

# Some words of hope for 'growing old with autism'

By Cami Weaver and Carol Fremault

It's a tremendous challenge, dealing with autism. And it's only going to get more challenging.

According to the Center for Disease Control, one in every 150 children born in the U.S. every year will be diagnosed with autism in the first several years of their lives. About 4.1 million children are born annually in this country, and that means we can anticipate the number of kids with autism to grow by more than 27,000 every year, too.

That's a lot of people who will need special assistance and services all of their lives. It demands a huge financial commitment by society.

And on a personal level, it presents a host of lifelong difficulties and obstacles to the children diagnosed with autism along with their families whose lives are forever altered to provide for the new family member's special needs.

But there is reason for hope. Children diagnosed with this unique kind of developmental disability can grow up to live happy and often fulfilling lives.

We offer these words of optimism in response to a recent Time Magazine article filled with hopelessness, dread and some resentment, that we fear it terrified thousands of parents of children newly diagnosed with autism.

"Growing Old with Autism" by Times and Sports Illustrated editor and writer Karl Taro Greenfeld's is a first-person account of Greenfeld's life with Noah, his little brother who has autism.

It's a moving and tragic account of one family's struggle to provide for a child a lifelong developmental disability. It is an important story in that it demonstrates the light years our society has traveled in just one generation in dealing with autism, from institutional care, where spanking and slapping were commonplace, to assisted living situations and group homes. And, painfully, it shows the years of difficulties for parents and siblings living with a member of the family who has autism.

Yet we found Greenfeld's memoir – adapted from his book, *Boy Alone: A Brother's Memoir*, and published May 25 in Time Magazine – disturbing and, perhaps, damaging to efforts by families and professionals dealing with autism.

We appreciate and understand the world that Greenfeld, his brother and parents have lived over the past 40 years. But we must take issue with the almost totally negative tone of Greenfeld's story, describing his brother as a "42-year-old man, balding, gaunt, angry and, literally, crazy."

We offer our comments as professionals. Together, we have spent almost 50 years combined working with people like Noah Greenfeld. We've taught at Sonoma Developmental Center, operated group homes in

Santa Rosa for adult men with autism, and at Becoming Independent provided support services for some 1,200 people – and their families – with all types of developmental disabilities in Sonoma, Solano and Napa counties.

We know people with autism who have grown up to be adults and, thanks to creative and innovative methods and supportive services, are leading happy and productive lives to the best of their abilities.

The grim, institutional living situations that were once part of Noah Greenfield's life don't necessarily have to be. Our goal for people with autism here in Sonoma County is to find assisted living situations and programs that provide individualized services to produce a quality of life for the Noahs of the world and, hopefully, peace of mind for their parents and families.

With early diagnosis of autism, parents and professionals are now better able to understand the extent of a child's disability, what is possible and what is not, and how to plan to provide the child and family with the best chance of happiness.

Greenfeld laments the fact that autism funding and research largely focus on children. Children with autism grow up to be adults, he points out, and we are only beginning to fully understand the extent of this adult challenge.

He's right on that. It makes sense that we should start with an early focus on children when they are diagnosed, but we must recognize the need for continuous support as they age.

This must include not only financial support but a tolerance and understanding by everyone in the community. People with autism are our neighbors.

This means a commitment in real terms – money for serves for people with autism and other developmental disabilities. Given the status of government resources, the economy, and the politics at work in Sacramento and Washington, D.C., that could be the greatest challenge of all.

*Cami Weaver is CEO of Becoming Independent where the Family Resource and Advocacy Center provides support for parents of children with autism and other developmental disabilities in Solano, Sonoma, and Napa counties.*

*Carol Fremault is Executive Director of California Programs for the Autistic, Inc., which operates two homes in Santa Rosa for 12 men with autism.*

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