Adolescents and adults with autism: Outcomes, needs, and future challenges

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ABSTRACT

The cohort of individuals with autism spectrum disorder (ASD) diagnosed as part of the first

wave of what is typically referred to as the autism epidemic are rapidly approaching adulthood.

And this cohort represents only the proverbial tip of the iceberg with some reports noting that

70% of the identified individuals with ASD are less than 14-years old. This is 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 supporting adults with autism indicates that, independent of current ability levels,

the vast majority of adults with ASD are either unemployed or underemployed; that for many

individuals with ASD, the transition requirements of IDEA are poorly implemented with little

attention to service coordination, direct family involvement or attention to evidence-based

practices; issues related to adult staff recruitment and retention present significant challenges to

the provision of effective services; and large numbers of adults with autism remain without any

appropriate services at all. As there, there is a significant and growing need for professionally

staff programs and services designed to meet the complex and lifelong needs of individuals with

ASD.

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Introduction

The past decade has seen reports citing the dramatic increase in the prevalence of autism and related disorders (ASD). From an earlier prevalence estimate of approximately 2.5 cases per 1,000 individuals (DSM-IV, 1994) the figure most often cited today is approximately 4-7 cases per 1,000 individuals with the higher estimate resulting in the 1 case per 150 individuals most recently identified by the Centers for Disease Control in 2007. While the reasons behind this increase remain unclear (e.g., Gernsbacher, Dawson & Goldsmith, 2005, Shattuck, 2006) and at times, controversial (e.g., Kirby, 2005; Williams, Mellis, & Peat, 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 and effective services for adolescents and young adults with ASD. Unfortunately, the needs in both areas continue to far exceed the available resources leaving a generation of individuals with autism and their families in a programmatic, financial, and personal limbo. For example, Howlin, et al, (2004) surveyed 68 adults with autism with an IQ of above 50 and found a majority (58%) were rated as having poor or very poor outcomes. With regards to employment status the authors found that only 8 were competitively employed; 1 was self employed earning less than a living wage; 14 worked in supported, sheltered or volunteer employment; and 42 had "programs" or chores through their residential provider. 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.

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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 neuro-typical peers. Fifty percent of the AS group were unemployed. The others 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 on-line 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; 78% were unfamiliar with agencies or professionals that might assist in job development; 19% of individuals with autism were employed at the time of the survey with 74% of those employed working less than 20 hours per week; and 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 those reported in the literature and, unfortunately, experienced daily by adults with autism and their families should be considered unacceptable. Among the reasons behind the continued poor outcomes for adults on the spectrum can be seen to include:

- Poorly implemented transition services to guide individuals from school to adult life

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- A generally lack of societal understanding as to the potential for adults with ASD to be employed, contributing, and active members of their community when the appropriate interventions and supports are available;

- A lack of coordination between the educational, behavioral, mental health, vocational rehabilitation, and Mental Retardation/Developmental Disabilities (MR/DD) systems intended to support individuals into adult life; and

- An absence of qualified staff to work with older learners.

Note that none of these challenges focus on the person with ASD. Rather, the potential of individuals with ASD to become employed and engaged adults is limited more by the failure of the systems charged with supporting them than by the challenges associated with being on the spectrum. 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., parents, professionals, employers, society at large) to correct these inadequacies, the costs can only be expected to grow in the coming years.

Despite the growing 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.

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Historical Overview

During the later part of the 19th and earlier part of the 20th century, the public perception of individuals with disabilities as non-productive and best suited for custodial care resulted in the growth of institutions as the primary service system for persons with developmental disabilities (Janicki, Castellani & Norris, 1983). Individuals with ASD were those routinely placed in such custodial settings with little or no voice in the matter or opportunity for proactive programming.

By the late 1960's, the deinstitutionalization movement was gaining acceptance and the movement from the institution to the community had begun (Mesibov, 1990). However, while an understanding of the needs of individuals with mental retardation may have entered a new era, the needs of persons with autism remained unaddressed (Schopler & Hennick, 1990). With the bulk of literature available at that time focused primarily on theoretical perspectives of etiology and classification of autism (Celiberti, Alessandri, Fong, & Gill, 1993). 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 behavioral systems of learning (e.g., Ferster & DeMyer, 1962; Lovaas & Simmons, 1969) the treatment literature at this time was hard to come by and, in the case of the psychoanalytic literature (e.g., Bettleheim, 1967), inaccurate and harmful.

It was not until the mid to late 1970's that a more comprehensive body of literature specifically devoted to addressing the educational and behavioral needs of children with autism came into being (Celiberti, Alessandri, Fong, & Gill, 1993). These early investigations (e.g., Carr, Binkoff, Kologinsky, & Eddy, 1978; Solnick, Rincover, & Peterson, 1977) helped form the basis for our

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understanding of many of the systems of education, training and support currently in use today (e.g., the use of applied behavior analysis in the classroom).

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 adulthood. Subsequently, service delivery entered a new phase, the recognition of differing needs of individuals with ASD across the life-span.

The 1980s produced a national emphasis on the school to work transition process for all special needs learners (e.g., Will, 1984; Lagomarcino & Rusch, 1987). The recognition of the appropriateness and subsequent benefits of employment for many individuals with disabilities prompted the development, nationwide, of a variety of supported employment initiatives intended to provide individuals with severe disabilities access to the world of work. This process continues today.

RELEVANT LEGISLATION

There are no federal laws or regulations specifically designed to provide for adolescents and adults with ASD in the vocational and employment arenas. These specific concerns are generally subsumed under the laws which provide personal and systemic protection for individuals with disabilities. Included in this cadre of relevant disability legislation are: 1) The Individuals with Disabilities Education Act of 2004; 2) The Vocational Rehabilitation Act of 1973and its subsequent Amendments (1988, 1992), 3) The Americans with Disabilities Amendments Act of 2008 and 4) the Ticket to Work and Work Incentives Improvement Act of 1999.

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The Individuals with Disabilities Education Act (IDEA) of 2004

In 1975 Congress passed the Education of all Handicapped Children Act (PL 94-142) which mandated that all children with disabilities are entitled to a free and appropriate public education in the least restrictive environment. Reauthorized in 2004, now called IDEA, one of the laws primary purposes is to ensure systems are in place to effectively prepare special needs learners for post-graduation education, vocational training, integrated employment (including supported employment), and community living and participation. Now, transition planning and subsequent services are required to be part of a student's Individualized Education Program (IEP) beginning no later than his or her 16th birthday. However, transition planning may begin at an earlier age if the team determines it appropriate, which is warranted, for most learners with ASD.

Transition services under IDEA are defined as a coordinated set of activities, provided to the student by the school and sometimes other agencies, to promote a successful transition from high school to postsecondary education or employment, and independent living. IDEA requires that transition services be based on the student's strengths, as well as his or her preferences and interests. The reference to "strengths" was intended to make clear that the development of transition goals should focus and build on the student capabilities and not skills deficits.

Under IDEA transitioning planning requires the development of measurable postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and independent living skills. In developing these goals, the IEP team should include the student

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to the greatest extent possible. Goals must identify what school and community-based instructional experiences will help prepare the student for a successful life post graduation.

IDEA mandates that schools are required to provide effective, individually determined transition planning. IDEA highlights the need for transition services to be comprehensive, thoughtful and consumer-based thereby stimulating greater professional awareness of the issues surrounding transition planning. However, for many adolescents with ASD the intended impact of IDEA's transition mandate has failed to materialize leaving large numbers of adults with ASD without the skills necessary to meet the demands of life post-graduation.

The Vocational Rehabilitation Act of 1973

The Vocational Rehabilitation Act of 1973 (VRA) provides access for individuals with disabilities to any program, service or activity receiving federal funds. Funds are made available to provide time-limited job training and employment development assistance at the state level. One component in particular, Section 504 of the VRA, is regarded as the "Bill of Rights" for individuals with disabilities as a result of its strong, anti-discrimination language.   In 1986 Congress amended the VRA to include language on the importance of transition and transition services" thereby offering a "major avenue of transition opportunity for young adults" (Wehman, 1992, p. 10).   The VRA amendments of 1992 codified the assumption of employability regardless of the severity of the disability (Smith, Belcher, & Juhrs, 1995).   On the state level, however, the majority of individuals with "classic" autism will find themselves ineligible for VR services due, in part, to outdated concerns regarding long term employability (Lawer, Brusilovskiy, Salzer, & Mandell, 2009; Revell & Miller, 2008).

The Americans with Disabilities Act (ADA) has been called the capstone to a public policy promoting community access and participation by people with disabilities. The ADA prohibits discrimination against individuals with disabilities in the areas of employment, transportation, public accommodations, public services and telecommunications. Further, the ADA makes it unlawful for employers to discriminate against potentially qualified employees on the basis of a disability.   Under the ADA employers are required provide "reasonable accommodations" to workers who are able, with such accommodations, to perform the essential functions of the job. The impact of ADA on the employment of individuals with autism has not yet been tested.

In terms of housing and residential supports, however, the U.S. Supreme Court issued strong case law in 1999 *L.C. and E.W. v. Olmstead.* L.C. and E.W. were two women with mental retardation and comorbid psychiatric conditions who resided in a state psychiatric hospital. Although the treating clinicians all agreed that they were appropriate for discharge into community programs such slots were not available at the time the case was filed in 1995. The Atlanta Legal Aid Society sued on behalf of LC and EW. The U.S. Supreme Court held that, under the ADA, the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. Therefore, the Court held that states may be required to provide community-based services as an alternative to institutional placement for such individuals with disabilities.   This ruling supports the right of individuals with disabilities to live, work, and enjoy life in the community. States are still working to address the significant programmatic implications of this important decision.

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Ticket to Work and Work Incentives Improvement Act of 1999

The Ticket to Work Program (as authorized by the Ticket to Work and Work Incentives

Improvement Act) is designed to provide individuals with disabilities receiving Social Security

benefits more options when seeking assistance in gaining employment. Under this program the

Social Security Administration (SSA) issues a "ticket" (this is an actual ticket) indicating

eligibility for services.   The eligible individual may then use this ticket to obtain employment-

related services either through an employment network (EN), vocational rehabilitation provider,

or other approved agency. ENs generally offer one or more services such as job readiness and

work-skills assessment, career counseling, employment placement, internships and

apprenticeships, job coaching, or transportation.

In 2006 the SSA established the Work Incentives Planning and Assistance (WIPA) program to

help address the need for effective benefits planning. Work Incentives are those programs under

SSA that allow individuals with disabilities to remain employed without the loss of medical

benefits (i.e. Medicaid). Work Incentives include, but are not limited, the Plan to Achieve Self-

Support (PASS), trial work periods (TWP) and the Income Related Work Expense (IRWE)

program.   SSA Work Incentives are available to all beneficiaries regardless of the source of their

employment services. It should be noted that SSA work incentives, in and of themselves, are not

new and have been both available, and significantly underutilized, for the better part of two

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decades. A user-friendly resource on work incentive programs and how they work together to support employment can be found at: http://www.socialsecurity.gov/redbook/.

TRANSITION PLANING

IDEA, as discussed previously, provides for functional transition planning to support the movement of the individual from school-age services and supports to the post-school world of work, living, and adult services. Transition planning will not be effective unless there is active coordination between all the necessary services both pre- and post-graduation, the goals of transition are clear and directly related to life as an adult, there is direct family involvement throughout the process, and the interventions used are evidence-based.

Coordination of Services

At the heart of effective transition planning is the question: "*To what outcome is the learner with ASD transitioning?*" Even the best school-based transition programs will be of little benefit if they are not coordinated with the state's adult service system. Although most states recognize the importance of coordination, challenges relating to the availability of funding, the length and type of services available, extensive waiting lists, and access to reliable transportation remain significant obstacles. In short, the best planning cannot overcome the prospect of nothing on the other side of transition.   A primary focus of transition "must be on assisting agencies to work more efficiently in coordination with one another" (Bates, Bronkema, Ames & Hess, 1992, p.128)

The Parameters of Adulthood

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In the United States adulthood tends to be defined along a number of complementary parameters. These would include what one does for a living, where and how one lives (e.g., urban v. suburban v. rural), one's membership in religious/community organizations, who one considers to be friends or acquaintances, and one's marital status and/or nuclear family membership. Unfortunately, the primary emphasis of most transition planning is the "school to work" transition process which, while critically important, should be considered a necessary yet not sufficient component for a complete adult life. As such effective, comprehensive transition planning should include goals across a variety of life domains that may function in support of society's widely accepted definition of competent adulthood. These topics will be discussed later under *Life in the Community*.

Family involvement and support

Direct family involvement in most every aspect of the transition process should be considered essential. Beyond their personal knowledge of, and relationship with, their child, many parents are well versed in the current state of autism services in their area through their networking with other parents, attendance at conferences, reading of relevant texts, and access to the internet. (Gerhardt, Mannion, Weidenbaum, Andretta & Wallace, 2003). As a result, any reduction in family involvement denies the transition team access to 1) valuable information regarding the individual learner in question and, 2) an educated colleague. Steps, therefore, need to be taken to encourage a family's active participation in their child's transition.

Perhaps the most important role that family members can play is that of advocate for their soon to be adult child. Despite a multitude of new stressors that may appear as their child enters the

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transition years, (e.g., an unfamiliarity with the adult system of services and supports, the potential inability of this system to meet the needs of their adult child, common life-cycle transitions, and uncertainty regarding the future), the need for parents to forcefully advocate on behalf of their child does not diminish with age. In point of fact, given the challenges which they and their child with ASD will, most likely, face in the transition process the need for parental advocacy at this time may be even more critical than ever.

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, Arnstein, Soorya, & Gillis, 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 & 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). Unfortunately, behavior analytic research specifically addressing the instructional needs of older learners is less available which can present a major challenge to those interested in supporting adolescents and adult on the spectrum. And while much of the research targeting younger learners can be generalized, with some modification, to use with older individuals this, in practice, would appear to be more the exception than the rule.

For those who know how to look for it, there is a broader research base supporting the use of behavior analytic interventions with adults on the spectrum. Take, for example, a study by Hagner & Cooney (2005). In this study the authors interviewed the supervisors of 14

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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, as presented in Figure 1, are not necessarily surprising. But what may be surprising is that despite being discussed by the authors in less than behavior analytic terms, all of the indentified strategies are well documented behavior analytic interventions. For example:

Figure 1

Hagner & Cooney (2005) Findings	and in Behavior Analytic Terms
Maintaining a consistent schedule and set of job responsibilities	Activity schedule and task analysis
Using organizers to structure the job	Visual supports
Reducing idle or unstructured time	Environmental modifications and/or providing instruction in appropriate use of idle time
Being direct when communicating with the individual employee	Provide a clear and accurate Sd
Providing reminders and reassurances	Prompting, shaping, and reinforcement

So if the research exists, why are such potentially effective behavior analytic interventions not used as frequently as would seem to be appropriate? One reason may be the continued confusion regarding the relationship of discrete trial teaching (DTT) to ABA. In brief, ABA is a field of inquiry dedicated to investigating and modifying behavior in a systematic way. ABA is data-

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based, analytical, able to be replicated, contextual, accountable, and results in socially valid behavior change. (Sulzer-Azaroff & 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 ABA 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. In less technical terms, it is probably safe to assume that for a typical 5-year old child with autism, DTT would be the method of choice to teach color discrimination. Let's also assume that for this particular learner 1,000 such trails were required in order for him or her to master the expressive and receptive discrimination of all 64 colors in the big box of Crayola crayons. Not all that much, actually, and so the response effort on the part of the instructor is relatively low (i.e., sit at a desk, present Sd, prompt, reinforce, and collect data) and the intervention (DTT) would be regarded as effective.

Now assume this same leaner is 16 years of age and instead of color discrimination the instructional goal is independent purchasing of lunch at McDonalds. If the resources are

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available to provide direct community instruction just once every other week, it would take approximately 40 years for the same number of instructional opportunities to be presented as were necessary to acquire a simple discrimination task (color ID) much earlier in life. So the low response effort in this case (one instructional opportunity every other week) would be insufficient to produce significant results -- independent responding -- and the implication would be that behavior analytic interventions (i.e., task analysis, shaping, chaining, prompting, and reinforcement) are ineffective with older learners. However, with a higher response effort, (e.g., daily instructional opportunities) independent purchasing of lunch may be acquired (particularly given the reinforcing value of task) and the associated interventions regarded as effective.

As children with autism become adolescents with autism who become adults with autism the instructional challenge becomes twofold. The first is to use instructional interventions that have the greatest research base and are, therefore, most likely to be effective. In the vast majority of cases these will be behavior analytic interventions. The second, however, is to ensure the implementation of these interventions in a way that is congruent with the research and, just as importantly, with sufficient response effort (i.e., instructional intensity) to result in significant, and socially valid behavior change.

Summary

Sadly, while much has been written about the transition process post-graduation outcomes for individuals with ASD remain unacceptably poor indicating that much still needs to be done. Given the often complex and long-term needs of many individuals with ASD, of particular

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importance is the development and maintenance of systems of interagency cooperation in order to best provide for a continuity of services on the other side of transition.   If the transition planning requirement of IDEA is to be consistently and effectively implemented the discrepancy between legislative intent and systemic practice needs to be fully resolved so that the necessary resources and services are more readily available.

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 & 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

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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.

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 & 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 to improve the lives of adults with autism. If

direct care staff once hired are to be retained, they must be 1) effectively trained in the

application of relevant, evidence-based practices and, 2) demonstrate a degree of competence in

their actual implementation. Further, effective supervision then 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

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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 (SE) can generally be defined as "an employment option that recognizes

the capacity of the adult with developmental disabilities while acknowledging his or her need for

ongoing support."(Kiernan & Stark, 1986, p. 109). 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

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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 & Wehman, 2008) which may include individual HCBS waiver funds if

available.

There are generally four traditional models of supported employment which may be available for

individuals with autism. They are the; 1) individual placement model, 2) clustered placement or

enclave model, 3) mobile work crew; and 4) entrepreneurial supports.   It should be noted that

many programs (and some innovative businesses) use a combination of these models to promote

the employment of adults with autism.   Further, individuals may be provided individual supports

for one job on one day but work the next day, at a different job, as part of a mobile crew.

Individual Placement Model

In the individual placement model, a job coach works to develop a job for an individual with a

disability within a private sector enterprise. Intensive on-site training and support provided by

the job coach in a one:one setting and is subsequently faded as job competencies increase,

freeing up the job coach to provide support for another individual. In general, social integration

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is high in the individual placement model as is the degree of individuality. Although developed

for individuals with significant challenges, the individual placement model tends to be

implemented with more able and therefore less resource intensive individuals. This tends to, in

practice, eliminate all but the most able individuals from participation in the individualized

placement model. Modifications to the model to allow for more long-term support should be

considered appropriate and may be funded through state developmental disabilities agencies.

Enclave or Cluster Model

The clustered or enclave model requires that, instead of one individual, the job coach now works

to support a small group of individuals (usually 2-6) with disabilities at a private sector location.

Job coach support is generally provided for the length of employment, although more intensive

supervision may be faded over time. Social integration may be high but limitations associated

with the physical set-up of a clustered placement may restrict more normalized interactions. For

this reason, the clustered model has been criticized as being a "private sector sheltered

workshop" and perhaps less ideal than the individual placement model for some individuals.

Mobile Work Crews

Similar to clustered placements, mobile work crews generally consist of a small number

individuals who provide an agreed upon level of contracted services (e.g., office cleaning)

throughout a specific geographical area. Due to the nature of many of the services offered by

mobile crews and the fact that many of these jobs are generally accomplished during times when

few people may be working, the level of social integration tends to be somewhat limited under

this model.

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Entrepreneurial Model

Entrepreneurial supports involve the development and promotion of a business entity, sometimes

referred to as a self-directed support corporation (Center for Self-Determination, 2004) 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.

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

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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 (see

Secure Employment/Day Habilitation section below). 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 Habilitation/Secure Employment

Day habilitation 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. Secure employment represents a variation on the day

habilitation model of adult services.   Holmes, (1998) described secure employment a program

model whereby adults with autism could be provided with a variety of employment

(subcontracted, supported, and competitive) and/or employment development and training

activities (e.g., from personal hygiene training to the development of appropriate interviewing

skills) within a day habilitation setting.   This, Holmes argues, provides "safety net" by which

concerns such as job loss or the challenges associated with challenging behavior do not result in

a loss of services.

Sheltered Workshops

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Unlike Day Habilitation Programs which are designed to provide life skills training and some community-based instruction in addition to job training and experience, sheltered workshops are designed with a single, primary purpose: to provide a large, enclave-like employment experience for adults with developmental disabilities. Levy (1983) in discussing the appropriateness of the sheltered workshop for individuals with autism argues that concerns regarding the lack of functional work tasks and employment training, little if any attention to training beyond the skills for minimal production, insufficient levels of staff training and expertise, and very high staff : client ratios may result in the sheltered workshop being a less than desirable option for many individuals with autism. In addition, sheltered workshops tend to function more as final placements for individuals with disabilities rather than as the transitional service (to a less restrictive employment placement) which they were meant to be.

Summary

A number of viable service models designed to offer employment training and support to adults with autism are currently available on a state by state basis. However, adult learners with autism continued to be unemployed, underemployed, and even simply underserved at levels far greater than should be possible or desirable. Less than adequate transition planning and coordination coupled with limited access to appropriate adult services continue to present significant obstacles to the development of adult lives of dignity, competence, and quality for both adults on the spectrum and their families.

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

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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 short supply and those that exist are usually

at capacity, quite 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

(NARPAA) "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 Living.

A variety of residential models exist although not all models are available in all states.

Important, however, is 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 programmatic models, as is

presented below, cannot present 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).

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Supported Living

Supported Living programs provide residential 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 programming is, as noted, directed by the individual adult on the spectrum. The responsibilities of the professional staff, therefore, 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

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Supervised living models are designed to provide residential services to individuals with autism and other developmental disabilities living in smaller residences such as apartments – which they may or may not own -- 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 (crisis support is available 24 hours/day). Daily schedules are generally provided (with input from the individual) and professional staff are available to provide direct instruction or support.

Group Homes

With the onset of deinstitutionalization came the movement of individuals with autism and other 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 condition. Typically, group homes have eight or fewer occupants and are staffed 24 hours 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

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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 hours 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.

Farmstead Programs

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

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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.

Intermediate Care Facility – Mental Retardation (ICF-MR)

The ICF-MR 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. As has been the case with larger group homes there has been a shift away from the development of new ICF-MRs and the transition of current residents into smaller, community based homes.

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Summary

There exist a number of viable models of residential services that may be considered appropriate for individuals with autism. A central difference between models is the number of individuals served per housing unit (e.g., condo, house, etc.) and the resulting level of community integration for each resident. Two issues bear repeating however. The first is that program models are not directly tied to either type or quality of services provided therein. As such, variability in implementation of each model may vary greatly from agency to agency. Second, the initial property costs (e.g., purchase of the actually residence) represent a relatively small expense when compared to the overall operating expenses of residential programs. As such, it is of critical importance that the availability of adequate long-term funding be taken into consideration when deciding upon a particular program model.

Life in the Community – Additional Challenges and Considerations

As previously mentioned, 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 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 core deficit has significant ramifications for community integration across a variety of potentially dangerous situations from avoiding an unfriendly dog or stranger/friend differential to the rarer, but far more dangerous, situations such as what to do when lost or during a fire or other emergency situation. Add the fact that individuals with

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autism are far more likely to be victims of abuse and exploitation than are their typical peers and you can understand the extent to which this issue requires significant instructional and programmatic attention. 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. Minimally, however, participation in a community of faith can also provide access to a regularly scheduled and structured social event developed around a predictable set of activities and set within a fairly consistent community of participants, a congregation which, in and of itself, may be highly beneficial.

In addition to the challenges associated with accessibility (e.g., transportation, potential necessity of support staff) challenges may also arise when an individual moves into a residential program and, due to the location of the program, switches congregations. In addition, given the diversity within and between faiths as well as the diversity between congregations within a particular faith, programs designed to promote participation in a particular congregation need to be highly individualized and somewhat localized.

Sexuality Instruction

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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 or 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, (2008) 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 ultimately placed in modified solitary confinement for their own safety. This issue must be effectively addressed if we are to ensure the future of adults with autism.

DISCUSSION
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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.

Adults with autism 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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