

SundayReview | OPINION

Adult, Autistic and Ignored

By ELI GOTTLIEB SEPT. 5, 2015

TWO months before she died of pancreatic cancer in November 2010, my normally strong, stoical mother broke down weeping in my arms over the fate of my autistic older brother.

Institutionalized for over 40 years, Joshua, then 55, was in a stable situation and seemed relatively happy. But my mother was undone by that fear that haunts all parents of disabled children: *What will happen to them when I'm gone?* Though I hastened to assure her that I would become his guardian and watch over him after her death, she was inconsolable.

In reality, given the nature of the bond between them, I shouldn't have been surprised. As is often the case between mother and disabled child, the two early on formed a deep, exclusionary attachment that relegated the other members of our family to the outer boroughs of maternal attention. My brother's marathon tantrums, his gory public (and private) displays of self-mutilation and his regular physical assaults on our mother left me balancing as a boy on a narrow emotional catwalk between instinctual love for my sibling and blind rage. But none of that altered the depth of her feeling for him in the least. He was her main passion in life, and would remain so till the very end.

After her death, as promised, I signed the guardianship papers and found myself suddenly a part-time resident in the island nation of adult autism in America. What I didn't realize at the time was just how uncharted the waters around that island would turn out to be.

I knew plenty about childhood autism, of course. Who doesn't? A malady sometimes described as a form of perceptual overload seems somehow a fitting response to today's speeding, signal-clotted life. And the numbers are dizzying: From a reported incidence of one child in 150 with autism in the year 2000, the prevalence has now risen to one in 68.

Meanwhile, a vast autism infrastructure has grown up around these numbers, with an array of new schools, websites, activist organizations, support and advocacy social networks, and eloquent voices at the very highest cultural and political levels of our society speaking of the rights of those with autism. Researchers are currently backdating the history of autism by reclaiming previously mysterious events — the holy fools of Russia, the so-called feral children of early modern Europe — as potentially having autism at their root. And the recent lumping of the Asperger's syndrome diagnosis and a variety of related childhood disorders under the rubric of "autism spectrum disorder," or A.S.D., has produced "sufferers" of autism so high-functioning they often regard their autism as a gift or visionary complement to life. This aggregate "big tent" approach to autism also partly explains the rise in the sheer numbers of children given that diagnosis.

But children eventually grow up. And children with autism have been growing up for over 50 years. Roughly 500,000 children with autism will become adults over the next 10 years, and as they step through the door of age 21, they'll find themselves inheritors of a sad paradox. The variety of federally mandated supports and services (under the aegis of the Department of Education) available to them until then will have expired; the source of their funding will switch to the far smaller pie of state-by-state money. These resources, along with Medicaid and Social Security, are more fragmented and difficult for families to navigate. So the financial support —

used to train them for jobs, find housing, obtain therapy and counseling — will dwindle at the exact moment in time they need it most.

A 2011 study found that 39 percent of young people with autism in the United States received no services whatsoever after high school. Loneliness and social isolation are major issues. Unemployment among adults with autism — most of them higher functioning than my brother — is common. An estimated 90 percent of adults with autism are unemployed or underemployed.

State funding, it seems, remains keyed to the idea that the same maturational curve applies both to “neurotypicals” and those with disabilities, and apparently relies on a magical-thinking belief that these young adults will somehow smoothly make the transition into adulthood without special guidance. Some states now get matching federal funds, but the steep drop-off — and the steep challenge for parents and children — remains.

It’s part of a larger disconnect. There is virtually no current substantive national discussion on the fate of middle-aged or elderly autistic people like my brother, who are living in therapeutic communities, or with their aged parents or in group homes, or sometimes undiagnosed in mental hospitals. Little research money is spent on members of this demographic, and there is almost no public policy debate on how best to serve them. Not much is known of the particular health problems linked to their long-term care, or how their autism progresses and changes over time, or what the cumulative effects might be of the medication they take to render them tractable enough to live in social settings. As Dr. Joseph Piven, a professor of psychiatry, pediatrics and psychology at the University of North Carolina at Chapel Hill, has put it, “There is almost no literature on older adults with autism in the field, so we have virtually no knowledge base.”

Joshua is fortunate. As the beneficiary of decades of the hard-working advocacy of my mother, he now resides in the social and medical equivalent of a perfect fit — a beautiful, well-staffed therapeutic community in central

New Jersey. Retired from active daily work after a long career of doing things like busing tables at McDonald's (too difficult); serving in a high school cafeteria (same) and working on the lawn crew of the large "farmstead" — a rural therapeutic community — where he spent many years (a job loathed but tackled with a certain grim tenacity), he was moved at age 57 from the main campus to another a few miles away, designed specifically for older residents.

But even this place grapples with the stark realities. I regularly receive terse calls from my brother announcing the departure of a care worker he'd grown attached to. Why? Because therapeutic communities and "congregate settings" for adults with autism suffer from a job turnover in direct care staff so high it can only be labeled a hemorrhage. Direct care workers, whom I've observed up close for 30 years, are the true unsung heroes of the mental health universe, providing the stability and warmth of family when family is gone or far away. But poor pay (a 2009 study found the national average for an entry-level full-time direct care staffer to be less than \$22,000 a year) virtually guarantees high turnover.

In terms of overall expenditure, government support for people with autism is considerable. The Combating Autism Act was passed under President George W. Bush in 2006 and authorized generous outlays for screening, early intervention, education and research. It was renewed in 2014 (its name was changed to the more palatable Autism Cares Act) under President Obama, and continues the disbursement of a large amount of money — about a quarter of a billion dollars a year — to a variety of federal, state and private initiatives. But a quick glance at the funding priorities shows little devoted to people my brother's age.

While more funds would help, it's not enough to throw money at adult autism. What's needed instead is an intelligent, directed deployment of resources and a larger seat at the table of policy debate at both state and federal levels.

Karen Parenti, the vice president of community solutions for Bancroft,

a large provider of services for individuals with developmental disabilities and brain injuries, which owns and oversees my brother's residence, noted an urgent need for things like longitudinal studies on the long-term effects of medications used in autism care and financial support for lifelong learning programs and public education. To Louis F. Reichardt, the director of the Simons Foundation Autism Research Initiative, distinguishing the needs of adults with autism from those of the younger population is paramount: We need to "identify what features these adults share or do not share with the pre-adult population, such as I.Q., verbal ability and social skills. This might tell us to what extent maturity and aging influence the severity of the deficits associated with autism," he wrote in an email.

In truth, what's simply needed is more of everything. And in the last several years there have, in fact, been a smattering of research initiatives into older adult autism. Much more is needed. But none of it will arrive in time to have an impact on the life of my brother.

On a recent visit to Joshua at his facility, the drill was the same as ever. My girlfriend and I greeted the affable staffers, and then took him out for a meal, where he defaulted to the same cycling, anxiety-fueled series of questions he does every time we're together: "I've come a long way, haven't I?" Or "are you happy I'm doing as well as I am while seeing you?" Or, repeatedly, "What time do I have to return home tomorrow?" We saw a movie in blessed conversational silence, stayed overnight in a hotel with him, in that way fulfilling his dream of getting off campus for at least a night, and the next day bid him a heartfelt goodbye.

When I was younger, these visits would shatter me, and I'd often drive home in tears. But such extremities of feeling are long behind me. I'm soothed by the thought that he seems reconciled with his destiny. It's reassuring to know that my brother will continue to live out his life as he has for the last many years, his mind stabilized by powerful medications, his thoughts revolving around his next activity and meal, the legacy of my mother's work visible in his neat, sunny room and sparkling surroundings.

Is ignorance a blessing? In certain circumstances, yes. Among the many things he'll be unaware of, blessedly, is just how lucky he is.

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