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A Generation of Autism, Coming of Age

By AMY LENNARD GOEHNER

As the explosion of children who were found to have [autism](#) in the 1990s begins to transition from the school to the adult system, experts caution about the coming wave.

“We estimate there are going to be half a million children with autism in the next 10 years who will become adults,” said Peter Bell, executive vice president for programs and services of the advocacy group Autism Speaks.

Services for adults with autism exist, but unlike school services, they are not mandated, and there are fewer of them. Combined with shrinking government budgets, the challenges are daunting.

“We are facing a crisis of money and work force,” said Nancy Thaler, executive director of the National Association of State Directors of Developmental Disabilities Services. “The cohort of people who will need services — including aging baby boomers — is growing much faster than the cohort of working-age adults that provide care.”

To help parents navigate this difficult journey, in January Autism Speaks introduced a [free Transition Tool Kit](#) for parents and their adolescent children with autism. The kit includes information about such critical issues as community life, housing, employment and developing self-advocacy skills. The tool kit can be customized by state for those who register online.

“There is a time you have to get over this hump where you are essentially acknowledging that your child is going to have autism for the rest of his life,” said Mr. Bell, the father of an 18-year-old son with autism. “Our hope with this kit is to help parents to start planning and not get frozen.”

Many young adults with autism have transitioned into large residential systems, whether group homes or institutions, offering round-the-clock services. But waiting lists can be long. And increasingly, in an effort to stem costs, states are moving away from the group home model into family-based care, a trend that started about 10 years ago.

“If an individual needs 24-hour services, the staffing ratio is one to one,” said Charlie Lakin, who heads the Research and Training Center on Community Living at the University of Minnesota. “That means fewer people will get served, resulting in long waiting lists for other

families.” Nationwide, 59 percent of people who receive autism services are living with their families, according to Mr. Lakin.

Living with one’s family may not always be best for a person with autism. Nor is it what many families, who assume their grown child will move into a group home, for example, envision for their future. But options are limited, and given the high demand for out-of-home residential services, Mr. Lakin said, “families really need to think about a longer and more central involvement in their adult child’s life than they have in the past.”

The good news is that many states are providing more support for people with autism who live with their families. They are also giving families greater flexibility and control over budgets with so-called consumer-controlled services, which reimburse families that hire friends or relatives, rather than outside caregivers, for regular care.

Connecticut and Arizona, for example, pay for care provided by family members, a growing trend. Other states, like Pennsylvania, have programs in which contracts are issued for people with autism to live with other families. And Vermont and New Hampshire pioneered a model of providing funding directly to families.

Some families have pooled their own money and entered into cooperatives with other families, a challenge that can take years. Families with children who have developmental disabilities “are relentless advocates and have been the most successful at garnering resources and services,” Ms. Thaler said. “I think it may be the vulnerability of people with developmental disabilities that evokes in families and professionals a level of extraordinary empathy that makes them powerful advocates.”

Among the most powerful advocates are siblings of those with developmental disabilities. “Sibs have always played a really important role; we just haven’t identified them as sibs,” Mr. Lakin said. “We’ve identified them as agency leaders and social workers occupationally. But the real impulse of their work is that they were a sibling.”

Don Meyer, the founder and director of the [Sibling Support Project](#) and the creator of Sibshops, a network of programs for young siblings of children with special needs, said: “Parents need to share their plans for their special-needs child with their typically developing kids. After Mom and Dad are no longer there, it is likely it will be the brothers and sisters who will ensure their sibling leads a dignified life, living and working in the community.”

Mr. Lakin said: “It’s really about having people live the best life they can, in the place and with the people they want to live with. There’s no magic to that.”

Bring on the magicians.

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