

When the School Bus Stops Coming

The Employment Dilemma for Adults with Autism

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"CHARLES VAUGHN" DEVOURS EACH ISSUE OF *DISCOVER* AND *SCIENTIFIC AMERICAN* AS SOON AS THE MAGAZINES LAND IN HIS MAILBOX. WITHOUT HESITATION HE CAN TELL YOU THAT THE SPEED OF LIGHT IS 186 THOUSAND MILES PER SECOND. HE MULTIPLIES GIGANTIC NUMBERS FOR FUN. WITH CHARLES' HIGH SCHOOL GRADUATION APPROACHING IN JUNE, HIS PARENTS SHOULD BE THRILLED ABOUT THEIR ELDEST SON'S PROSPECTS. INSTEAD, THEY ARE TERRIFIED. CHARLES IS AUTISTIC. NOW 21, HE HAS DIFFICULTY STARTING A CONVERSATION.

Even though he has an above average I.Q., he has not learned to drive and he prefers to spend his free time watching cartoons on T.V. Until this year, he has received much of the help he needs through school under a federal law that allows people with disabilities to continue their public education until the year in which they turn 21. Through the school, he has started taking a computer course at the local community college, and he has a part-time job inputting at a communications company. But all that could end in June, when he dons a cap and gown and accepts his high school diploma. When Charles Vaughn turned 21 on January 11, he walked into a bureaucratic black hole. Charles lives in a state that provides no services for autistic adults. (Hillary Waldman, *The Hartford Courant*, February 16, 2006).

One of the greatest hoaxes a person can play is to give someone the expectation that life will be better following an exercise that requires significant investment in effort, time and money, and then inform him at the end that they knew all along that it really wouldn't work out. Unfortunately, this hoax is played hundreds of thousands of times on people with autism, their families and the communities in which they live.

America has one of the best public education systems in the world. It promises to prepare its children to be able to live the American Dream, yet for people with autism that promise is rarely, if ever, realized. After years of struggling through their education years, most adults with autism find themselves without any opportunity to enjoy gainful employment or to live and recreate to their capacity in their communities (Holmes and Shore, 2005).

The problem lies in two areas: the lack of proper preparation for work during the education years and the lack of laws and funding to entitle adults with disabilities to the same rights established for children under IDEA (Individuals with Disabilities Education Improvement Act of 2004). Both areas must be addressed immediately, if America is to stem the tide of unemployment among its citizens with disabilities.

It is a generally accepted fact that more than 75% of Americans with disabilities are unemployed (Gerhardt and Holmes, 2004). It also has been established that if adults with autism do not find employment after their educational training, they have a 70% chance of not being gainfully employed throughout their life (Rebuck, 2006). Further, some studies have revealed that only 6% of people with autism spectrum disorder have a full-time job (National Autism Society, 2006). The remainder of individuals with autism are either unemployed or under-employed (Holmes, 1998).

The dilemma for adults with autism is that, unlike the entitlements they have for "an appropriate education" under the IDEA, once they leave the education system, there are no seamless entitlements. There are some federal and state procurements that might enable a modicum of services for adults, but they do not exist in the quantity and quality necessary for most adults with autism.

The Rehabilitation Services Administration (RSA) is responsible for serving adults with autism, but currently is serving fewer than 2,000 (Dew and Allan, 2007). If a person is eligible for Supplemental Security Income (SSI) or Social Security Disability Income (SSDI), they will receive monthly funds that can be used to support their living and employment arrangements. However, these funds are minimal (averaging \$400 per month) and not nearly enough to afford an appropriate

employment opportunity, let alone an appropriate living arrangement (Kaplin and Moore, 2000).

If a person is eligible for Medicaid funds, which have asset restrictions (less than \$2,000 in assets) and, frequently, I.Q. restrictions (less than or equal to 70 I.Q.), they can be placed on a waiting list for adult services—services that may or may not be appropriate for their needs and may take years to acquire. Further, utilizing intelligence quotients for eligibility is ill conceived when it comes to autism. The most significant deficit many people with autism have is in the area of social skill development. A high I.Q. with low social skills (social quotient) leaves an individual severely compromised in the adult world.

Over the years it has been a struggle to get autism recognized as a unique and distinct disability from mental retardation. In fact, it was included under the Developmental Disabilities Act well over two decades ago. Yet most states continue to have departments or divisions of mental retardation servicing people with autism, but only if they have an I.Q. of less than 70, leaving many ineligible for services. This incongruity must be remedied to enable more advanced adults with autism to be fully productive in life.

The Services Conundrum

With the passage of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA 1990), people with autism have access to opportunities afforded all Americans and accommodations that are reasonable (Thomas, et al, 2000). Of course, accessibility and funding are two separate issues, and accessibility without funding, for most people with autism, is no accessibility at all.

Even with improved awareness of the needs of adults with autism, and decades of advocacy for appropriate employment services and opportunities for these adults, the majority are living at home with their aging parents with few if any meaningful job opportunities (Howlin, Goode, Hutton and Rutter, 2004). Most people with autism who have significant behavioral and cognitive challenges receive custodial care at best or no care at all. Those with higher cognitive capacities may graduate from college only to end up in psychiatric hospitals, drug treatment centers or even worse, jail, because they cannot access appropriate employment supports due to their average or above average I.Q. (Howlin, et. al., 2004).

And when families can find adult services, they often are too generic and, therefore, inappropriate. For example, it would be unconscionable to remove a wheelchair from physically disabled adults when they graduate from high school or college, thereby eliminating their prosthesis, which enables them to

navigate their world. However, time and again this happens to adults with autism; their prosthesis—that is, their “prosthetic environment” (Holmes and Chaffee, 2007)—is taken away. A prosthetic environment for an adult with autism is one that is structured, consistent, dependable, reliable, supportive, accommodating, calming, comforting; but most of all, predictable (Holmes, 1998).

When we place people with autism in an employment opportunity or setting that does not have the attributes of a prosthetic environment, we have uniformly stripped them of the prostheses necessary for success. It is no wonder that the majority of adults with autism, if they are capable of finding employment opportunities, will fail.

Following are some case examples of the struggles that adults with autism face in securing employment:

rely on him.” However, when a job became available in dining services, he was turned down because the manager “thought him odd.”

In Salt Lake City, Utah, Dawn and Brian Schmidt have a 22-year-old son who is aging out of the special education services school system. They said that without the structure and supervision that the school provides, their son Ryan is left to his own devices. He spends most of his days watching television and eating. The Schmidts watched their son deteriorate over the summer as boredom took hold and he lost the skills that he worked so hard to learn.

Ryan is one of 2,225 residents of Utah on a waiting list for services (Kirsten Stewart, *The Salt Lake Tribune*, 7/21/05). Ryan has been on the state’s waiting list for eight years and is existing on a \$570 monthly Social Security check.

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Ann Bauer in a *Washington Post* op-ed piece, “Willing, Able and Unemployable,” states,

“My 18-year-old son shambles. There is no other word for it. He walks like an old man—scraping the soles of his feet on the floor, tilting his head to one side and tucking it into the space between his neck and shoulder. Andrew has autism. When he was 16, I told him it was time to get a part-time job. I took him first to the coffee house where I wrote each morning, introducing him to the manager, and took my usual table. But even from a distance I could see things weren’t going well. The interview took three minutes, ending abruptly ... Next, I took Andrew to Target, a company known for its history of working with disabled people, only there is a catch. I was told when I called that their policy was to employ “visibly handicapped” workers ... People in wheelchairs qualified ... My son ...does not.” (Bauer, October 30, 2006)

Bauer’s frustration continued in attempt after attempt to get her son employed, instead receiving responses that her son was “a potential liability.” The only job she was able to get for him was a “starter job,” volunteering in a local nursing home “trundling a library cart from room to room.” She said he was “unfailingly patient and kind” and that the residents “grew to

Finding Appropriate Placement

The difficulties of finding appropriate adult placements are too numerous to describe. Take, for example, John, whose mother has been advocating for appropriate applied behavioral analysis (ABA) services for her adult son. John eventually was placed in an out-of-state organization providing residential and employment services that utilize the principles of ABA.

Once there, he thrived. After many months of privately paying for the services, his family petitioned their state to help to pay for the services. The state declined and offered John a placement in a local program that offered generic services to a variety of people with disabilities. This agency allowed those in their care to do what they wanted, when they wanted, as part of their philosophy of “person centered planning.” John was placed in an apartment with one other resident and was given a job with a mobile crew that went to various locations cleaning and dispatching with trash.

Initially, John enjoyed being out with the crew but quickly tired of the work and asked to be returned to his apartment so he could play with his DVD games. When not accommodated, he would have behavioral outbursts, which led to his not going

to work at all. Today, John spends his day playing with his DVD games along with his roommate, both of whom refuse to go to work.

In a recent correspondence from his mother, she stated:

“John is now refusing to go anywhere with the staff, even to places he likes. Last week he was aggressive towards the staff and towards his roommate. He threw a couple of ceramic canisters at them, knocked a few chairs over and was basically intimidating them. Last Sunday morning the staff went outside to smoke a cigarette and he locked them out and started teasing his roommate. This resulted in the police coming once again. There is no program until February (current date is early January). I looked at the one possibility they have. There are eight individuals with three staff basically doing hand-over-hand activities and all practically nonverbal. They stamp bags and put cans and boxes into bags and do some clothes sorting, although I think that all of the activity is made up, nonmeaningful and probably [will] only keep John’s attention for 10 minutes. He shadowed the program last week. He liked the staff. The first day he thought he was Mr. Important. They eat lunch at 10 a.m. when they get there. After the second day he ate lunch and was ready to leave ... I think that having the police be part of their behavior plan is inappropriate and that their program is not meaningful or useful.”

These situations are all too common. Throughout the educational years of children with autism, it is a generally accepted maxim that they need predictable environments. Yet when they graduate from school, if they can find employment, they literally are placed under conditions that are not predictable

Recently, the Combating Autism Act was passed to find the root causes of autism. This landmark legislation is a huge step forward in attempting to find the causes and cures for autism. However, as important an effort as that is, for adults living with autism today, having appropriate services now can mean the difference between a life fulfilled or a life wasted.

In response to the “epidemic proportions” of autism and the “tsunami effect” of youth graduating from school and entering the adult workforce, the federal government’s Interagency Autism Coordinating Committee (IACC) developed a roadmap for autism under President Bush’s Executive Order #13217, “Community Based Alternatives for Individuals with Disabilities.” One of the constructs that came from this effort was entitled, “Youth Transition to Adult Services Work and Independence.” The goal for this construct is that “all individuals with autism spectrum disorder will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.”

Coupled with this construct was another entitled, “Appropriate Financing of Care.” The goal of this construct is “to expand and standardize public and private finances of autism spectrum disorder related services so that individuals with autism spectrum disorder and their families have access to early and continuous screening, comprehensive diagnosis and needed health, mental health, and education and social services.” This “road map” and its respective constructs were signed off by all of the federal agencies responsible for autism spectrum disorder through the lifespan of a person with autism. A complete copy of

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and, therefore, highly anxiety producing and nonreinforcing. People under these conditions do what John did: engage in behavior that removes them from the unpleasant situation in order to be returned to reinforcing situations, like playing DVD games in the comfort of their home, without demands. Such conditions are counterproductive for adults with autism and result in significant skill and talent loss, which could be brought to use for the benefit of the community.

But what can be done to mitigate such conditions? First, it is important to get the federal government and Congress’ attention regarding the seriousness of the matter.

the “Autism Spectrum Disorders Road Map for Services” can be found at the Autism Society of America’s Web site, www.autism-society.org. Advocates can use the road map as they advocate to get their respective states to identify adults with autism, create employment opportunities for them and adequately fund these initiatives.

Adult Employment Options

What are some of the employment expectations that one should have for an adult with autism? First would be post-secondary

educational opportunities where people can learn a trade or engage in advanced educational pursuits leading to a profession.

Next, competitive employment would be the ultimate goal for all people with autism. Competitive employment means not having extraordinary supports while engaging in meaningful and comparable employment pursuits available to those without a disability.

If competitive employment is not a reasonable expectation, then supported employment must be considered. Supported employment has many configurations. The less supported approach entails a job coach visiting the employee on a weekly or semiweekly basis and offering guidance as to what areas may require improvement and reinforcement where success has been noted.

However, for most adults with autism requiring supported employment, a more intimate relationship with a job coach is necessary. Here, a job coach is with the employee on a permanent basis, guiding and directing as needed and running “interference” when “damage control” is required.

If, due to cognitive or behavioral issues, supported employment is not indicated, then secure employment must be available. Secure employment is a setting where people with autism perform meaningful work activities in group or individual stations with significant support by highly trained staff. Secure employment is the “safety net” for those with autism if they lose their competitive or supported position for lack of work or behavioral

Planning for the Future

While arguing for increased resources for adults with autism, you also can access a variety of employment support services. However, although the framework for accessing these services is straightforward, it is inconsistently employed. Under the IDEA, a transition individual education plan (IEP) must take place no later than the student’s 16th birthday. This does not mean that a transition IEP can’t occur prior to the 16th birthday, but it must occur no later than that.

For those with autism, it is recommended that a transition IEP occur no later than age 14. In the transition IEP planning process, it is critical to have representation from the state’s Division of Vocational Rehabilitation Services and its Division of Developmental, Disabilities/Mental Retardation. IDEA is clear about such representation, and for the sake of the student with autism, having a clear understanding of what must transpire for employment preparation over the remaining educational years, as well as what services are available post-education, is critical (Holmes, 2005).

When an appropriate transition IEP is developed and implemented, the outcome for the individual can be remarkable. For example, Joshua Galperin joined the staff of the Colonial Bank in Dallas, Texas, after years of preparation during high school. The transition services program in his high school trained him to use public transportation, exposes him to a

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challenges. A secure employment setting must be dynamic to ensure that the “safety net” does not become a “hammock” (Holmes, 1998).

Finally, of course, for some people with autism, employment may not be an option, but should be a last resort, as work is therapeutic and enables those with autism to actively participate in life and become productive members of adult society. Unemployment must only be reserved for those with chronic health concerns and those who are advanced in age or otherwise too frail to engage in the rigors of active employment. If a person has independent financial resources and doesn’t need to work, then volunteering to help others is a good alternative.

variety of jobs, and taught him interview skills, activities in daily living and impulse control. He now is an expert in creating reports and is seen as a critical member of the team at the bank (Jeremy Roebuck, the Dallas Morning News, 2/27/2006).

If it is determined that students with autism will require post-education living and employment supports, it is important that they be added to the waiting list for Division of Developmental Disabilities/Mental Retardation Services. Waiting until the student requires post-educational adult supports is not advised, as the wait may be many years (Hinkle, 2004).

Upon graduation from school, two plans must be established for the student, an IHP (Individualize Habilitation Plan), through the Division of Developmental Disabilities/Mental Retardation, and an Individualized Plan for Employment (IPE), through

the Division of Vocational Rehabilitation. Both of these plans will serve as the new design for employment, day services and residence services for the person through his adult life.

Under the Division of Developmental Disabilities/Mental Retardation, every state has a Medicaid waiver program called the community care waiver (CCW). Under this waiver, the federal government will match state dollars paid for services to those with autism and other disabilities on a 50% basis. As such, it is critical that the graduating student with autism be determined as Medicaid eligible to access these funds.

The criteria for eligibility under Medicaid reflect the degree of disability and financial need. When it is determined that an adult with autism has significant social, behavioral and cognitive challenges, and therefore is eligible to receive services under the Medicaid waiver, the second criteria is to ensure that the individual has fewer than \$2,000 in actual assets (Hinkle, 2004). To this end, if the person has resources in excess of \$2,000 or expects to receive, through inheritance or otherwise, resources that will exceed that amount, a special needs trust must be established for the person to supplement, rather than supplant, dollars for services rendered (Hinkle, 2004).

Dollar supports from the Office of Vocational Rehabilitation supplement the Medicaid waiver funds. Every state has a Division of Vocational Rehabilitation Services with the statutory requirement to afford its citizens employment opportunities. Vocational rehabilitation dollars for supported employment, as well as continuing education, can be used to supplement Medicaid waiver dollars. A graduating student with autism must petition the Division of Vocational Rehabilitation Services for such supports.

Once funding has been secured, it is time to determine the best and most appropriate employment opportunities. Identifying the person's sensorial, social, behavioral and cognitive qualities, and analyzing available jobs to ensure that they will compliment the person's profile, is important.

After a job has been identified and the proper supports have been put in place, constant monitoring and assessment is necessary. Remember that those with autism are more affected by seasonal changes and other environmental conditions in the workplace than others. As such, accommodations must be adjusted more frequently and with greater immediacy.

Progress Being Made

The needs for adults with autism in America are significant, and the capacity of agencies to meet those needs is not keeping up with the current demand, yet alone the projected significant demand increase, in the not too distant future. To this end,

stakeholder groups such as ASA have increased their advocacy at the federal level to free up additional dollars to create greater service opportunities for adults with autism (ASA, 2001).

Additionally, service providers and their organizations also have increased initiatives to step up capacities going forward. The Office of Rehabilitation Services has just completed its 32nd Institute on Rehabilitation Issues (IRI) focusing on adults with autism and their employment needs (Dew and Alan, 2007); the International Easter Seal Society—which recently joined forces with ASA on service delivery for autism—also has increased its initiatives to secure expanded capacities for serving adults with autism (www.easterseals.com); and the Counsel for the Accreditation of Rehabilitation Facilities (CARF) recently completed its assessment of quality indicators for rehabilitation services for adults with autism.

The timing is right for petitioning local, state and federal government to secure appropriate adult employment services. And with hundreds of thousands of adults with autism who are unemployed or under-employed, it is interesting to note that “over, the next 10 years, a record number of people are set to retire, creating what experts expect will be a shortage of 10 million to 15 million jobs” (Michele Harris, 2007, *The Erickson Tribune*). The job market will have a huge void, and finding people to fill the void, will be a challenge. Adults with autism are able, and willing and, with proper supports, capable of meeting the challenge.

ABOUT THE AUTHOR

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Article references available upon request.