

LETTING GO

Give children the tools, and let them take the steps



JONNI AND MICHAEL SEGNA

BY KAREN MOULT

PHOTO CREDIT FOR DR. PICKVANCE AND SON:
SHANE BEVEL

Bixby mom Jonni Segnar sat down 10 years ago and wrote down a list of goals for her son Michael, now 14 and a freshman at Bixby High School. The goals were not to establish a prearranged path for Michael, diagnosed with Asperger's Syndrome at a young age. The goals instead were to inspire Michael.

"There is no reason to feel he cannot attain the goals on the list and be independent. Michael sees and feels that, and so do we," Segnar smiled.

All parents go through the heartfelt anxiety of children exploring their independence. Whether it is watching a young child toddle away only to stumble and fall or a teen driving away from the house with a newly attained driver's license in pocket, letting go is not an easy process for a parent. And, for parents of children with dis-

abilities, watching their children learn to steer through everyday life can be, as Segnar described it, "heartbreaking at times and incredible at other times."

Tulsa University (TU) Professor and Chair of Psychology Department, Judy Berry, Ed.D., said youth independence is an intimidating process for any parent whether the child has a disability or not.

"Parents must remind themselves that everybody goes through this process," she said. "Parents are already attuned to their child's moods, likes and dislikes. Although this can be a frustrating time, parents should honor how well they do know their child and trust their instincts. Parents are more prepared for these changes than they think."

Encouraging independence in children with disabilities not only improves their self-esteem but also entices them to take a more

active role in their world. With independence, new opportunities at school, new friends and new challenges arise. A parent's job, said Berry, is to help them navigate.

During Michael's elementary school years, Segnar admits she often advocated for him academically. "I knew he had to learn the responsibilities that go along with school during these years if he is to have success in middle and high school," she said. "School was tough because he could not understand that school work many times carried over into his time at home in the evening. He fought the homework task. But I always told him he needs to learn to do things right so he can do it right later."

While Michael has an Individual Education Plan (IEP) he was mainstreamed into a regular classroom early on in his school career. His IEP has allowed him to work with an occupational and speech therapist during

>>>

the school day. During Michael's fifth- and sixth-grade years Segnar worked closely with his teachers to push him academically.

"I did not want him to become lazy or not challenge himself academically, especially in English class," she said. "His best subjects are math and science. He had to work hard in English, and I did not want the teachers to remediate him. He had some special teachers who guided us both. I knew he was capable of doing the work all the children were doing."

It is important, said Berry, for parents to listen to what teachers and therapists have to say because they are seeing the child away from you and in the school environment.

"A parent needs that viewpoint and must start early really trusting others," she said.

Segnar said Michael did not have a social life during his elementary school years.

"It becomes heartbreaking when they are younger," she said. "Your child is not invited to birthday parties and play groups. You feel isolated as a parent. You walk down the hall at school, and you realize you do not know these other moms because your child is not playing soccer or basketball or other activities."

He ate lunch alone every day, she said.

"It made me want to cry. I had to tell myself it was okay. He, on the other hand, never said anything about it."

Berry tells parents to resist the desire to fix situations. "It takes a lot of patience. Let your child evolve," she said. "Parents need to seek the friendship and advice of parents in their same situation. These parents become your source of information and can give you important support. They have been there and can give you advice on when to step in and when to let go."

In 2011 Segnar started Aspergers Mom's Network as a place for moms with children diagnosed with Asperger's Syndrome to meet and share experiences. "Because your child is not usually involved in activities like other children at their school, you find you really don't have any peers at your child's school," Segnar said. "The network gives myself and other moms an opportunity to meet and talk about what is happening in our lives and our child's lives. We have a huge thing in common, our children have Aspergers. The network has become a place of acceptance"

Segnar had a nice surprise during Michael's middle school years. Michael no longer ate lunch alone, but instead he sat

with a group of fellow classmates.

"In seventh grade, a group of nice boys and very involved boys asked him to join them at their table," she said. "They sincerely thought he was funny and wanted him around. They stood up for him. I'm glad I never stepped in. It happened without me intervening, and he made friends on his own. I have realized and had to tell myself all along that when Michael is ready he will do things on his own. I just have to give him the tools and he will take the steps."

A path toward independence is not always easy for a child with a disability. Michael now makes his own lunch, sorts laundry, cleans up his room and mows the lawn. Segnar said that many times an Asperger's child might not have the coordination of other children, so some of these tasks may take longer to learn. "Parents should be patient and be ready for mistakes. But given the opportunity, Michael is capable of doing all that he tries and is asked of him."

Segnar no longer checks Michael's grades online as often as in the past.

"Grades are available online or by talking with teachers," she said. "There were years in there where I checked things regu-

And eventually Michael did. Holding him accountable worked. Today Segnar does not have to "hover."

"He has caught onto the consequences," she laughs. "Michael is two years ahead in math and is in the engineering program offered to high school students at Tulsa Community College."

College and independent living are on the list of goals Segnar jotted down years ago.

"I really had to think for our family where we want Michael to be in the future. It is up to us to help him with goals and plans," she said. "We want him to go to college and be able to live in a dorm. He has the intelligence and, like any young person, he is developing the skills to do this."

Berry said parents must always stay focused on the future. "Can and will my child be capable and have an interest in going to college, or, do we need to guide them to a vocation or work? Will they live independently? The family and child must discuss all these things. Together, the right path will fall into place."

Director and ADA/504 Coordinator Center for Student Academic Support Tulsa University, Tawny Taylor Ph.D., said TU is



ELIZABETH PICKVANCE, M.D., THE CHILDREN'S HOSPITAL AT SAINT FRANCIS.

larly and reminded Michael of problem areas. I set high expectations. If he did not turn in an assignment, I asked him about it and expected him to correct the situation on his own."

admitting a growing group of students with Asperger's Syndrome.

"We currently have an academic counselor who works individually each week with these students to do academic coun-

>>>

cover story



TIMUR PICKVANCE.

selling and work on social issues," she explained. "In addition, we host a weekly workshop on topics of interest for the group. We also coordinate a monthly social outing together—like going to the movies, to dinner, bowling, to a museum, etc. The students seem to really enjoy it and find it beneficial."

Dr. Elizabeth Pickvance, M.D., Warren Clinic Pediatric Orthopedic Surgery, has high expectations for her 7-year old son, Timur, who has born with mild cerebral palsy.

"I have always said to him, you are going to go to college and going to be a man of honor and a good friend, worker and husband someday," she said. "It is what I expect."

Dr. Pickvance, who is British, adopted Timur from Russia.

"I went there thinking I was going to come home with a girl. I wanted my other son, Collier, who I adopted from the Ukraine, to have a sister. But," laughed Dr. Pickvance, "another child grabbed my heart. The smile on Timur's face when I first saw him...he was meant to be mine and I knew that we could work through any difficulties."

Timur's cerebral palsy affects his left side. He no longer wears a leg brace but walks with a bit of a "wobble." He is slowly

learning to use his left hand.

"We did very aggressive occupational therapy with Timur," Dr. Pickvance said. "We even cased his right hand forcing him to use his left. He must train himself to use that hand. When we eat dinner, I have my boys hold their knife and fork in a traditional British fashion that requires using both hands. This has forced Timur to use his left hand along with his right when eating."

Dr. Pickvance counsels her patients' families at the Children's Hospital at St. Francis on how to help their children with disabilities work toward self-sufficiency. "A child with a disability must learn how to participate in the family and the parents must allow and teach the child to do this," she said. "Even if it is small stuff around the house, a parent can make the child responsible, at some level, with a chore. If they are in a wheelchair, they can still help fold laundry. It is a parent's choice. Do you want your child independent from you or dependent on you?"

Timur's gait is a bit slow, Dr. Pickvance explained, and he is not as agile as most boys his age, but he does everything other children do.

"When playing sports, many times he cannot keep up, but I tell him you may not be as fast, but you can play smart. I do not allow him to not participate. It is not part of

our family values."

Dr. Pickvance said that parents who allow their child to be independent also must be ready for messy results.

"Parents should realize that children with a disability might be slow when first learning a new chore or activity. When they pour milk, they might spill more. They might fall down more and there might be some skinned knees. But you have to let go." Timur is self-determined because his mother provides just the right amount of positive reinforcement for her son.

"Kids will figure out what they need to figure out," she said. "If Timur trips and falls and gets himself up, he will figure out next time why he tripped. Was he dragging his foot, not paying attention? Next time he will most likely not fall. He must learn for himself. I always ask him if he is okay when he falls. He says, "Yes ma'am" and gets himself up, and we move on. I do not pick him up. He learns how to pick himself up and also how to manage the situation."

Parents' positive attitude toward their child's efforts can prove important in the child's overall development. According to a study conducted at Brigham Young University and published in the 2012 issue of *Research in Developmental Disabilities*, positive parenting can be particularly effective in helping young children with developmental disabilities become more independent and cooperative.

"A child with a disability requires added time, education, coping skills and family support. But, despite the sacrifices, for parents who engage in positive parenting practices, the pay-off can be significant. In households where positive parenting is applied, the symptoms and severity of the child's disability are more likely to decrease over time. The positively parented children in the studies exhibited higher levels of independence, language skills, emotional expression and social interaction with adults and peers. They also demonstrated improved temperament," researchers stated in the study.

Yet, there is one part of Michael's independence that Segnar hopes she can face with a smile, the teen rite of passage, driving. Segnar admits she is a bit nervous about Michael approaching the age of 16 and getting behind the wheel.

"The big feat coming up soon is Michael learning how to drive. I am trying to be open to this. It's on the list," she laughs.