

The face of autism has always been the face of a child.

He is detached from his peers. He speaks little or not at all. He is troubled and troubling.

The image is as heart-wrenching as it is incomplete.

Autism is not a childhood disorder. It never goes away.

The child born in 1980 - the year the American Psychiatric Association first added autism to its list of known mental disorders - is now nearly 30 years old.

The new face of autism is a young adult, trying to carve a place for himself in society.

He is beginning to step away from his parents who have gone to great lengths to nurture and protect him.

He is looking for work and acceptance because the children of autism are no longer children, and they are here to stay.

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Eric Foley loves cameras and stereo systems. He snaps his fingers when he walks, the clicks in perfect rhythm with his steps.

And, at age 26, he has never spent a day apart from his parents. Eric is autistic.

They are with him nearly every moment of every day.

"We don't go out for romantic dinners," Donna, 60, said with a laugh. "We spend Valentine's dinners with Eric. We are three people. But it was our choice. And it was the right the choice."

Donna knew there was something different about Eric, the youngest of three siblings, before he was 18 months old.

"I kept saying to my husband, 'I think there is something wrong. Something is not right.'"

The Foleys began a long series of doctor's appointments and testing.

There were diagnoses and re-diagnoses and finally, at age 4: autism.

They placed Eric in a Montessori preschool. Then a special school for children with development concerns. Then public school.

Finally, in seventh grade, they found a specialized academy that worked for Eric.

"We spent our entire college fund for Eric in his first year there," Rob, 62, said.

Homework, therapy sessions, and doctor appointments, plus the responsibility of raising Eric's brother and sister, could feel overwhelming.

His entire childhood was an exercise in survival.

"When he was a boy, you were concerned about getting through that day," Rob said.

Even feeding Eric was a constant struggle. Most foods he would not eat. Prescriptions dimmed his appetite.

Through it all Eric remained the same sweet, if remote, boy. Some days broke Donna's heart.

"I would pick him up from school some days and he would be crying because he had not eaten," Donna said. "He had headaches and nausea. I would pick him up with a Ziploc bag filled with food he might eat."

Eric graduated from high school when he was 20 years old.

After years of just trying to get through the day, the task of raising an autistic child was done.

The Foleys, suddenly, needed to switch from just getting Eric to adulthood, to preparing him for life as an adult.

They always knew Eric would likely live well past them, but suddenly it seemed so real.

"It's like that dream. The dream when you have to take a test and you know you have not studied enough," Donna said. "It's not a good feeling."

Rob and Donna have worked hard to leave Eric financially secure, but for Donna, the question of Eric's future is not as simple as money.

"I'm 60. I'm not going to live forever," Donna said. "Who is going to care for him? Who will treat him with tolerance and patience? Who will love him?"

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Autism is a complex neurobiological disorder that impairs a person's ability to communicate with and relate to others.

Different people with autism can have very different symptoms. Health-care providers think of autism as a "spectrum" disorder, a group of disorders with similar features.

The condition occurs in all racial and ethnic groups. It is four times more likely to strike boys than girls.

For decades, autism was believed to occur in 4 to 5 per 10,000 children.

In 2007, the Centers for Disease Control and Prevention released new data, which showed an astounding increase in the number of diagnosed cases.

A broad survey of 8-year-old children showed that nearly 67 per 10,000 were living with an autism spectrum disorder, an increase of well over 1,000 percent. The increase is largely because parents and doctors now do a better job of identifying the symptoms and better classifying the children.

The CDC also acknowledges an actual increase in the number of children with the disorder, though the reasons are unknown.

In 2008, Easter Seals conducted a national study and found that 1.5 million Americans have an autism spectrum disorder. Twenty percent, or 300,000, of those people are age 22 or older.

The details of the study told a story that parents of children with autism have known all along.

- 76 percent of teenagers with autism over the age of 16 have never looked for a job.
- 79 percent of parents of children with autism are "extremely" or "very" concerned about their children's future independence. Of "typical" parents, by comparison, 32 percent are equally concerned.

- 79 percent of adults with autism still live at home.

Denise Resnik is the mother of Matthew, an 18 year-old with autism, and is a longtime advocate for people living with the disorder.

For parents, Resnik said, the job of parenting an adult with autism does not get easier.

"I thought it was complex with Matthew as a kid," she said. "It is infinitely more complex with Matthew as he is becoming an adult."

Autism advocacy groups are growing up, too.

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On a recent summer afternoon at Southwest Autism Research & Resource Center (SARRC) in Phoenix, Erin Onacki was readying three young men for a rite of passage.

The three sat in their chairs completely silent. There was no nervous small talk, not even an acknowledgement that other people were in the room.

SARRC began more than a decade ago to support families affected by autism.

At that time, most parents were concerned about education and child-rearing. They wanted help figuring out how to get their autistic child to go to school, to pay attention in class, to deal with the social minefield of the lunchroom.

They needed to find the best teachers or doctors or support groups.

This year, SARRC opened the Opus West Vocational & Life Skills Academy.

There are classes on cooking and cleaning and money management. There are also classes on how to find work.

That's why Onacki was standing before the three young men.

She broke the silence in the room by creating a game to help them practice the start of a job interview.

"When the employer walks into the room, you stand up and say hello," Onacki said. "Then you introduce yourself while extending your right hand to shake the employer's hand. Then you squeeze his hand like a brake on a handlebar. Meaty part of the hand to the meaty part of the hand."

She asked them to practice with each other.

She spoke about what to wear to an interview. About the importance of being on time.

Then she stopped. Two of the men were facing each other - still shaking hands.

She had to laugh. "You can let go now," she said. She advised them to just shake twice. "Up-down once. Up-down twice. That's enough."

Some autistic adults will not be able to find work. Others, usually those with less severe forms of the disorder, can.

Autistic adults from SARRC work as busboys and prep-cooks at Outback Steakhouse. They take tickets at Harkins Theatres. They stock shelves at PetSmart and CVS pharmacies.

To date, 100 adults have worked with SARRC's employment services division. Twenty-five have been placed and the others are on their way.

Matt McMahon owns 18 Outback Steakhouse franchises in the Southwest, and has committed to having at least one autistic adult working at each one of them.

For him, it's personal. His 12-year-old son is autistic.

"Remember your first real job? Remember how you felt?" McMahon said. "They come to work feeling that way every day."

Resnik, a co-founder of SARRC, says employers have told her the workers with autism can be model employees because they arrive on time, they don't mind repetitive tasks, and they don't steal.

"For the past 20 years, we've been talking about how horrific autism is," Resnik said. "And now we are saying that we need these young people to live with you. To be in society."

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In 2007, Lisa Giungo called a meeting with the staff at her central Phoenix restaurant, Lisa G Cafe Wine Bar.

They would be getting two new hands, she told them. Adam Bernstein would be a prep cook, and Zoe Talaska would bus tables. Both were autistic.

Some of the staff were less than enthusiastic.

Giungo insisted. She was creating an internship where autistic adults could get their first taste of a real job.

Someone so inexperienced, and autistic on top of that? Her chef needed convincing.

"He was about to be a father, so I told him it might be a good way for him to learn some patience," she said.

Almost immediately, the chef changed his mind. Adam was a perfect fit in the kitchen.

"He was so good," Giungo said. The chef "only had to tell him how to do something once. After like one week, (the chef) came to me, and said 'God, Lisa, he's perfect.'"

Zoe's path in the dining room was bumpier.

In the menu, Lisa put a note that explained who the new employees were: "These young adults will be in the restaurant with a job coach several times a week developing vocational skills that will help them with their career development If you have any questions please ask us."

But many diners missed the explanation. Zoe seemed brusque. Some patrons were put off.

There was the day a woman put her purse on the floor. Zoe insisted, repeatedly and strongly, that the woman pick it up.

There were days when she would clear a table or pour water with none of the pleasantries that diners expect.

Giungo was getting worried. She was committed to helping the SARRC clients, but as a small-business owner, she could not afford to put off her customers.

Finally, she found a simple solution. A name tag.

Zoe wore it around her neck when she was working. It explained who she was, and why she was there. "People loved her then. They asked to sit in her area specifically," Giungo said. "People understood, and it made all the difference."

Each job placement provides an opportunity to make the autistic and non-autistic comfortable.

It's a big part of Onacki's job.

"I just spoke to 100 workers at US Airways about autism because we have placed one worker there," she said. "That's invaluable to us. They had so many questions. The more they knew, the better it seemed."

Every time a SARRC client is placed, a job coach learns about the new job, then spends two weeks at work with the new employee to ease the transition, and to answer any questions other workers may have.

Teaching people about how to work alongside the autistic, then letting them actually do it, are the key to a future where autistic adults will fit into the world around them, she said.

"We have to do this," Resnik said. "Autism does not go away, and neither do the people living with it. We have to learn how to live together."

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Even as an adult, feeding Eric is a challenge.

He spends each day at work with his parents. For lunch, they go to their usual restaurants.

Eric likes the pepperoni pizza at Johnnie's Chicago Style Pizza, the flaming cheese appetizer at Saba's, and a double cheeseburger, plain, at McDonalds.

"We know his diet is not ideal," Rob said. "But even his doctor said the aggravation of trying to get him to eat better is not worth it."

On a recent lunch break, they were seated at a table near the kitchen at Saba's.

Their waiter approached. "Hello," he said. Eric looked up and blurted: "Flaming cheese."

The waiter smiled. He knows the family well by now. Eric's order, he said, was already in.

Eric's parents have always described him as "mildly impaired."

And on the wide autism spectrum, he is.

He is handsome and always impeccably dressed. He is quiet but well-mannered and obviously bright.

When he meets new people, he shakes their hands and looks them in the eye. But moments later his eyes fall back to the floor.

Eric is now in the middle of SARRC's job-training program. Soon, he will interview for a job at a Harkins Theatre near his parents' home.

Scottsdale-based Harkins has worked closely with SARRC to find work for qualified applicants.

The Foleys, who have spent the past 26 years constructing a cocoon around Eric, know they need to start letting him go a little bit.

"Even people who are close to us have a hard time understanding why (Eric) is not employed. Or driving. Why he is not more independent," Donna said. "I don't think they understand because there is no visible sign of impairment."

The Foleys are as concerned about Eric's emotional development as they are worried about him working.

The Foleys hope desperately that Eric will start to make friends.

Rob is a charming and gregarious man. He is as adept in social situations as Eric is awkward.

"He is missing out on so much," Rob said. "That is a real sadness for me. I hope he develops those relationships. I don't know if he will. Probably not."

It is hard to know how much Eric feels that loss.

Eric speaks in a quiet monotone, his eyes low.

Is he happy? Yes, he says.

Does he know his parents love him?

"That's fine. That's good. They love me."

Does he know what autism is? Not really. He knows he has it, but can't explain it.

Children of autism approach adult world

<http://www.azcentral.com/arizonarepublic/news/articles/2009/07/12/200...>

Are his parents old?

"Older than me. I wouldn't consider them old."

Does he ever wonder what his life will be like when they die?

"I haven't thought about that. I wonder what I'll do when they are gone. I don't know."