

Betting on hope: Mother of an autistic college professor reaches out to other parents

April 3 2009, By Jeff Seidel

Eustacia Cutler sat at a piano, practicing Bach. Her daughter, Temple Grandin, was on the floor -- lost in her own world. Lost inside her 2-year-old mind.

Temple couldn't talk and refused to communicate. She started humming, crumpling a newspaper. Squeezing. Shredding. Tossing. Staring blankly as the pieces floated to the ground. Jagged fragments. Isolated and alone. Mental debris. Destined for the trash can.

Cutler stopped playing, trying to get her daughter to engage, trying to get some love. That was the hardest part of having an autistic child, not feeling a shred of love, not feeling like a mother.

"See the bright colors?" she said to her daughter.

Temple sat there, unable to climb out from behind those numb, baby blue eyes.

Frustrated and afraid, unsure what to do, Cutler started playing again. And Temple started humming.

Back in the late 1940s, when Temple was a child, her doctor called it infant schizophrenia. It was a rare disorder, affecting one in 10,000 children. Many were sent to an institution, locked up, discarded.

Today, the same thing is called [autism](#). It affects 1 in 150 children. It's

more common in boys, affecting 1 in 94.

Through love and determination, not to mention the help of some amazing teachers, Cutler pulled her child out from behind those baby blue eyes. "I was going to pull her to me," Cutler said. "I was going to pull her into the world with me."

And Temple grew up to be a remarkable success story _ the poster child for autistic achievement.

"Temple Grandin has been known for years in the autism community," said Dr. Colleen Allen, the director of the Henry Ford Center for Autism and Developmental Disabilities in Detroit. "She is an example of a person who can go through this life with this kind of disability and really make it."

But it was Temple's mother who was behind the scenes, gently pulling her into this world.

SHARING HER STRUGGLE

Cutler is 82 and lives on New York's Upper West Side. She travels around the country, giving 12 to 15 speeches every year to families with autistic children.

She will come to the Detroit area and be the keynote speaker at an autism workshop next month.

In her speeches _ Cutler calls them lectures _ she tells families how her daughter grew up. Temple didn't speak until she was nearly 5 but she entered a small country school, where she received individual instruction. "Temple was mainstreamed at 5," Cutler says. "But we didn't call it that back then."

Cutler tells the families how Temple graduated from high school and college, earning a bachelor's degree from Franklin Pierce College, a master's degree from Arizona State University and a doctorate in animal science from the University of Illinois.

She tells the families how her daughter is a professor now at Colorado State University.

She tells the families how Temple became a media darling, appearing on television programs, including "20/20" and NBC's "Today" show. She has been featured in several publications, including People magazine, the New York Times and Time magazine.

She tells the families how her daughter has found peace. She has found herself, found a place in this world.

"Temple is a smart girl who has overcome a severe disability," Cutler says. "What I think is important for people to understand is we are not going to cure autism. What we can do is help our children be fulfilled."

Most of all, she gives the families hope.

Cutler finishes her story and then she waits. Sometimes, she goes to the ladies room and washes her hands slowly. Deliberately. Stalling. Waiting for the approach.

In the quiet, after the crowds have left, they come up to her _ parents from the present, asking for advice from a mother who has already gone through the hell.

"They would come up to me privately and tell me, 'Your story is my story,'" Cutler said.

'MOTHERS WERE BREAKING DOWN'

As scientists and researchers debate the cause of autism -- Is it genetics? Vaccinations? Pollution? A combination of everything? What? -- there is a profound struggle inside the families with an autistic child.

More often than not, it rips apart marriages. Eighty-six percent of the marriages with an autistic child end in divorce, according to Allen.

"Most of these children are raised by single mothers," Cutler said. "In a sense, I was a single mother."

Like so many others, Cutler's marriage ended in divorce. She waited until after her husband's death to write her best-selling book, "A Thorn in My Pocket" (Future Horizons, \$24.95).

"I struggled through a marriage where Temple's father wanted her institutionalized and I wouldn't," Cutler said. "Therefore, he went to work to try to prove I was crazy. In those days, in the '50s, he could have succeeded. There was a tremendous feeling against mothers in those days. What people didn't realize was mothers were breaking down."

So she tries to give the parents some inspiration.

"I try to give them an emotional compass," Cutler said. "With that compass, I try to give a simple guideline for what they can expect out of an autistic child."

Cutler said that autistic children will struggle with concepts and context. They struggle to make social connections. And it is important for parents of an autistic child to explain to others that autistic children do not always make eye contact.

"It is hard for these children to look at somebody in the eye," Cutler said. "They don't understand what we are getting from each other. They are not being shifty-eyed. Once you understand that, you can deal with it."

But most of all, she tries to give the parents a simple message: Never give up hope.

"Hope is different than control. It's not Hallmark cards -- oh, it's all going to be all right. It's really a bet. You check out the odds, and you place your bet. That's how I describe hope. And I bet on Temple's growth."

INSPIRATION AND ADVICE

Eustacia Cutler has words of wisdom for parents who are raising a child with autism. But parents of any child can heed her advice:

"What do you want for your children? For them to be fulfilled as they would like to be fulfilled. Not your idea or my idea of fulfillment, but theirs."

"Never give up hope. They will find their way."

"Your child will be who your child will be, and you will come to terms with it."

"The more our children are educated, the more they will join the workforce, and be able to manage for themselves, all their lives."

EARLY DIAGNOSIS

Dr. Colleen Allen, the director of the Henry Ford Center for Autism and

Developmental Disabilities, said it is important to identify children who have autism early in life.

"Pediatricians are supposed to be administering an autism tool beginning at 18 months of age," Allen said of testing for the disorder. "If a child fails that, they should be referred" to a specialist.

The majority of children affected by autism are boys.

"It's one in 94 males," Allen said. "Even in my own caseload, it's a majority of males when we look at the kids coming into the autism clinic every week."

According to the Autism Society of America, some of the early warning signs are:

- Lack of or delay in speaking
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

FOR MORE INFORMATION ABOUT AUTISM

- The Autism Society of Michigan can be reached at 800-223-6722 or www.autism-mi.org.

- The Henry Ford Center for Autism and Developmental Disabilities can be reached at 313-916-4665 or autismcenter@hfhs.org.
- Jack's Place, named for the autistic son of former Detroit Tiger Jim Price, can be reached at 248-443-7427 or go to www.jacksplaceforautism.com.

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