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FAMILIES & **AUTISM**

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FAMILIES & **AUTISM**

AUTISM DOESN'T JUST IMPACT FAMILIES DURING CHILDHOOD. FINALLY, SOMETHING IS BEING DONE TO HELP THEM PREPARE FOR A LIFETIME OF CARING.

By Sheryl Flatow



“What will happen when my parents are gone?”

That question begins to haunt many teenage siblings of individuals with autism spectrum disorders (ASDs). Caring for a person with autism is often a lifetime proposition, but, until recently, little attention was paid to the effect that ASDs have on the family unit.

Leading that shift has been Gael Orsmond, associate professor in the Department of Occupational Therapy. A developmental and clinical psychologist, she’s co-director and co-investigator of a large-scale longitudinal study, funded by the National Institute on Aging, that examines the long-term impact of caregiving on family members and explores how autism evolves from adolescence to adulthood.

“Do they get better?” says Orsmond. “Are there other conditions that occur? When we began this study, nobody had looked at what happens to people with autism in adulthood, and how family members adapt over time. The focus had always been on childhood.”

The study was launched in 1999 in partnership with the University of Wisconsin-Madison and has observed 405 families divided between Massachusetts and Wisconsin. When the project began, the age range of those with autism was 10 to 53 years old; roughly two-thirds were adolescents and young adults. “It was harder to find adults than we anticipated,” says Orsmond. “They’re out there, but some of them were never properly diagnosed.”

Every 18 months, comprehensive in-home interviews have been conducted with the primary caregiver, almost always the mother. “The interview focuses on the symptoms of the son or daughter with autism, so that we can track the disorder over time,” says Orsmond. The study seeks to determine whether there are discernable changes: in eye contact, the ability to have a conversation, social impairment, repetitive behaviors. “The mother also completes a set of questionnaires ahead of time,” she says, “which mostly address her well-being.”

Orsmond received an additional grant from the National Institute of Child Health and

Human Development to collect data from siblings between the ages of 12 and 18, to see how well they cope with their family situation.

“I wanted to focus on adolescence because it’s such a crucial time for well-being,” she says. “It’s a given that a person with a disability can create stress within a family. But research shows that when a child has autism, other family members are more likely than the general population to show mild, sub-threshold impairments. They might have social difficulties that couldn’t be diagnosed as autism: somebody who has difficulty making friends, for instance, or who has hobbies that are really intense. So I wanted to look at whether siblings were having problems, and whether those problems were due to the environment, or a genetic component, or perhaps a combination.”

Research revealed that siblings who are most likely to have depressive symptoms are those with these sub-threshold symptoms combined with environmental stress, such as recurring disruptive behavior from the child with autism. “It took those two things together to impact siblings,” she says. “It wasn’t just one or the other.”

The findings so far provide some encouraging news to families. The rates of nonclinical depression in siblings of individuals with autism are no worse than in those of typical adolescents in the general population. And although many siblings point out that their parents spend a good deal less time with them because their brother or sister requires so much attention, they express little resentment as adults. One respondent said, “It taught us tolerance and unconditional love and selflessness to see how our parents cared for our brother.” Another commented, “It has probably brought us all closer together.”

And people with autism do show some improvement as they mature. “Symptoms tend to decrease in their severity over time, especially the repetitive behaviors that are most stressful to families,” says Orsmond. But the ability to make friends remains elusive.

Orsmond hopes that the findings of the principal study, which is funded through 2012, will help families of individuals with autism understand what to expect over time. “We share >



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See next page for more family stories.



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> some of our findings with them every six months,” she says. But Orsmond would like the research to have an even wider impact.

“We hope to see an improvement in services and support as we get our data out there. We publish a lot in scholarly journals, and we also try to get this information to the people who have the power to make changes. Unfortunately, in this economic climate where services are being cut, that is not happening now. But it is very much one of our goals. Families need so much support. Siblings want information. We hear things like, ‘How do I talk with my family about future planning?’ ‘What should I expect when my parents are gone,’ ‘I don’t know how to work with services.’ So part of our job is raising issues, and figuring out what kinds of intervention or support or services there are. There is still so much to learn.”

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GAEL ORSMOND



FAMILY STORIES OF AUTISM

HOW LIFE CHANGED—OR DIDN’T—FOR BROTHERS AND SISTERS OF SIBLINGS WITH AUTISM

Childhood: “I felt very protective of my sister while we were growing up. I tried to help my parents keep the household running and spend time with my sister. I had more responsibility than most of my friends my age. But it was responsibility I chose to take on myself.”

Community Acceptance: “My mother was very progressive-thinking, inclusive, and dedicated to trying to help my brother overcome his disability. Unfortunately, the rest of society can’t fulfill this standard for him.”

Relationships: “I know I can’t marry anyone who won’t be supportive and accepting of the fact that one day I/we will be responsible for my sister.”

Starting a Family: “I am terrified to have a child with a disability such as my brother’s. I don’t think I could handle it. Genetics counseling before planning pregnancy is definitely a necessity.”

A Different Life: “You don’t do things as a family as much as other families do. You make sacrifices. You do without things. But in the end, you’re stronger, closer, more vulnerable, more honest, a little more responsible.”

The Future: “I would give my brother anything. I would love to have him with me, but he needs constant supervision and structure that can be better provided at a residential care setting. I also want to give my children (in the future) all I have, and, if he was with us, I know that would be difficult, if not impossible.”

Taken from: *Adolescents and Adults with Autism: A Study of Family Care-giving*, “Reflections from Adult Siblings who have a Brother or Sister with an Autism Spectrum Disorder.”



WEB Extra

Read the autism study research reports and personal stories of living with autism at www.bu.edu/sargent/autism.