



Each and Every Child



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When Mitchell descended into the spectrum

Early intervention is giving this boy hope – and a leg up

DES MOINES – Kathy Wilcox took 15-month-old Mitchell to Burger King one day for chicken nuggets. Nothing particularly memorable. Until.

"He looked right at me, and said, 'Mom I love you,' and it was like he knew something was happening," Wilcox said.

Something was happening. Mitchell descended into the thick murkiness of the autism spectrum. The little boy who had been particularly advanced for his age drifted backward, his speech gone, his eye contact non-existent.

"The thing that gets me is for the first year, besides the flapping of hands and feet, he was talking, saying my name, telling me when he wanted a book even before he was 15 months old," Wilcox said.

Despite the horrendous development, Wilcox – and in particular Mitchell – had a leg up. They had regular visits from a provider through the Des Moines Public Schools' Early ACCESS program. And the provider noticed something was very wrong.

Thanks to training on Autism Navigator, Des Moines' Autism



Photos by Iowa Department of Education's Deborah Darge

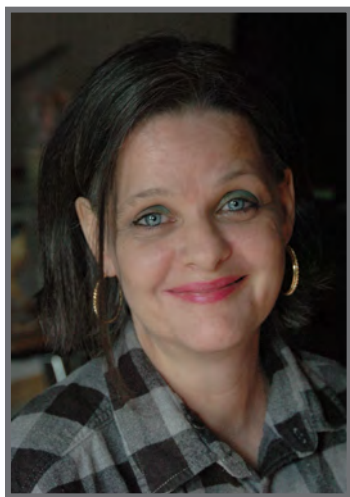
Kathy Wilcox with Mitchell

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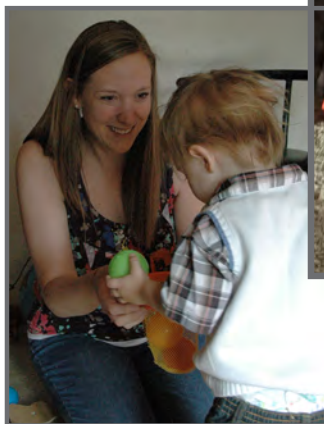
Navigator Team Lead Kristin Lampkin and Early Intervention Teacher Stephanie Shattuck were able to see the signs indicative of autism spectrum disorder (ASD), which was then confirmed through a district autism specialist. Through a grant from the Iowa Department of Education, the Des Moines schools' personnel have been given intervention tools which, once learned, is scalable and sustainable.

Autism Navigator is a training module that helps providers identify signs of ASD early in a child's development – which is key.

"Early diagnosis is critical because the core deficits of ASD – such as deficits in social communication and interaction, restrictive and/or repetitive behaviors or interests – can interfere with a child's ability to access learning opportunities which may lead to a cascading effect on development," said Wendy Trotter, an autism consultant for the Department of Education. "In toddlers we often see an unfolding of symptoms of autism. At 12 months the red flags may be subtle and easy to miss. A toddler may just appear to be quiet and minimally engaged with others in his environment. But because he is not engaged and not paying



Kathy Wilcox



Above, Mitchell offers Kristin Lampkin a ball while Heather Donoho looks on. Left, Mitchell works with Stephanie Shattuck.

attention to important information in the learning environment, he may begin to exhibit increasing deficits in social communication and brain development. So that by 2 years of age, he is exhibiting a lot more obvious signs of ASD such as delayed language, limited nonverbal communication, lack of social reciprocity, and repetitive behaviors."

An early diagnosis can put appropriate interventions in place to effectively minimize learning deficits.

Autism Navigator is a training module developed for early interventionists to learn more about autism spectrum disorder and work with families who are impacted. It was introduced last year to 51 individuals statewide, including all nine area education agencies. Another 57 participants started this year. Beyond early identification, the tools include interacting with families and developing communication and challenging-behavior strategies.

"We need to build the capacity of children with ASD to be actively engaged so they can benefit from the

natural learning environment," Trotter said. "A linchpin of early intervention is helping families of toddlers with ASD enhance their child's active engagement to support learning and development in the natural environment."

Heather Donoho, Early ACCESS lead consultant for the Des Moines district, said Autism Navigator has given the providers critical tools.

"All providers who work with young children should become aware of developmental norms and milestones so they can recognize early on if a child is not meeting those milestones," Donoho said. "Providers should especially be trained in recognizing the early red flags for autism – the earlier the intervention begins, the greater impact of the interventions can be."

If a provider isn't aware of the red flags for autism spectrum disorder or isn't sure how to approach parents about these concerns, there are resources out there.

"The Autism Navigator program



Mitchell is drastically improving in making eye contact with his mom, teachers and even strangers.

does a wonderful job teaching early interventionists how to identify delays in social communication and how to address these concerns with parents," Donoho said.

Parents should also be aware of the developmental milestones that their children should be reaching in the future. Attending regular well-baby checks, for instance, enables parents to stay on top of the child's development and identify any concerns as they arise.

"Parents are their child's best advocate and first teacher, and they know their child better than anyone else," Donoho said. "The goal of early intervention is to address these priority concern areas in ways that are functional to the child and embedded in daily routines that are important to the family."

Now nearly 3 years old, Mitchell's progress has been steady.

"His motor skills are where they should be," Lampkin said "Interaction is much better. We are also focusing on eye-to-eye contact."

"We try to problem-solve together," Shattuck said. "For instance, we will go to the grocery store together to get ideas. We have since created a picture book called 'Mitchell Goes to HyVee.' They read about it before they go, getting him prepared for what to expect.

"There's also a picture book of a bedtime routine, so that Mitchell will know what to expect step by step."

Wilcox says that while an autism diagnosis is hard, parents need to hear it as soon as possible.

"There are a lot of parents who hear that their child is autistic, and they go into denial," she said. "And I say, 'hey, don't ignore the situation, get on with what you need to do.'"

And she's determined about Mitchell's future.

"He's going to talk again," Wilcox said. "Before he declined, he liked to sing. So I think he's eventually going to be a singer."

The most common red flags

- Not responding to name
- Lack of speech (not talking at all) or repetitive, non-functional communication (nonsense words or repeating the words that others use instead of communicating their own wants and needs)
- Regression in communication or other skills
- Not making eye contact
- Using other people as a tool (taking mom's hand to grab something rather than getting it himself)
- More fixated on objects than people
- Flapping hands, spinning, rocking back and forth



Iowans work toward evidence-based practices in autism

We are not doing right by our students who are on the autism spectrum. To be sure, it's not just an Iowa problem. Nationally, statistics show that those on the spectrum tend to have worse problems in adulthood than nearly all other disabilities – *combined*.

That's simply not acceptable, so say a group of Iowans who are determined to find evidence-based practices that are sustainable and scalable. Their goal? To have the practices in place statewide by 2023.

Created in 2015, the Autism Spectrum Disorder Leadership Team is comprised of autism representatives from each area education agency, Des Moines Public Schools and Iowa Department of Education Autism Consultant Wendy Trotter.

"The state leadership team was formed with the purpose of coordinating efforts across the state through collaboration and networking," Trotter said.

Currently, she said, each AEA is providing its own supports to the districts.

"Historically, there has been limited collaboration across AEAs and inconsistencies in services from one region to the next," Trotter said.

"We're hoping to achieve statewide consistency of evidence-based practices so that no matter where you live in the state, you are receiving the supports and services you need in order to excel and grow."

The leadership team created a design group which is focused on creating a framework to provide tools, supports and learning for school personnel and families to ensure that learners on the autism spectrum receive effective instruction and support.



Wendy Trotter

"We have identified several areas of focus in order to build a scalable and sustainable framework of supports," Trotter said. Among them:

- The need to address leadership at the state, district and local level. "We are hoping if administrators understand and embrace the principles we are proposing, they will be supportive and prioritize resources. Without leadership, it won't go anywhere. It's important for them to embrace the concepts."
- "We also need to establish the infrastructure to support this work. We are trying to build a tiered network of supports and training for families, AEA, and school personnel, similar to Multi-Tiered System of Supports, except these supports are for those working with the student rather than for the student himself. We are looking at providing universal supports, supplemental supports (some specific strategies), and intensive supports where more intensive coaching needs to occur for staff working with a particular student."
- Work also needs to occur in developing teams at each school throughout the state. "It shouldn't

be one teacher, it should be a building team. We have to have everyone understanding the supports that the students need."

- Day-to-day practice also needs to be addressed. "In training school personnel across the state on evidence-based practice, we need to ensure they understand the unique characteristics of autism and design effective instruction for each individual student."

"Our hope is that through this collaborate effort, we will be providing supports to school personnel and parents to help the students to be the best they can be so that they can graduate from high school and be successful in the next step of life, whether it's additional training or college or career," Trotter said.

The timeline for this project remains fluid, but it's hoped that by next year, the design work will be wrapped up. Then between 2018 and 2020, pilot sites will be selected in which the AEAs and local schools will test the work and flesh out any changes and modifications. By 2020, the project will start moving out statewide with the goal of having it fully incorporated within three years.

A tip from a teacher

Model what it means to have a growth mindset for your students! Partner with a teacher leader by participating in a coaching cycle. Set goals for student learning and professional growth and make them visible for students. Take time to celebrate student achievement and commitment to learning!!



Teacher Leader Heather Howland, Janesville CSD

Save the date!

The annual conference for the Division on Career Development and Transition is coming to Cedar Rapids next year. The conference is scheduled for Oct. 24-26, 2018.

The division's mission is to "to promote national and international efforts to improve the quality of, and access to, career/vocational and transition services, increase the participation of education in career development and transition goals, and to influence policies affecting career development and transition services for persons with disabilities."

The conference is for teachers, administrators, special education directors, parents, Department of Education personnel, college instructors and professors, para educators, students, Vocational Rehabilitation representatives, support services personnel, work experience staff, and coordinators.

This year's conference is being held in Milwaukee. More information about next year's conference will be forthcoming.

Tips from Keystone AEA

Here are some tips to help all Individualized Education Program team members participate in a meaningful way during these annual meetings.

Tips for Schools

- Contact parents and other team members at least 10 days before the IEP is due to schedule the meeting.
- If a required team member cannot attend, ask parents to excuse him/her before the meeting date.
- Greet the family and begin with introductions, stating the purpose of the meeting.
- Tell parents the IEP is a DRAFT and can be changed.
- Remind parents and other team members that decisions are made as a team.
- General education teachers: Explain the curriculum, supports in the classroom, and how the student is doing in class.
- Special education teachers: Explain IEP goal progress and the special instruction you provide.

Tips for Families

- If a required team member cannot attend the meeting, you have the right to ask for the meeting to be rescheduled.
- Think about your child's strengths, interests and preferences and explain these at the meeting.
- Talk about your concerns for your child's education.
- Share goals you have for your child – what do you want him to be able to do that he can't do now?
- Ask questions if you don't understand something that is shared.

Have a tidbit you'd like to share? Send to jim.flansburg@iowa.gov.