of high school. (I know! I can't believe it either!) It's time to start thinking about life after High School: where will he work, where will he live, who will help him make decisions after I'm too old? (Or maybe sooner -- young men probably don't want mom making all the choices.)

If you know Jaden, you know he is pretty good at speaking his mind and saying what he likes and doesn't like. But he is going to need a good deal of help with handling money and running a household. I am in no hurry to have him move out, but he may want to live with friends or even get married at some point instead of living in his childhood bedroom in our home.

Since they were small, Jaden's brothers have been very protective of him, ready to jump to his aid whenever someone so much as looks at him funny. They've mellowed a bit over the years, but they still are all-in when he needs help. But they also joke around and tease a bit -- treating him just like they treat each other -- like brothers. It used to bother me until I realized that it was a good thing that they weren't treating him with kid gloves -- they saw him simply as their brother, not their "special-needs brother." I hope that as adults, they will be supportive but continue to be authentic in their relationship with him and each other.

The sibling relationship is going to probably be the longest relationship and deepest partnership your children will have. Siblings will have the opportunity to be involved in helping the sibling make decisions and live a self-determined life.

I had the opportunity to hear Angela Martin of the Developmental Disabilities Institute of Wayne State University share at a seminar in Grand Rapids on June 29.

"Brothers and sisters are not default caregivers. Sometimes you just have to have a sibling relationship," said Martin. "Sometimes we assume disability assumes living arrangements. We need to have these conversations. Everyone is going to have their own opinion."

Martin has a sister with a developmental disability. She was as the seminar as well. She lives independently with support and mentioned that she likes her living arrangement and does not want to live with Martin.

Jaden has wonderful, close relationships with his brothers Chris, Frankie & Henry. While they are under no obligation to be his full-time caregivers, or even have him live with them, I know that they will be active participants in his life and between them will help him wherever it is needed. (His closest brother, Frankie, was upset with me when I suggested they didn't have to live together!)

I think it's important to set up the expectation and attitude that the child with a disability is not a burden or challenge to be handled (though there are definitely challenges to be handled in this life). They are a part of the family, and as family, we stick together and look out for each other. But as my boys all become men, my hope is that we will find supportive caregivers and staff and that Jaden's brothers will be able to continue to have a great sibling relationship, sharing holidays and fun family gatherings, helping each other where needed.

"As a sibling, I'm not looking to be a caregiver, I'm looking to be a support," said Martin. "As siblings, we need to advocate 'with' not 'for' -- the 'with' is key," Martin said. "Help that person develop their voice. The role of siblings is alongside their sibling."

"Every sibling relationship has its ups and downs -- disability is just another layer," Martin said. "Our family experiences need to be shown in a positive light. There are times -- this is crappy. But our family lives are good."

Some online resources for siblings:

siblingsupport.org

siblingleadership.org/

misibs.org

By Susan Judd

Peer Michigan Parent Mentors

Parents of children with disabilities often feel alone.

Peer Michigan matches these parents with a veteran parent who has learned to navigate the system, according to Kate Jones, a parent mentor for Peer Michigan. Jones spoke March 2, 2018 at the Michigan Council for Exceptional Children Conference in Grand Rapids.

"Being able to talk about being in that other person's shoes is huge," Jones said. "There is an intense connection when they're with someone who gets it. "What it says in the book isn't always true."

Parent mentors provide ongoing support in a nonjudgmental way, according to Jones. They help the parent know their feelings are normal, she added. Requirements to be a mentor include completing parent mentor training, making at least four contacts with the parents seeking support within an eight-week period via phone or email, being willing to share experiences and information with another parents, and simply being a good listener.

The Parent-to-Parent movement was started in the early 1970s by parents, Jones said. Parent-to-Parent is now a national nonprofit organization whose mission is to provide emotional and informational support to families of children with special needs. There are individual programs in 38 states and that number continues to grow.

Research has shown that families involved in the program felt less stressed and more knowledgeable about their child's disability, according to Jones.

"We try to match personalities as much as possible as well as needs," Jones said.

Primary caregivers of individuals with autism are at risk for depression and anxiety, Jones said. Families who participated in the mentoring program felt more able to cope, she added.

In Michigan, the Family Center for Children and Youth with Special Health Care Needs in Lansing is the statewide Parent-to-Parent Support Network. Parents of children with special needs staff the center.

The Family Center provides training for mentors, scholarships for individuals with special needs to attend camps and scholarships for parents to attend conferences. The scholarships are not based on income. The center also is working to build a statewide network of parents and youth to focus on special education policy and feedback.

For more information, contact Family Center for Children and Youth with Special Health Care Needs, 320 S. St. Flr. 6, Lansing, MI 48913;
800-359-3722 or 517-241-7630;
email cshcsfc@michigan.gov.

Winter Speaker Series – free event

Wednesday – see date and topics below
6:30 – 8:30
1703 Despelder St Grand Haven Michigan
This is a free event registration is required. Email: contact@asws.org with your name and phone number.
Light refreshments will be served.

Dr. Kaarin Anderson – Ryan will lead an interactive seminar

March 6, 2019: Strategies for Increasing and Decreasing Behavior/Crisis Management
This presentation gives an overview of basic principles of reinforcement and punishment, and describes how various schedules of reinforcement can be implemented to teach and maintain new skills.

March 20, 2019: Managing Transitions
This presentation overviews the transition difficulties that individuals with ASD and other disabilities may encounter. The training provides a variety of practical solutions to prepare individuals for transitions from one place or activity to another. Evidence-based research articles highlighting specific examples of transition supports will be reviewed.

April 10, 2019: Anxiety and Autism
This presentation will provide an overview of anxiety, including basic features as well as symptoms of anxiety disorders. We will discuss the prevalence anxiety in autism spectrum disorders. Tools and strategies for managing anxiety will be presented.

All sessions are free but please register the date(s) you are attending, your name and number attending.

Board Message

The START Project has put together a newsletter reviewing the **Michigan ASD State Plan 2018 Progress Review and Recommendations: A Call to Action,** ASWS board recommends that you familiarize your self with this document. This is an opportunity to give input at the state level. This is an opportunity to share your thougs on behalf of your child. The following link will lead you to the information.

MDHHS
Michigan Department of Health & Human Services

MICHIGAN AUTISM SPECTRUM DISORDER STATE PLAN
2018 PROGRESS REVIEW

Infrastructure

INSURANCE REFORM

In 2012, Michigan passed autism insurance reform to require state regulated health insurance companies to provide an autism benefit, increasing access to diagnostic, Applied Behavior Analysis (ABA), and other services.

ONE AUTISM COUNCIL ESTABLISHED

State advisory body formed in 2012 to enhance the system of care for supporting individuals with ASD.

17,000+

LAW ENFORCEMENT AND FIRST RESPONDERS

received training to enhance response to situations involving individuals with ASD.

Early Identification and Early Intervention Services

$ 5 MILLION

Michigan legislators allocated 5 million dollars of new funding in 2018 to Early On® to enhance birth–3 services.

17 Approved Autism Evaluation Centers exist in Michigan. In 2012, **only 4 centers** existed.

Physical, Mental and Behavioral Health

14,285 YOUTH

14,285 youth have received services through the Medicaid Autism ABA benefit between 2013 and 2018.

10TH IN THE U.S.

Michigan's Certified Behavior Analysts workforce has grown to 10th in the country, from 118 in 2012 to 873 in 2018.

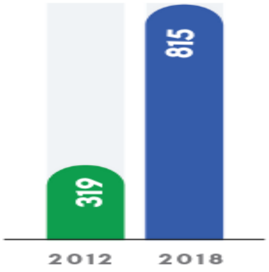
Adult Services and Supports

OVER 19 PROJECT SEARCH SITES

established statewide to increase competitive employment opportunities.

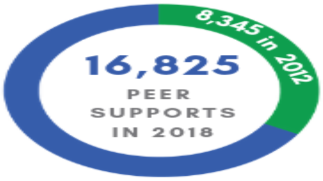
Educational Supports and Services

School personnel provide special education services to 20,595 children and young adults with ASD (June 2018). The START Project supported schools to establish 815 Peer to Peer programs, connecting 4,530 students with ASD to over 16,000 peers.



Total # of school buildings with a peer to peer support program

 # Students with ASD receiving special education services



# of peers who support ***4,530*** *students with ASD in peer programs*

Family Engagement and Involvement

In 2018, MiNavigator provided direction, assistance, and information to 1,850 Michigan families affected by ASD.

In the News

Michigan ASD State Plan 2018 Progress Review and Recommendations

Michigan Autism Spectrum Disorder State Plan

The Michigan Autism Spectrum Disorder State Plan was developed to build the state infrastructure for comprehensive, lifespan supports to individuals with ASD and their families through access to information and resources, coordination of services, and implementation of evidence - based practices.
https://www.michigan.gov/autism/0,4848,7-294-63679---,00.html

MCEC offers the opportunity for students with an active IEP to apply for funding to attend a summer camp in Michigan

This is an opportunity for students to apply for funding (up to $250) to attend a summer camp in Michigan. These camperships are open to students with an active IEP, in need of financial support, and would otherwise not have an opportunity for a summer camp experience.
Nomination packets must be submitted by March 15, 2019. Notifications will be mailed by April 30, 2019.

Registration link:
https://docs.google.com/forms/d/1lkfFMz8snbgtKnSMehFvPTv5F5C6_US6caQWKU_Ri1I/viewform?edit_requested=true

$1B autism bill would bolster support for those who 'age out'

Jerry Carino, **Asbury Park Press** Published 5:00 a.m. ET Feb. 8, 2019 | **Updated 7:45 p.m. ET Feb. 8, 2019**

https://www.app.com/story/news/health/2019/02/08/autism-funding/2810292002/

Over the past several years, as diagnoses mushroomed, society has developed an increasing number of resources to help children with autism and their families. But once those children become adults, the resources become scarce. A $1 billion bill introduced in the House of Representatives on Thursday seeks to, among other things, remedy that drop off in support.

The bipartisan bill, named the Autism CARES Act of 2019 (HR 1058) is sponsored by Republican Chris Smith of New Jersey, whose 4th Congressional district stretches across Monmouth, Ocean and Mercer counties, and Democrat Mike Doyle of Pennsylvania. A Senate version of the bill was introduced Friday by New Jersey's Robert Menendez, a Democrat, and Mike Enzi, a Republican from Wyoming.

“Our new legislation will reauthorize vital federal research on earlier interventions for children with autism and expands funding for critical research, education, housing and other programs that assist the countless children and adults on the spectrum, and their families,” Smith said in a statement. “The bill will also help ensure that the estimated 50,000 persons with autism each year who ‘age out’ of critical assistance programs and enter adulthood are supported, as many individuals and communities are unprepared for this transition.”

That last part is music to the ears of Millstone resident Amy Rohrer, whose 18-year-old son Tim Rohrer has autism.

“It’s so needed,” she said via phone Thursday night. “It’s kind of scary as a parent, not knowing who’s going to take care of your children when you’re not around to take care of them. I’m fortunate that Tim is high-functioning — he speaks, he drives — but not all those on the spectrum are like that.”

New Jersey has the highest rate of autism in the United States, with one in every 34 children identified with autism spectrum disorder, according to a study by the Centers for Disease Control and Prevention released last year. In November, Tim Rohrer made a splash by writing a teaching guide on how to be a good influence to people with disabilities. It was published by the New Jersey Coalition for Inclusive Education and widely circulated on social media. Although he walked with his class at Allentown High School's graduation last spring, Tim Rohrer has two more years of schooling available after June before he "ages out" of his education.

Millstone's Amy Roher (left) with her son Tim Rohrer after he walked during Allentown High School's graduation last spring.

(Photo: Dan Rohrer)

"We are at the point where we're looking for a career for him, and there are not enough employers willing to give him a chance," Amy Rohrer said. "If they could develop more programs and opportunities, that's huge."

"I cannot tell you how many parents I've met over the years who lay awake in bed worrying what will happen to their kids when they grow out of school-based support, or what will come of their adult children on the spectrum when they are gone someday," Menendez said Friday, in unveiling the Senate bill. "These hopes and dreams and fears have been at the forefront of my mind while drafting the Autism CARES Act of 2019."

Sen. Bob Menendez presented the Autism CARES Act of 2019 at a press conference in Midland Park Friday.

(Photo: Sarah Nolan/NorthJersey.com)

The bill would authorize funding for programs at the National Institutes of Health, Centers for Disease Control, and the Health Resources and Services Administration over five years, reauthorizing a similar bill from 2014. It would fund a combination of research, detection and intervention programs, and cover the expansion of autism-related activities.

According to a news release from Menendez, Autism CARES 2019 would:

- Authorize research under the National Institute of Health to address the entire scope of autism spectrum disorder.
- Designate regional centers of excellence for autism spectrum disorder research and epidemiology.
- Direct activities to increase public awareness of autism, improve the ability of health providers to use evidence-based interventions, and increase early screening and detection.
- Increase funding to $23.1 million to the CDC for developmental disability surveillance and research.
- Increase funding to $50.6 million to the Health Resources and Services Administration for education, early detection and intervention, with priority for new grants given to applicants in rural or under-served areas.
- Require the Department of Health and Human Services to provide a report to Congress on the health and well-being of individuals of all ages with autism spectrum disorder and other developmental disabilities.

Crucially, for those with autism who are entering adulthood like Tim Rohrer, it amends sections of the Public Health Service Act to reflect the need for research, surveillance, education, detection, and intervention for individuals with autism spectrum disorder of all ages — not just children.

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