

# Addressing the Needs of Adolescents and Adults with Autism: A Crisis on the Horizon

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**Abstract** The cohort of individuals with autism spectrum disorder (ASD) diagnosed as part of the first wave of what is often referred to as the autism epidemic is rapidly approaching adulthood. This cohort represents only the proverbial tip of the iceberg with some reports noting that 70% of the currently identified individuals with ASD are less than 14-years old. These numbers represent a looming crisis of unprecedented magnitude for adults with autism, their families, and the ill-prepared and underfunded adult service system charged with meeting their needs. A review of the current literature on outcomes for adults with ASD indicates that, independent of current ability levels, the vast majority of adults on the spectrum are either unemployed or underemployed and, further, that large numbers of adults with autism remain without any appropriate services. Many have had inadequate transition programming including little attention to service coordination, minimal direct family involvement and/or absence of treatment based on evidence-based practices. Lastly, issues related to staff and provider recruitment and retention present significant, systemic challenges to the provision of effective services. As such there is a significant and growing need for greater attention to individual needs of adults with ASD if we are provide the opportunity for a positive quality-of-life.

**Keywords** Autism spectrum disorders · Transition · Adult services · Evidence-based practice

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## Introduction

The past decade has seen reports citing the dramatic increase in the prevalence of Autism Spectrum disorders (ASD). From an earlier prevalence estimate of approximately .25 cases per 1,000 individuals (DSM-IV 1994) the figure most often cited today is 1 case per 110 (CDC 2009). While the reasons behind this increase remain unclear (e.g., Gernsbacher et al. 2005; Shattuck 2006) and at times, controversial (e.g., Kirby 2005; Williams et al. 2005), what is generally accepted is that there are greater numbers of individuals being diagnosed with ASD than ever before and subsequently, steadily growing numbers of adolescent and young adults on the autism spectrum. The increase in prevalence has created an increased demand for appropriate services for adolescents and young adults with ASD.

Unfortunately the employment, day, community, and residential needs of these individuals continue to far exceed the available resources leaving a generation of individuals with autism and their families in programmatic, financial, and personal limbo. For example, Howlin et al. (2004) surveyed 68 adults (average age of 29 years) with autism and a performance IQ of above 50 and found a majority (58%) were rated as having poor or very poor outcomes. Individuals with a performance IQ of at least 70 had significantly better outcomes than those with a performance IQ below 70. Within the normal IQ range outcome was very variable and, on a case by case basis, neither verbal nor performance IQ proved to be a consistent indicator of positive outcome. With regards to employment status the authors found that only 8 of the 68 individuals in the sample were competitively employed; 1 was self employed as a fabric printer; 14 worked in supported, sheltered or volunteer employment; and 42 had “programs” or chores

through their residential provider. Additionally, more than half (51%) were reported as having no friends.

Jennes-Coussens et al. (2006) sought to assess the quality of life of young men (mean age of 20.3 years) with Asperger Syndrome (AS) in Canada. Although a small sample size ( $n = 12$ ) all adults with AS reported a lower quality of life than did those in a control group of age- and language-matched typical peers. Fifty percent of the AS group were unemployed. Those who worked earned approximately half of what those in the control group did.

In the United States, the University of Miami/Nova Southeastern University CARD (2008) conducted an online survey of approximately 200 families of transition-age and adult constituents with ASD in southern Florida. The results indicate that 67% of families surveyed had no knowledge of available transition programs and settings; 83% relied on family members as their primary source of transition planning assistance; and 78% were unfamiliar with agencies or professionals that might assist in job development; only 19% of individuals with autism were employed at the time of the survey with 74% of those employed working less than 20 h per week; 85% still lived with parents, siblings, or older relatives. Overall, outcomes were generally regarded as being poor and access to necessary and appropriate services severely limited.

While not wholly unexpected, outcomes such as these should be considered unacceptable. Among the likely reasons behind the continued poor outcomes for adults on the spectrum are minimal professional attention to evidence-based practice in transition planning and intervention; a general lack of societal understanding as to the potential for adults with ASD to be employed, active, and contributing members of their; an absence of programmatic attention to evidence-based practice in transition intervention, and an absence of qualified staff to work with older learners.

Note that none of these challenges focus on the individual challenges of living with autism. Rather, the potential of individuals with ASD to become employed and engaged adults seems limited more by the failure of the systems charged with supporting them than by the challenges directly associated with their diagnosis. Not surprisingly, the economic cost of these systemic inadequacies is rather far reaching. As Ganz (2007) notes, “Autism is a very expensive disorder costing our society upwards of \$35 billion in direct (both medical and nonmedical) and indirect costs to care for all individuals diagnosed each year over their lifetimes.” (p. 343). Absent a concerted effort on behalf of all stakeholders (i.e., families, professionals, employers, society at large) to correct these inadequacies, the costs can only be expected to grow in the coming years.

Despite recognition of the complex and lifelong needs of adolescents and adults with autism, the development of

appropriate and effective services continues to lag far behind those currently available for persons with less severe disabilities. This disparity between the potential for an integrated and productive life and the lack to services to achieve this potential represents an ongoing challenge to parents, professionals and adults with autism.

## Historical Overview

In their overview of the history of adult services in America, Gerhardt and Holmes (2005) note that the later part of the 19th and earlier part of the 20th century saw the public perception that individuals with disabilities were non-productive and in need of care result in the growth of institutions as the primary service system for persons with developmental disabilities (Janicki et al. 1983). By the late 1960's, the deinstitutionalization move was gaining acceptance and the movement from the institution to the community was underway. However, while an understanding of the needs of individuals with an intellectual disability may have entered a new era, the needs of persons with autism remained under-recognized and unaddressed.

With the critical exception of the debate regarding psychoanalytic models of intervention (e.g., Rimland 1964) and the noteworthy early investigations into the efficacy of behavior analytic interventions and systems of learning (e.g., Ferster and DeMeyer 1962; Lovaas and Simmions 1969) the treatment literature at this time was all but nonexistent and, in the case of the psychoanalytic literature (e.g., Bettelheim 1967), inaccurate and harmful. Not until the mid to late 1970's was that a more comprehensive body of literature specifically dedicated to the educational and behavioral needs of children with autism (Celiberti et al. 1993).

As the cohort of children referenced in these early studies aged-out of educational services, the attention of the families, interested professionals and, most importantly, the individuals themselves turned to issues pertaining to adulthood. Subsequently, service delivery entered a new phase, the recognition of differing needs of individuals with ASD across the life-span and the 1980s saw a national emphasis on the school to work transition process for all special needs learners and a reconceptualization of actual employment as a desirable outcome for individuals with significant disabilities. This process, while it continues today appears to have produced less than desirable outcomes for adults with ASD.

## Transition Planning and Evidence-based Interventions

The currently exist myriad unsubstantiated treatments for autism as a disorder or for one of autism's core symptoms

(e.g., Romanczyk et al. 2003). However, among the many interventions currently available to educate individuals with autism, those based upon the principles of applied behavior analysis (ABA) are the most well documented and empirically validated (Rosenwasser and Axelrod 2001) with over 35 years of research support resulting in over 500 published reports on the use of ABA with autism (Matson et al. 1996). More recently, the National Autism Center released the results of their comprehensive National Standards Project and noted that of the 11, well-established evidence-based interventions in autism interventions most, if not all, should be regarded as being based in applied behavior analysis (National Autism Center 2009).

Unfortunately, behavior analytic research specifically addressing the instructional needs of adolescents and adults is scarce which can present a major challenge to those interested in supporting adolescents and adult on the spectrum. For those who know how to look for it, however, there is a body of research supporting the use of behavior analytic interventions with adults on the spectrum. For example in a study by Hagner and Cooney (2005) the authors interviewed the supervisors of 14 successfully employed individuals on the spectrum to determine effective supervisory practices. A qualitative analysis found that a specific set of supervisory strategies were associated with employment success. Their results are somewhat unsurprising but what may be surprising is the fact that all of the identified strategies (e.g., providing reminders and reassurances) are well documented in the behavior analytic literature as including task analysis, activity schedules, visual supports, differential reinforcement of alternative behaviors, prompting, shaping, and positive reinforcement.

While behavioral analytic research exists there continues to be a large gap between the research and actual practice. One reason for this gap might be the continued misinterpretation of Applied Behavior Analysis (ABA) as consisting solely of discrete trial teaching (DTT). ABA is data-based, analytical, able to be replicated, contextual, accountable, and results in socially valid behavior change. (Sulzer-Azaroff and Mayer 1991). DTT, on the other hand, is simply one instructional intervention that meets these criteria. These same criteria are also associated with a broad range of behavior analytic interventions (e.g., modeling, prompting, reinforcement, pivotal response treatment, shaping, relaxation training, chaining, precision teaching, etc.) that can be used to the benefit of adults on the spectrum. The potential applications of behavior analytic interventions with adults are as diverse as the challenges they are intended to address once a broader, and more accurate, understanding of such interventions is put into place.

A second reason may be that the response effort associated with the effective use of behavior analytic

interventions with older learners may be significantly greater than that required by other, less well documented (and less effective), instructional interventions. And absent that effort, previously effective interventions may no longer produce significant outcomes. For example, many of the instructional opportunities presented to younger individuals with ASD consist of short, repeated trials in the context of the classroom. However, for an older individual to master a complex community-based skill such as grocery shopping (through shaping, chaining, prompting, etc.) multiple, lengthy instructional opportunities in a location distant from the classroom, day program, or group home (i.e., grocery store) will need to be provided. In the first case, the response effort on the part of the teacher is minimal while in the second case, it is significant. A similar difference in effort may be seen between intensive community-based instruction (an evidence-based practice) and, for example, the provision of a sensory diet.

### Services for Adults with Autism: Employment and Day Services

In the United States, participation in employment and the resulting job-related social status and increased financial independence are generally seen as central to an individual's post-school quality of life. Further, our occupational choices are one way in which we define both ourselves and others in a variety of social situations. Unfortunately, for most adults with autism employment remains elusive (Dew and Alan 2007) with anecdotal reports indicating an unemployment/underemployment rate for individuals on the autism spectrum being greater than 90%.

#### Direct Care Staff: The Challenge of Recruitment, Retention, and Supervision

The ability of any program or agency to provide quality services to adults with autism rests, at least in part, on the ability of the program to recruit, retain, and supervise qualified, direct service staff. Unfortunately, and with certain exceptions, the issue of staff recruitment, retention, and supervision has proven to be a difficult one for many programs providing services to adults with autism and other disabilities. According to the federal Department of Health and Human Services (2004) the combined, annual average staff turnover rate for programs serving adults with developmental disabilities is 50%. In addition, such programs report an ongoing staff vacancy rate of about 10–11%. The report goes on to note that even if the turnover rate was not 50% but rather 35%, this would be considered debilitating in most other industries. Among the reasons most often cited for the high turnover/vacancy

rates are low pay/inadequate benefits, excessive staff to client ratios, physical or behavioral challenges presented by clients, inadequate training, and limited professional status.

As noted, one reason for this high turnover rate is that direct care staff are often inadequately trained and supervised to provide the level and complexity of services they are being asked to provide whether in a group home, job setting, or day program. Unfortunately, in the field of human services much of what constitutes staff training and supervision is based upon fads, folklore and idiosyncratic systems or traditions (Reid and Parsons 2006) and while potentially effective in some instances, this is generally not the case. For example, much of staff training typically consists of lectures coupled with succinct demonstrations and, rarely, brief hands-on practice. While this tends to increase staff knowledge of the topic, it does little to increase staff performance (Gardner 1972) and, therefore, little improvement in the lives of adults with autism. If direct care staff once hired are to be retained, they must be effectively trained in the application of relevant, evidence-based practices and, demonstrate a degree of competence in their actual implementation. Further, effective supervision needs to be made available so that acquired staff competencies are maintained over time, across settings, and across the adults if staff are to feel effective and feelings of “burnout” are to be minimized.

Sadly, given the increased demands for adult services associated with the growing number of adults expected in the coming decade, difficulties in recruiting, retaining, and supervising qualified staff can only be expected to grow and this critical challenge to effective service provision worsen.

#### Adult Day Program/Employment-Related Programs

While employment is generally the goal of all models of adult services, an argument can be made that no single model of service delivery would be adequate to meet the needs of all individuals with ASD. Current program options include customized employment, supported employment, entrepreneurial supports, day habilitation/secure employment training and sheltered workshops.

#### Supported Employment

Supported employment is generally regarded as an employment option that recognizes the capacity of the adult to be employed while acknowledging his or her need for ongoing support. Over the last decade, states and provider agencies have moved away from more “center-based” models of adult programming and have promoted supported employment as a more appropriate service

model. Among the reasons often cited for this move include improved societal perceptions as to the employability of individuals with disabilities in general, concerns about the segregation and isolation that may be associated with center-based models, and issues related to cost-efficiencies in service delivery.

Customized Employment is a relatively new and highly specialized derivative of supported employment. Supported employment tends to match individuals with previously existing jobs. Customized employment, on the other hand, goes beyond that and works to create highly individualized, yet economically viable, jobs through active employer negotiation. At the core of customized employment is a focus on person-centered planning resulting in an active give and take (sometimes referred to job carving or job restructuring) which focuses on the needs, interests, and abilities of both the employee with autism and the employer, the result of which is a highly personalized (or customized) job description designed to meet the needs of all stakeholders. Funding too, is distinct from that available for typical supported employment. While supported employment is a recognized service delivery option under Medicaid and can receive direct funding, customized employment is not and generally requires a mixture of funding sources (Targett and Wehman 2008) which may include individual HCBS waiver funds if available.

A particularly innovative employment model, entrepreneurial supports involve the development and promotion of a business entity, sometimes referred to as a self-directed support corporation (SDSC) around a very limited number of individuals (usually just one or two adults) In this model, the skills and interests of the individual[s] are used as the basis to form a for-profit corporation, the intent of which is to generate sufficient income to pay the salary of the individual and that of the individual’s support staff. Entrepreneurial models generally require the development of a governing microboard (a small, functioning board of directors formed to support an individual in the management of the business), consisting of family members, support personnel, community members and, ideally, at least one member with experience running a for-profit business. As with any small business, start-up costs may be high but future earned income is generally expected to offset these early expenses. Along with potentially high start up costs, a challenge to the expanded use of the entrepreneurial model is, as with any business venture, there is no guarantee of short or long term profitability. As such, investments may not be recouped and the necessary supports for the adult with autism may not materialize. Still, if a particular business model makes sense for an individual, entrepreneurial supports should be considered a reasonable and viable option.

## Self Determination Initiatives

Self Determination Waiver Initiatives are not technically program initiatives but are, instead, ways by which Medicaid funding may flow directly to the adult with autism (or other developmental disability) so that he or she may select, purchase, and direct the particular services that he or she may need at a particular point in time. This is important as, historically, Medicaid was used almost exclusively to fund institutional placements for individuals with developmental disabilities. Subsequently, the Medicaid Home and Community Based Services (HCBS) waiver program, (also designated as 1915C waiver) was developed to help fund services in the community to individuals who, without these services, would require institutional care. In that case, however, it is important to note that HCBS waivers are made at the state level and monies go not to individuals but to programs. Self determination waivers represent a specialized class of HCBS waivers for which states may apply that allow the individuals themselves to receive and direct funding under certain guidelines.

## Day Programs

Day habilitation day programs tend to be congregate, facility-based programs designed to teach “pre-employment” skills and skills related to activities of daily living (e.g., cooking, cleaning, laundry, grocery shopping, etc.). Staff to client ratios tend to be fairly high and the degree of social integration is generally low. Unlike day habilitation programs which are designed to provide life skills training and some community-based instruction and job training experience, sheltered workshops are designed with a single, primary purpose: to provide a large, congregate employment experience for adults with developmental disabilities.

## Services for Adults with Autism: Residential Services

At some point in their lives the majority of individuals with autism will require some type of residential service or support. Some may require such services for a limited amount of time while for other individuals a life time of such services may be both necessary and appropriate. In either case the absence of such services can have significant and long lasting negative consequences for the individual and their family and, by extension, society at large. In general, appropriate and effective residential services are in extremely short supply and those that exist are usually at capacity, costly, and difficult to adequately staff and maintain. The challenge is so acute that, according to the National Association of Residential Providers of Adults with Autism (NARPA) “there is now a national crisis in

services to adults with developmental disabilities, especially residential services, and especially to those with autism. The most critical issue is woefully inadequate funding. We cannot allow another generation of our adults with autism to go without the vital services that any humane society knows is necessary for a life of dignity and worth” (<http://www.narpaa.org/index.html>). Most, if not all, states maintain waiting list for services and Parish (2002) estimated that in 1998 there were over 87,000 individuals with developmental disabilities in the U.S. awaiting residential placement.

## Models of Residential Services and Supports

A variety of residential models exist for adolescents and adults with ASD although not all models are available in all states. It is important to note, however, that with few exceptions (e.g., foster care) the type of housing is not tied to the type of services provided. As such any description of a residential model cannot represent the entirety of services that may actually be available as part of each model. Current residential program models for adults with autism include supported living, supervised living, accommodated living, group home living (including teaching family model), farmstead programs, and Intermediate Care Facilities – Mental Retardation (ICF-MR).

## Supported and Supervised Living

Supported Living programs provide residential supports services to adults with developmental disabilities who are able to live in homes they themselves own or lease in the community. Among the core tenets of supporting living are that (1) everyone, independent of current skills sets, can benefit from supporting living; (2) programming and instruction are directed by the consumer and not by the program; (3) to be effective, communities of support must be built around the person and promote their involvement, and; (4) smaller numbers results in greater levels of community integration. Supported living is designed to foster individuals’ full membership in the community as they work toward their long-term personal goals.

In supported living the responsibilities of the professional staff are highly individualized and may range from helping the individual hire/fire staff or chose a housemate, to assistance in completing many of the common activities of daily living to, ultimately, becoming an active and participating member of the community. This, along with a high level of individualization and community integration, can be seen as significant strengths of the supported living model. Costs, however, appear to be somewhat higher than other models (economy of scale does factor in here) though good cost comparison data do not appear to be available at

this time. Similar to individual placement model of supported employment, supported living was conceived to address the needs of even the most complex or challenged individual. In practice, however, supported living models may be more readily suited for individuals with an established repertoire of life skills and those who do not engage in significant levels of challenging behavior.

Supervised living models are designed to provide a similar service to adults with ASD but with greater oversight and direction than might be provided in a supported living context (but less than group home living). In addition, although individual residences may be small (no more than one or two adults with autism per residence) there may be a number of such residences scattered throughout the apartment complex allowing for more great staff accessibility and therefore oversight (e.g., crisis support is generally available 24 h/day).

### Group Homes

With the onset of deinstitutionalization came the movement of individuals with developmental disabilities from large, congregate care facilities to smaller, more typical homes in the community. Group homes are small, residential facilities (i.e., actual homes) located in the community and designed to serve children and adults with autism, intellectual disability, or other chronic conditions. Typically, group homes have eight or fewer occupants and are staffed 24 h a day by agency trained staff. Ownership of the house usually lies with the provider agency (as do staffing decisions) and not with the residents of the house. A primary goal of group home living is to promote increasingly greater levels of independence in the residents. As such, instruction in daily living and self help skills including meal preparation, laundry, housecleaning, home maintenance, money management, hygiene, showering, dressing, and appropriate social interactions are provided by the agency staff. Group homes have come under some criticism as of late for their supposed lack of individualized programming, limited access to the community for residents, and a lack of resident participation in programming and service decisions. As such, there has been a move away from the development of new group homes or, minimally new 6–8 resident group homes, and toward the development of smaller residences (2–3 residents) with more emphasis on self determination and resident home ownership.

A specialized model of group home service provision is the Teaching Family Model. The Teaching-Family model is built upon the identification and training of the core treatment team, in most cases, a married couple (Teaching-Parents/Family-Teachers). Teaching-Parents live in the house (usually in somewhat separate quarters) and

generally provide up to 55 h per week of supervision to other members of the treatment team and direct service to residents. Reports indicate that staff turnover in the teaching-family model is significantly less than that of residential models whose staff work in shifts. One reason why Teaching-Parents, in particular, may stay longer in their jobs is that they are provided with private living quarters rent-free (or at a greatly reduced rate) as part of their compensation package. Not only does this provide greater consistency to the residents but also helps to reduce ongoing staff recruitment and development costs. In fact, Schneider et al. (1982) noted that positive resident outcomes coupled with reduced costs speaks well of the Teaching Family Model when implemented correctly. More recently, Fixsen et al. (2007), in their recent discussion of the history and implementation of the Teaching Family Model with individuals with diverse challenges noted that, while time consuming, the Teaching Family Model does represent a useful, and potentially effective model.

### Large Residential Programs

A larger residential model than a typical group home, farmstead programs provide residential programs and services in the context of a working farm. Although somewhat isolated by nature, farmstead programs endeavor to meet the complex needs of adults with autism (and other developmental disabilities) through a individually designed instructional programs. Vocational training is generally limited to farm-related work (e.g., horticulture, greenhouse management, woodworking, animal care, landscaping, etc.) although other opportunities may be available in nearby communities. Residents tend to work along with staff at tasks relevant to the care and maintenance of the grounds and the farm. A criticism of the farmstead model is that, due to the nature of the program, there is generally little in the way of community integration or community based-instruction. In addition, life skill instruction is generally provided relevant only to those skills associated with life within the farmstead community so there may be little opportunity for transition to less congregate residential opportunities.

Different from both farmsteads and group homes, the ICF-MR (Intermediate Care Facility-Mental Retardation) is a large, congregate residential program which receives full funding through Medicaid for the provision of active treatment to individuals with an intellectual or development disability. (Active treatment is generally regarded as meaning the consistent implementation of a program of specialized and generic training, treatment, health and related services to allow the individual to function with as much independence as possible).

Currently, all 50 States have at least one ICF-MR facility. The majority of residents in ICF-MRs are non-ambulatory, have seizure disorders, behavior problems, mental illness, visual or hearing impairments, or a combination of the above.

### **Life in the Community—Additional Challenges and Considerations**

Competence and active adulthood is defined by more than just where one works or where one lives (although they are both important). This section is intended to provide a brief overview of some additional considerations that require programmatic attention if we are to provide adults with autism the quality of life they so richly deserve.

#### **Community Safety**

One of the primary anecdotal descriptors of individuals with autism is a lack of awareness of dangerous situations. This skill deficit has significant ramifications across a variety of potentially dangerous situations in the community from avoiding an unfriendly dog to rarer, but potentially far more dangerous situations such as what to do when lost or in an emergency. If we then include the potential for physical or sexual abuse (e.g. Mandell et al. 2005) the importance of personal safety as an instructional target becomes more than clear. Across the age and ability spectrum, however, this is an area of autism intervention in need of significantly more research (i.e., Taylor et al. 2004) and professional attention.

#### **Communities of Faith**

For many families the inclusion of their son or daughter in their community of faith is an important and very personal goal. As each child becomes an adult and, ideally, establishes an identity outside of his or her nuclear family, access to worship services may remain (or become) an important facet of an individual's life. In addition, individual participation within a community of faith can provide access to a regularly scheduled and structured social event that is developed around a predictable set of activities and is set within a fairly consistent peer community (i.e., the congregation) This, in and of itself, may be of great benefit to the individual.

While challenges associated with accessibility (e.g., transportation, potential necessity of support staff) may present a temporary barrier, additional challenges may arise when an individual moves into a residential program some distance from their community of faith and a new such community must be identified and, as necessary,

educated. Given the diversity within, and between, faiths as well as the diversity between congregations within a particular faith, this may be a fairly complex and, at times, challenging prospect but, for some individuals a personally important one.

#### **Sexuality Instruction**

Individuals with autism are, by definition, sexual beings. Yet sexuality education for individuals with autism is often regarded as a “problem because it is not an issue, or is an issue because it is seen as a problem.” (Koller 2000, p. 126). In practice this means issues related to sexuality are generally ignored until they become problem, at which point they are generally regarded as a significant problem. A more appropriate and, ideally, more effective approach is to address sexuality as just another instructional area, the teaching of which allows adults with autism to be safer, more independent and more integrated into their own communities. As noted by Koller (2000), the question no longer can be *if* sexuality education should be provided, but rather how it will be offered.

#### **Involvement with the Criminal Justice System**

Professionals have been aware of high rates of learning and behavior disorders among incarcerated youth for some time (Moffitt 1990) leading some professionals to characterize the juvenile justice system as a default system for special needs learners with more complex emotional and behavioral challenges (Quinn et al. 2005). Only recently have we, as a field, started to discuss the very real potential for individuals across the spectrum to become involved in the criminal justice system, either as victim or perpetrator of some criminal act. For example, Paterson (2007) looked at two adults with Asperger Syndrome incarcerated in the U.K. Both individuals faced challenges understanding the complex formal and informal social hierarchies of prison life and accepting unfamiliar or non-preferred rituals and routines. Both were, not surprisingly, unsuccessful and ultimately placed in modified solitary confinement for their own safety. While how many individuals with ASD will become involved with the criminal justice system on annual basis remains unknown, for those that do the implications of our failure to provide necessary support are, potentially, devastating.

### **Discussion**

An entire generation of our nation's most vulnerable citizens is about to leave the entitlement-based world of special education and enter the already overwhelmed and

under-funded world of non-entitlement adult services. And while exceptional adult programs and services exist in every state, they tend to be more the exception than the rule; leaving many individuals and their families to, in effect, fend for themselves. This should be considered completely unacceptable.

If we are to more effectively and appropriately meet the needs of adults with ASD some significant changes to current systems of planning and intervention would appear to be necessary. While additional funding of the adult services system is certainly necessary, the reality is that little additional funding is likely to materialize on a state by state basis for the next decade or longer resulting in the most immediate changes needing to take place in, at best, a challenging budgetary environment. Among these critical changes are:

- There exists a significant need to further identify and research potential evidence-based, and socially valid, interventions for adolescents and adults with autism in the community. While interventions based upon the principles of applied behavior analysis have the most research, much more is necessary given the current emphasis on life in the community.
- Adult outcomes indicate that transition plans developed under the Individuals with Disabilities Education Act of 2004 (IDEA) for individuals with ASD fail to comply with the transition requirements contained therein such that individuals with autism are generally not provided with the skills necessary to successfully move from school to post-secondary education, *integrated employment* (including supported employment), adult services, *independent living*, or *community participation (emphasis added)*. Not only does this need to change but the fiscal resources necessary to support such change are, potentially, available, under IDEA.
- Within the developmental disabilities adult system more effective strategies of staff recruitment, training, and retention (e.g. Reid et al. 1989) need to be developed and implemented on a consistent basis to ensure both better trained staff and more consistent programs and supports for adults with ASD.
- While continuing the necessary focus on biomedical, genetic, and/or etiological research, an addition emphasis on research addressing “quality-of-life” and related intervention variables for adults with ASD needs to be actively implemented and the results disseminated in such a way to accessible to both families and professional staff.
- Efforts need to be undertaken to shift at least some of the focus of current public awareness efforts away from emphasizing the deficits and challenges associated with

living with ASD to include attention to the strengths and competencies of individuals on the spectrum and the benefits of their active inclusion in adult life in the community.

Adults with ASD deserve the same opportunities and options that those of us not on the spectrum, more often than not, take for granted. This would include the opportunity for a real job, a home in the community, people in their life for whom they care and who, in turn, care for them, to be free from abuse and neglect, to have access to healthcare, leisure and, if desired, a community of faith, and to be treated with dignity and respect. As former U.S. Vice President Hubert Humphrey once said: “The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy and the handicapped.” For generations of adults with autism and their families, this is a test we cannot afford to fail.

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