

**ASPERGER**  
FOUNDATION INTERNATIONAL

Falling Through the Cracks:  
Services for “Higher-Functioning”  
Adults on the Autism Spectrum

Lynda L Geller, Ph.D.  
John M Cavanagh, M.A.

AspFI’s previous study, “Services Throughout the U.S. for Adults on the Autism Spectrum” (2005) – online at [www.aspfi.org/documents/AspFI\\_Study\\_on\\_State\\_Policies.pdf](http://www.aspfi.org/documents/AspFI_Study_on_State_Policies.pdf) – compared official state policies across the country regarding services for adults with Asperger Syndrome and high-functioning Autism. This follow-up, qualitative study explores the experiences of individuals on the autism spectrum with the publicly funded developmental disability, mental health, and vocational rehabilitation agencies across the United States that those policies govern.

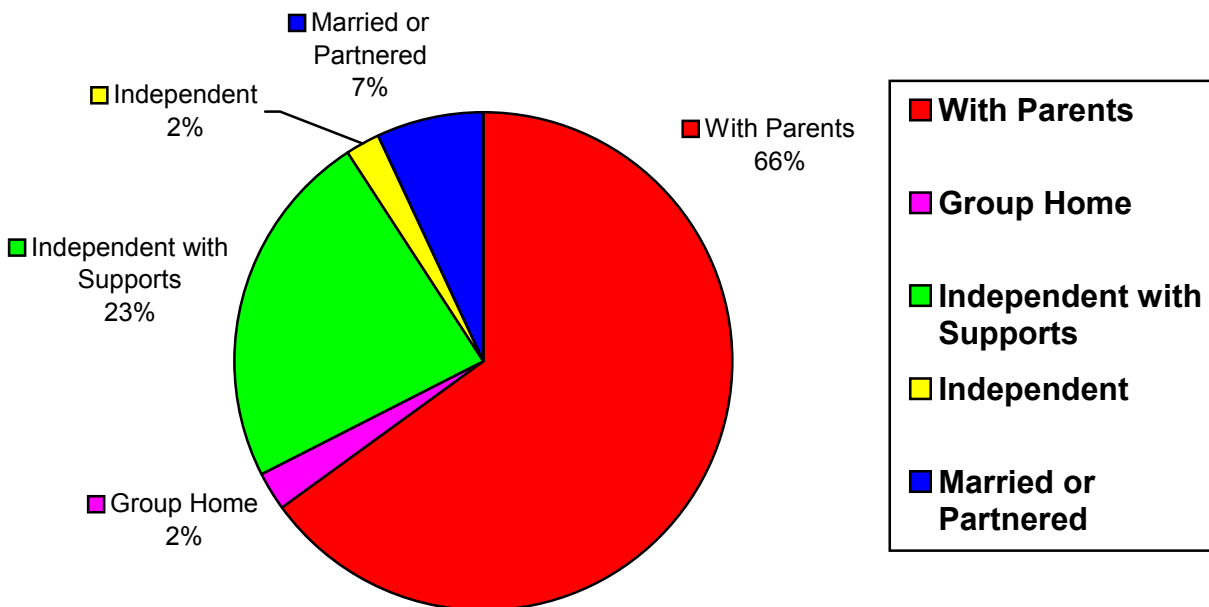
**Profile of Participants**

14 adults on the spectrum, 28 parents, and 1 professional advocate who represented a woman with Asperger Syndrome in a relevant case were surveyed about their experiences of applying for services or opting not to apply. 17 of the surveys were telephone interviews and the remaining 26 came from an online survey on Asperger Foundation International’s website. A concerted effort was made to include affected individuals, not just family members.

26 surveys were concerning adults with a diagnosis of Asperger Syndrome, 10 with Pervasive Developmental Disorder-Not Otherwise Specified (PDD), and 6 with Autism. One individual had no official diagnosis, but believes she has Asperger Syndrome based on what she learned through her child’s diagnosis. Two of the individuals with Asperger Syndrome had previously been diagnosed with PDD and Autism, respectively.

Table 1 compares the living arrangements of participants: those who are still living with their parents, those who are living independently, those who are living with a spouse or partner, those who are living in a group home, and those who are living on their own with some periodic supports.

Table 1: Living Arrangements



The age range spanned from 18 to 60, with an average age of 27.7 years. Participants lived in

18 states: Arizona, California, Colorado, Connecticut, Florida, Hawaii, Illinois, Iowa, Maryland, New York, New Jersey, North Carolina, Ohio, Pennsylvania, Texas, Virginia, Vermont, and Washington state. 29 of the affected individuals were male, and 14 female.

## **Eligibility**

The difficulty in qualifying for services under many state policies that AspFI's previous study (2005) found among this population was echoed by many of the participants in this study. One mother of a 20 year-old son with Asperger Syndrome lamented that "there has to be more out there. I just don't know where to go." In some states, mental retardation, as measured by IQ score, is the only condition that can qualify as a developmental disability, so the entire population in this study would automatically be excluded from developmental disability services. However, IQ level does not always correlate to life skills: as a 25 year-old woman with Autism so succinctly pointed out, "autism is not always about knowing, but rather being able to DO things."

Few states classify these conditions as mental illnesses. Vocational rehabilitation is theoretically mandated by the Federal Rehabilitation Act and applicable to all disabilities. However, lack of supplemental services, such as long-term job coaching, through other funding streams (e.g. developmental disability services) can limit the effectiveness of this comparatively short-term service that was not designed with the complexities of neurobiological disabilities in mind.

## **Types of Services**

For those who are eligible for services, the interviews and surveys revealed a wide array of services that are being offered across the country.

The easiest vocational support services for many participants to receive appeared to be tangible, material provisions that are not directly related to the specific disability, or even to disabilities in general. This includes transportation to work, money to buy appropriate clothing to wear to interviews and on the job, and vocational testing during transition services.

Case management was also a common service, and participants varied widely in how effective they found it to be. One 37 year-old woman with Asperger Syndrome praised her caseworker for "serv[ing] me as an individual with a disability, not just the disability," while a mother of a 27 year-old son with Asperger Syndrome in another state complained that "it is impossible to talk to the case managers."

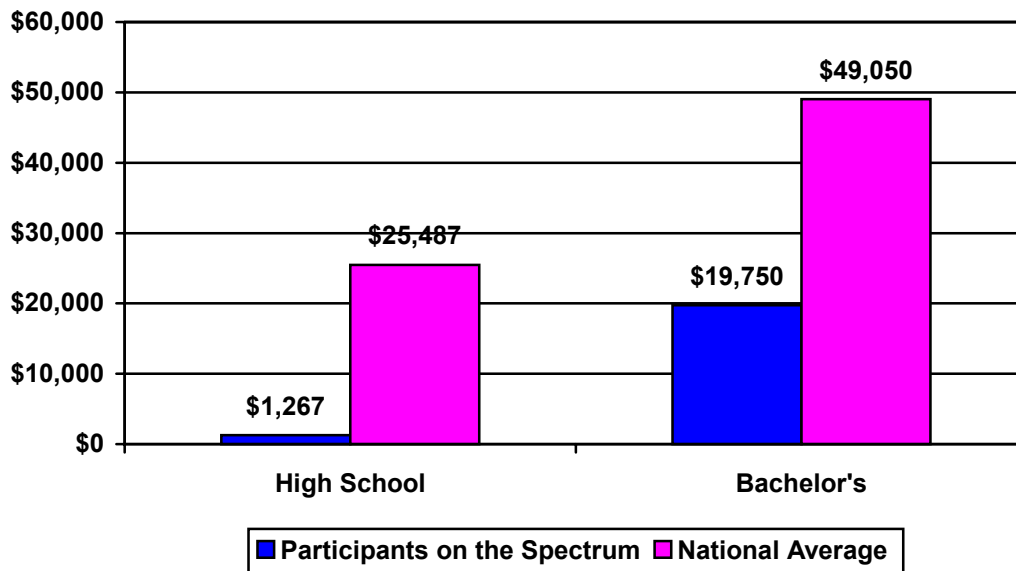
Day habilitation, life skills support, home care aides, supported housing, and in some cases group homes were also available in some cases, though in many cases only after many months, and sometimes years, on waiting lists. These are all crucial services for adults who are unable to live completely independently, however services designed to facilitate greater independence seemed to be more elusive. The need for support with finding and keeping work came up in nearly all of the surveys, and a great deal of frustration was expressed with current employment situations.

Less than 7% of participants were employed full-time, though some were still in school and at a typical age for still being in school. This is comparable to figures from the National Autistic Society of the United Kingdom, estimating that only 6% of individuals on the spectrum in the U.K. are employed full-time and only 12% of individuals with Asperger Syndrome in particular are employed full-time (Barnard, et al, 2001). No correlation between receiving services and having a job

and/or achieving more independence could be found in this study; on the contrary, a number of participants who have been found eligible for job services are unemployed, waiting for a staff member to help them find a job opening.

Table 2 compares average income for the participants with high school diplomas and bachelor’s degrees, respectively, with 2003 U.S. Census Bureau statistics (2004) on average income for people with those same degrees in the general population:

Table 2: Mean Annual Income by Education Level



Participants who were still working toward further education are not included in this table, because they might not have been pursuing full-time employment and thus are not necessarily representative of those seeking financial independence. The sample of participants with terminal associate’s, master’s, and doctoral degrees was not large enough to make a meaningful comparison with overall census data, though the small numbers of participants in those groups were all earning well below the national average as well.

### Agency Staff

Very few participants classified the staff with whom they dealt as being overtly disrespectful when asked. One mother characterized the way in which staff spoke to her 21 year-old son with PDD-NOS as “degrading,” but a number of others gave more ambivalent assessments, such as “respect, yes; comprehension, no” and “when they do connect, they’re very nice” and “neglectful more than disrespectful.” Other respondents reported positive experiences with individual staff members, in some cases with people who had a particular knowledge of the autism spectrum because of affected family members. A recurrent theme when discussing staff, however, was problems within the larger system itself that stymied individual performance.

A number of participants perceived the agencies they were describing as understaffed,

without enough employees to adequately provide services for the large number of cases they are assigned. Frequent staff turnover also came up again and again in interviews and surveys, and going through multiple case managers in a relatively short period of time was not uncommon.

One mother of a 26 year-old son with PDD sees the low pay and lack of prestige for job coaches, case managers, and their colleagues as attracting only people who are “passing through” on the way to or from college. “No one looks at it as a career – until they do and until it pays better you’re not going to get people who...you know, professionals who are going to help our kids.” Indeed, the staff turnover appears to be correlated with the lack of knowledge about the complexities of autism spectrum disorders among staff members. By the time providers have worked with enough Asperger Syndrome cases to begin to understand, they are likely to be moving on to a higher-paying job – perhaps in a different field.

Possibly because of staff inexperience with the autism spectrum, parental involvement in dealing with staff came up again and again – for participants who have parents who are able and willing to be actively involved, of course. A mother of a 20 year-old son with Asperger Syndrome advises adults applying for services to

have a member of the family or whoever helps the individual be in attendance for the session so they can help them after they leave the session. I know in my son’s case, they told him things without me being there that he just does not remember. He finally told them that maybe I should be in there while they talk because it was so much information, that he didn’t think he could remember it all.

This echoes similar impressions from several participants. At the same time, a mother of a son with Asperger Syndrome who had also worked in her state’s developmental disabilities system warns that parents advocating for their adult offspring must try to be objective, or they could ultimately jeopardize their eligibility:

Many of these folks have adaptive behavior scales filled out by folks who try to make them look good. I found that many families overestimated the individual’s ability to perform routine daily living skills and function independently in the community. Unfortunately this resulted in many individuals falling on their faces and then coming back to us with much poorer functioning.

### **Adult Issues Remaining Unrecognized**

Professionals and the general public have come to know a great deal more about the concept of autism as a spectrum in the past 15-20 years. Many strides have been made in promoting awareness of these challenges among teachers and school administrators, and many promising educational programs have been developed to maximize learning and inclusion for children with Autism, Asperger Syndrome, and PDD. That is not to minimize the hurdles that so many students and their parents still encounter when seeking appropriate education; more progress is needed, but a great deal of progress has already been made.

However, comparatively little attention has been paid to accommodations for adults, though the American Psychiatric Association classifies all of the autism spectrum disorders as lifelong

conditions (1994) and schooling is often thought to exist to prepare students for functional adult lives. As a 46 year-old woman with Asperger Syndrome put it, “C’mon!! This ain’t Trix Cereal y’all are dealing with here! It’s AUTISM and affects [you] regardless of age.”

## **Recommendations**

Respondents generated a number of ideas for improving services, ranging from specific policies to broader attitudinal shifts. A mother of an 18 year-old son with PDD suggests “a federal mandate that all states be required to serve [developmental disabilities] equally with [mental retardation] or [mental illness],” in addition to the creation of a Home and Community-Based Service Medicaid Waiver specifically for autism spectrum disorders, “since many in these categories fall through the cracks.”

A 49 year-old woman who has suspected she has Asperger Syndrome since she learned of the condition when her adolescent daughter was diagnosed suggests that the entire disability services system needs to move beyond the mentality of “there’s something wrong with you, so you need help.” She believes “it would be more beneficial if there were more open dialogue of understanding of each other...it would be more useful to everybody to have more understanding and communication [about both] assets and deficits,” and cites her own propensity for numbers and her daughter’s above-average IQ as examples.

## **Discussion**

More research, on a larger scale, is needed to corroborate these figures in a larger sample pool, as well as to locate and assess adult services that are actually producing positive outcomes. However, these initial findings raise a number of troubling issues.

A 7% employment rate – in a population that, by definition, has many cognitive skills – and the disproportionately low income level compared with neurotypical individuals of the same education level should be unacceptable to any vocational rehabilitation agency. The number of participants still living with their parents in their 20s, 30s, and beyond is also alarming. Research suggests that being solely or primarily responsible for an adult offspring with special needs without sufficient additional supports can take a heavy financial and emotional toll on parents (Hare, et al, 2004). Furthermore, the likelihood that an adult on the autism spectrum, like any adult, will outlive his or her parents makes living at home indefinitely unviable in the long run. A 40 year-old woman with Asperger Syndrome wishes she had some kind of “financial foundation” because “my parents are both retired and they are getting older. I need stability for my years now and my senior years up to my death.”

Services must be developed and/or expanded to more effectively empower adults across the autism spectrum to maximize their independence and use their assets to contribute to society. For taxpayers, it costs a great deal more to maintain dependent citizens than it would to fund services that might channel the skills, intelligence, and in many cases advanced education that clearly are present into jobs through which those individuals could contribute to society. And in terms of quality of life for affected individuals themselves, if these participants are representative of what is happening to “higher-functioning” adults on the autism spectrum across the U.S., then the situation constitutes nothing less than a crisis.



## References

- American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders (4th ed.)*. Washington, DC: Author.
- Asperger Foundation International (2005). Services throughout the U.S. for adults on the autism spectrum. Retrieved May 16, 2006, from [www.aspfi.org/documents/AspFI\\_Study\\_on\\_State\\_Policies.pdf](http://www.aspfi.org/documents/AspFI_Study_on_State_Policies.pdf)
- Barnard, J., Harvey, V., Prior, A., and Potter, D. (2001). *Ignored or ineligible: The reality for adults with autism spectrum disorders*. London: The National Autistic Society.
- Hare, J.H., Pratt, C., Burton, M., Bromley, J., and Emerson, E. (2004). The health and social care needs for family carers supporting adults with autism spectrum disorders. *Autism*. 8 (4). pp. 425-44.
- U.S. Census Bureau (2004). Income in 2003 by educational attainment of the population 18 years and older, by age, sex, race alone, and Hispanic origin. Retrieved May 16, 2006 from [www.census.gov/population/socdemo/education/cps2004/tab08-1.pdf](http://www.census.gov/population/socdemo/education/cps2004/tab08-1.pdf)