The Current State of Services for Adults with Autism

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This document was first presented at the Advancing Futures for Adults with Autism: Think Tank in January 2009. The following document was developed to provide an overview of the types of the service systems and models that currently exist which are designed to provide adults with ASD the continued and necessary support to be engaged, active citizens and lead lives of competence, quality and dignity.

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ANALYSIS

The group of people with autism spectrum disorder (ASD) diagnosed as part of the first wave of what is typically referred to as the autism epidemic is rapidly approaching adulthood. This group represents only the proverbial tip of the iceberg. 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 ASD, their families, and the ill-prepared and underfunded adult service system charged with meeting their needs.

The document you are holding was developed by to provide an overview of the current status of adult services in the United States for individuals with ASD as well as identify gaps in the current service system. The primary findings relate solely to housing, employment, and community integration. Despite its importance, the critical issue of healthcare and adults on the spectrum was not included because it is the subject of a much larger national discussion. The results are as follows:

- *Outcome studies of adults with ASD document that, independent of current ability levels, the vast majority of adults with ASD are either unemployed or underemployed.*
- *The majority of adults with autism continue to live with parents, siblings or older relatives.*
- *The current economic slowdown can be expected to a have a direct, and negative, impact on the availability of adult services.*
- *For many individuals with ASD, the transition requirements of IDEA are poorly implemented with little attention to service coordination or direct family involvement.*
- *The Federal Department of Health and Human Services reports that the combined, annual average staff turnover rate for programs serving adults with developmental disabilities is 50% coupled with a staff vacancy rate of 10-12%.*
- *While appropriate and effective residential and employment models exist, access to these models is greatly restricted due, primarily, to a lack of adequate funding.*
- *The smaller the unit of service (e.g., individual supervised living or customized employment) the greater the likelihood for community integration.*
- *There is a great need for programs, services, and naturally occurring supports for such critical aspects of adult life as personal safety, transportation, leisure, health/wellness, and sexuality.*
- *The greatest impediments to the development of integrated lives of quality and dignity for adults with autism are system inadequacies coupled with a public perception of adults on the spectrum being unemployable.*

__Source__: State of California, Department of Developmental Services

The Current State of Services for Adults with Autism

I. <u>INTRODUCTION</u>

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 need for such services continues to far exceed the available resources leaving a generation of individuals with ASD 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 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. 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:

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- 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;
- 74% stated that they wanted to work but were currently unemployed;
- 19% of individuals with ASD were employed at the time of the survey;
- 74% of those employed worked less than 20 hours per week; and
- 85% still lived with parents, siblings, or older relatives.

In a larger survey, the Easter Seals' *Living with Autism Study* (2008) reported on the overall experience of parenting a child with ASD (1,652 respondents) as compared to parenting a child without any special needs (917 respondents). The findings indicate that:

- 61% of families of children with ASD reported incurring debt to meet family needs as opposed to only 46% for typical families.
- When compared to typical families, families of children with autism report being significantly more afraid that:
  - Their child will not have sufficient financial support after the parent dies,
  - The cost of caring for the child will drain the family's current and future financial resources, and
  - The cost of raising their child with autism will have a financial impact on other siblings.
- Long term independence and personal quality of life is of significantly greater concern to parents of children with autism than to parents of typical children.
- 59% of children with autism aged 16-years or older have not yet looked for work while 75% of their same-age peers are already working.

While not unexpected, these outcomes are unacceptable. The reasons behind such continued poor outcomes include, but are not limited to:

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

- A lack of understanding that people with ASD have the potential to be employed, contributing, and active members of their community when the appropriate 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.

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. "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." (Ganz, 2007, 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.

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II. <u>HISTORICAL OVERVIEW</u>

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). The treatment literature at this time was hard to come by and, in the case of the psychoanalytic literature (e.g., Bettelheim, 1967), inaccurate and harmful. What was available focused primarily on theoretical perspectives of etiology and classification of autism (Celiberti, Alessandri, Fong, & Gill, 1993). In addition there was the critical debate regarding the psychoanalytic model of intervention (Rimland, 1964) and the noteworthy early investigations into the efficacy of behavioral systems of learning (e.g., Ferster & DeMyer, 1962; Lovaas & Simmons, 1969).

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 helped form the basis for our understanding of many of the systems of education, training, and support currently in use today (e.g., the use of applied behavior analysis and the emphasis on evidence-based practice in the classroom). (e.g., Carr, Binkoff, Kologinsky, & Eddy, 1978; Solnick, Rincover, & Peterson, 1977)

As the group 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 as service providers recognized that the needs of people with ASD changed as they grew into adulthood.

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 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 work. This process continues today.

Despite the growing recognition of the employment-related needs and abilities of adolescents and adults with ASD, the development of employment-related services for persons with ASD continues to lag far behind those currently available for persons with less severe disabilities. This disparity between what can be done and what is being done for adults with ASD represents an ongoing challenge to the field.

III.   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; 2) The Vocational Rehabilitation Act of 1973and its subsequent Amendments (1988, 1992), 3) The Americans with Disabilities Amendments Act, and 4) the Ticket to Work and Work Incentives Improvement Act.

A. The Individuals with Disabilities Education Act (IDEA)

In 1975 Congress passed the Education of all Handicapped Children Act (PL 94-142), currently referred to as the Individuals with Disabilities Education Act (IDEA), which mandates that all children with disabilities are entitled to a free and appropriate public education in the least restrictive environment. Reauthorized in 2004, one of the law's 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 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.

> *IDEA is an affirmative supports statute requiring states to provide educational services to all individuals with disabilities regardless of the severity of the disability.*

B. <u>The Vocational Rehabilitation Act of 1973</u>

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).   However, on the state level the majority of individuals with "classic" autism will find themselves ineligible for VR services due, in part, to outdated concerns regarding their ability to remain employed over the long term and following the cessation of the time-limited supports (Revell & Miller, 2008) authorized under the VRA.

> *Section 504 of the Voc Rehab act is an Antidiscrimination/Equal Access statute requiring that qualified individuals with disabilities have equal access to organizations or employers that receive financial assistance from the Federal government.*

C. The Americans with Disabilities Act

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 *L.C. and E.W. v. Olmstead (1999).* L.C. and E.W. were two women with mental retardation and co-morbid 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.

> *The ADA is an Antidiscrimination/Equal Access statute requiring that qualified individuals with disabilities have equal access to community organizations, activities, or employers whether or not they receive financial assistance from the Federal government.*

D. 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 an employment program for individuals with disabilities receiving Social Security benefits. The goal of the Tick to Work Program is to increase opportunities and choices for eligible adults to obtain specific employment-related services from both public (VR) and private (Employment Networks) providers. Under this program the Social Security Administration (SSA) issues a "ticket" (this is an actual ticket) indicating eligibility for employment services. The eligible individual may then use this ticket to "purchase" employment-related services either through an employment network (EN), vocational rehabilitation provider, or other approved agency operating in their geographic area. 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 decades. A user-friendly resource on work incentive programs and how they can be utilized to support individual employment goals can be found at: http://www.socialsecurity.gov/redbook/.

Ticket to Work and Work Incentives Improvement Act is an affirmative supports statute in that it provides specific financial resources in support of adults with disabilities.

IV.   TRANSITION PLANNING

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, and there is direct family involvement throughout the process.

A. Coordination of Services

At the heart of effective transition planning is the question: "*To what outcome is the person 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)

B. The Parameters of Adulthood

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 below under *Life in the Community*.

C. 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 ASD 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 transition years, (e.g., unfamiliarity with the adult system of services and supports, potential inability of this system to meet the needs of their adult child, common life-cycle transitions, and uncertainty regarding the future), the

> 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.

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.

D. <u>Summary</u>

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 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.

V. <u>ADULT SERVICES OVERVIEW</u>

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. Our occupational choices are one way in which we define both ourselves and others in a variety of social situations. Other critical choices include where and with whom we might live, what we do with our free time, and who we consider our friends. Unfortunately, for most adults with ASD employment remains elusive (Dew & Alan, 2007) with anecdotal reports indicating an unemployment/underemployment rate for adults with autism of greater than 90%. In terms of where one lives, waiting lists for residential services are lengthy -- New Jersey, for example, maintains a residential waiting list of over 8,000 individuals with developmental disabilities -- and the necessary funding for these services are scarce. ***This significant lack of services can be viewed as the most significant challenge to development of integrated and valued lives of quality and dignity for adults with ASD.***

A. Direct care staff: The Challenge of Recruitment, Retention, and Supervision

> *"Direct care staff" refers to those employees charged with assisting individuals with developmental disabilities in group residential settings, supported living, family homes, community employment, and vocational or day habilitation settings. Specific job titles may include, but are not limited to, aides, job coaches, therapists, residence counselors, respite workers, personal care assistants and home health aides.*

The ability of any program or agency to provide quality services to adults with ASD 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 ASD and other disabilities. The U.S. Department of Health and Human Services (2004) reports 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 and 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 often cited for this high turnover rate is that direct care staff are 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

Direct Service Turnover in Residential/In-Home and Vocational/Day Services, 1998-2003*

Setting Type	Number of Studies	Average Rate
Residential/In-home	11	53.6%
Vocational/Day	6	46.0%
Both	9	48.1%
Combined Average	26	50.0%

*Source: *The Supply of Direct Service Professionals Serving Individuals with Intellectual Disabilities and other Developmental Disabilities. Report to Congress (2004).* Department of Health and Human Services; Washington DC. Available on line at http://www.ancor.org/issues/shortage/aspe_dsp_11-09-04.doc.

services much of what constitutes staff training and supervision is based upon fads, folklore and idiosyncratic systems or traditions (Reid & Parsons, 2006) which are not generally effective. For example, much of staff training typically consists of lectures coupled with succinct demonstrations with instances of 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 ASD. 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 must 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.

B. Funding Mechanisms

On a state basis most community-based services to adults with ASD are funded through two state administered agencies which receive federal funding: **Vocational Rehabilitation (VR)** or **Developmental Disabilities (DD)**. State **Vocational Rehabilitation** agencies offer time limited job training, employment support, counseling, education, and other services deemed necessary to prepare an individual to work. Historically, the term vocational rehabilitation referred to any program that sought to restore any individual who had become disabled to their optimal physical, mental, social, vocational, and economic ability,. This system assumes that a finite amount of time and services would be required to rehabilitate the individual. Accordingly, VR agencies provide services that are time-limited as a function of the service itself (e.g., a semester long course) and the individual's rehabilitative goals. **Developmental Disabilities** agencies, on the other hand, assume an ongoing need for intervention. DD agencies generally provide more long term services including supported employment, day programming, residential services, and case management. Eligibility for services provided by both Vocational Rehabilitation and Developmental Disabilities agencies varies on a state by state basis with some state DD agencies restricting eligibility to those individuals with an IQ below 70.

Federal funding for community-based day and residential services is primarily provided through the **Medicaid Home and Community Based Services (HCBS) Waiver**. HCBS waiver funding

is made available to individual states and state developmental disabilities agencies in order to provide community-based services to individuals with disabilities who otherwise would be require institutional care. HCBS waiver funds are primarily used to fund programs and related services and are not made directly available to individuals with ASD or their families.

Pennsylvania, however, has been approved for a limited number (up to 200 individuals/year) of individual, ASD specific HCBS waiver "slots" which allow the adult with ASD to, in effect, purchase the services and supports which they require to live and work in their community. Sometimes referred to as self-determination initiatives, a number of states (e.g., New Jersey, Maryland, Florida, etc.) have been approved for similar HCSB waiver slots but these are generally available to individuals within the broad category of developmental disabilities and are not ASD specific.

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 (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 direct funding (under certain guidelines). Examples of self determination initiatives include New Jersey's *Real Life Choices* and Maryland's *New Directions* programs.

VI.   MODELS OF EMPLOYMENT SUPPORTS

A. Supported Employment

Supported employment (SE) can generally be defined as category of employment options "that recognize the capacity of the adult with developmental disabilities while acknowledging his or her need for ongoing support."(Kiernan & Stark, 1986, p. 109).

Basic Supported Employment Terms

- *Employment Specialist/Consultant (Job Coach):* A person employed by a job training and placement organization serving people with disabilities who matches clients with jobs, provides necessary supports during the initial employment period and then facilitates the transition to natural workplace supports while reducing his or her role.
- *Natural supports:* Support from supervisors and co-workers occurring in the workplace to assist employees with disabilities to perform their jobs, including supports already provided by employers for all employees. These natural supports may be both formal and informal, and include mentoring, supervision (ongoing feedback on job performance), training (learning a new job skill with a co-worker) and co-workers socializing with employees with disabilities at breaks or after work. The use of natural supports increases the integration and acceptance of an employee with a disability within the workplace.
- *Carving/job creation:* The process of breaking down jobs into their key components and assigning them to employees based on efficient company operations and customization to meet the skills of the employee with a disability. This process results in either job restructuring or job creation.
- *Job development:* Locating jobs for people with disabilities through networking with employers, businesses and community leaders. The use of Business Advisory Councils is an excellent way to develop contacts that lead to employment for people with disabilities.

Source: U.S. Department of Labor. Available on-line at http://www.dol.gov/odep/archives/ek01/support.htm

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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.

There are generally four traditional models of supported employment which may be available for individuals with ASD. They are as follows: 1) **individual placement model**, 2) **clustered placement or enclave model**, 3) **mobile work crew**; and 4) **entrepreneurial supports** which is discussed separately below.   It should be noted that many programs (and some innovative businesses) use a combination of these models to promote the employment of adults with ASD. For example, the **Supported Employment Division of Eden W.E.R.C.s**, in Princeton, New Jersey utilizes a variety of supported employment models as a function of individual needs

coupled with the demands of a particular job. Further, individuals may be provided individual supports for a job on one day but work the next day, at a different job, as part of a mobile crew. A new type of support called customized employment is discussed below.

1. Customized Employment

A relatively new and highly specialized derivative of supported employment, supported employment tends to match individuals with previously existing jobs in the community. 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 ASD and the employer. Consequently, a highly personalized, or customized, job description designed to meet the needs of all stakeholders is developed. Funding too, is distinct from that available for typical supported employment. While supported employment is a recognized service delivery option under Medicaid and can, therefore, receive direct funding, customized employment is not so recognized. Customized employment generally requires a blending of funding sources (Targett & Wehman, 2008) which may include self determination waiver (HCBS), SSA Work Incentives, and state specific funding when available.

2. Individual Placement Model

In the **individual placement model**, a job coach provides intensive one: one on-site job training and support. This is subsequently faded as job competencies increase or more naturally occurring supports are developed (e.g., a co-worker assuming some of the coaching responsibilities), freeing up the job coach to provide support for another individual. In general, social integration 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.

3. Enclave or Cluster Model

The **enclave or cluster model** requires that the job coach now works to support a small group of individuals (usually 2-6) with ASD at a community location. Job coach support is provided for the length of employment, although more intensive supervision may be faded over time. Some enclave models have the participating individuals clustered in a single area while others may have them dispersed throughout the place of employment. Social integration may be more restricted or more normalized depending on the physical set-up of a clustered placement. Since the physical setup is often restricted, 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. The **TEACCH Program** provides employment services across North Carolina and utilizes a "dispersed" enclave model along with mobile crews and individual placements to meet the diverse needs of their constituents.

High Integration

Competitive Employment

Customized Employment

Supported Individual Placements

Enclaves or Cluster Model

Day Habilitation or Sheltered Workshop

Low Integration

Fig. 1. Degree of expected community integration as a function of day or employment program model.
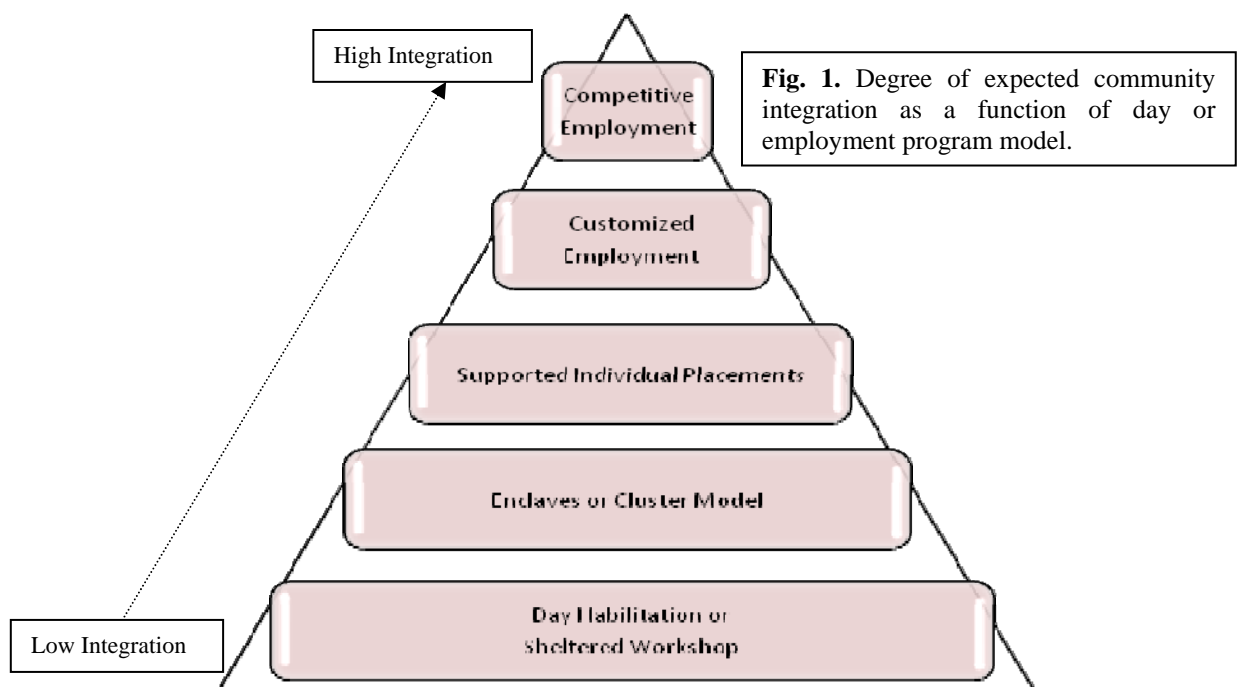
4. Mobile Work Crews

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 limited. In New Jersey a

number of local ARCs offer mobile crews including the **ARC of Bergen and Passaic Counties ARC** which provides mobile crews for janitorial services.

Employer Initiatives and Tax Incentives

Recognizing the potential of individuals with autism to be competent and productive employees, a number of large corporations (e.g., Walgreens®, Marriott® , Wachovia®, etc.) have established specific programs designed to recruit, train, and hire individuals with special needs. In addition to accessing this vastly under-utilized pool of workers, these corporations are able to take advantage of a number tax incentive programs designed to assist with some of the costs that may be associated with training and/or accessibility. These initiatives include the:

- Work Opportunity Tax Credit, which allows employers tax credits of up to $2,400 per person for hiring people with disabilities during their first year of employment;
- Small Business Tax Credit: IRS Code Section 44, Disabled Access Credit, which helps small businesses cover the cost of making their businesses accessible, up to a maximum benefit of $5,000 per person; and,
- Architectural/Transportation Tax Deduction: IRS Code Section 190, Barrier Removal, which allows businesses an annual deduction of up to $15,000 for expenses incurred to remove physical, structural, and transportation barriers for persons with disabilities at the workplace.

Please note that employment initiatives and tax incentives may change on an annual basis so please check with the US Department Labor before claiming any such deduction.

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5. Entrepreneurial Models

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) with ASD. The skills and interests of the individual[s] are used as the basis to form a corporation, the intent of which is to generate sufficient income to pay the salary of the individual and the support staff.   Entrepreneurial

models generally require the development of a governing micro-board, a small board of directors formed to support the corporation. The board usually consists of family members, support personnel, community members and, ideally, at least one member with experience running a business. As with any small business, start-up costs may be high but future earned income is generally expected to offset these early expenses. A challenge to the expanded use of the entrepreneurial model that there is no guarantee of short or long term profitability. Therefore investments may not be recouped and long term supports for the adult with ASD may not materialize.

B. 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. A variation on the day habilitation model is **Secure Employment** (Holmes, 1998) in which adults with ASD are 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 provides a "safety net" by which concerns such as job loss or difficulties associated with challenging behavior do not result in a loss of services.

C. Sheltered Workshops

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. Sheltered workshop may be a less desirable option for adults with ASD due to a 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 (Levy, 1983). In addition, sheltered workshops tend to function more as final placements for individuals with disabilities rather than a transitional service to a less restrictive employment placement as they were meant to be. The

sheltered workshop system has large numbers of persons with disabilities, isolated from more normalized daily events and interactions, working on repetitive tasks with limited reinforcement and supervision. This fosters dependence within a tightly supervised, non-therapeutic environment rather than towards encourages independence in the less supervised community at large (Gerhardt & Markowitz, 1993; Moore, 1994). Although still common, the appropriateness of the sheltered workshop for many people with ASD is questionable.

D. <u>Summary</u>

A number of viable day and employment service models for adults with ASD are currently available on a state by state basis. However, adults with ASD continued to be unemployed, underemployed, and even simply underserved at levels far greater than should be acceptable. 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 with ASD and their families.

VII. <u>MODELS OF RESIDENTIAL SUPPORT</u>

At some point in their lives the majority of adults with ASD will require some type of residential service or support. Some may require services for a limited amount of time while others may need such services throughout their lives. In either case the absence of such services can have significant, long lasting negative consequences for the individual and their family and, by extension, society at large.

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 states maintain waiting lists for services and in 1998 it was estimated that there were over 87,000 individuals with developmental disabilities in the U.S. awaiting residential placement (Parish, 2002).

"The current economic slowdown may well lead to significant cutbacks in services and supports for people with developmental disabilities [ ]. "Overall, the demand for community services is growing rapidly due to aging family caregivers, litigation promoting access to community services, the increasing longevity of persons with developmental disabilities, and the downsizing of public and private institutions. This growing demand is frequently unanticipated by federal, state, and local agencies, resulting in a crisis for families and state and local service delivery systems."

 David L. Braddock, Ph.D., Executive Director
Coleman Institute for Cognitive Disabilities
Source: http://www.aaidd.org/index.cfm

The majority of residential programs are funded through a combination of the HCBS Waiver with individual state support through their developmental disabilities agencies. Other sources of financial support can include grants from the Department of Housing and Urban Development (HUD) to renovate or purchase property, resident contributions via Supplemental Security Income (SSI), and family and community contributions. ***Contrary to popular belief, however, 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.***

A. <u>Introduction</u>

A variety of residential/housing models exist although not all models are available in all states. The description of a residential model mostly relates to the facility in which the adult with ASD lives, the number of people who live there, the intensity of staff support provided, and the level of community integration. 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 residential models cannot present the entirety of program options that may actually be available as part of that residential model. Current residential program models for adults with ASD include transitional models, supported living, supervised living, accommodated living, group home living (including teaching family model), farmstead programs, and Intermediate Care Facilities – Mental Retardation (ICF-MR).

B. <u>Transitional Models</u>

Transitional residential programs offer a relatively short-term (e.g., one month to two years) residential experience with the expressed goal of transitioning the individual back to their previous environment upon completion of the program. Transitional programs generally fall into one of three categories: 1) programs providing intensive, inpatient behavioral evaluation and intervention for individuals with severe behavior disorders, 2) programs providing an intensive life skills course of instruction for individuals who, upon completion of the program, are expected to live independently, and 3) college support programs.

1. <u>Intensive In-Patient Behavior Treatment</u>

The **Neurobehavioral Unit (NBU) of the Kennedy Krieger Institute** is a multi-bed inpatient program for the assessment and treatment of severe problem behavior displayed by some individuals with ASD and intellectual disability. Criteria for admission include the severity and/or intensity of aggressive, self injurious or disruptive behavior and is at risk for long-term residential placement. As this is a transitional program, individuals are placed at the NBU for a period not to exceed 6 months. As placement draws to a close, individual caregivers (e.g., parents and teachers) are trained to implement the developed interventions outside of the NBU. Intensive outpatient services are initiated at the time of discharge to help ensure a smooth transition from the NBU to the individual's home. Thereafter, the intensity of outpatient services varies depending on the needs of the patient and family.

It should be noted that while the overall number of adolescents and adults with ASD who may require intensive inpatient behavioral evaluation and treatment is small they remain a vastly underserved group of individuals with ASD. For those few programs that do exist, waiting lists are long and many of the necessary services are not covered by insurance or other funding sources leaving families responsible for large out-of-pocket expenses. The long term costs to society of failing to address the needs of these very complex individuals is significant and can include injury and lost work time for family members, psychiatric hospitalization for the individual in question, an overuse of psychiatric medication as "chemical restraint" and, worst case scenario, the institutional (and very expensive) placement of the individual with ASD.

2. Intensive Life Skills

Focusing on the other end of the autism spectrum, **The REACH Program** at Chapel Haven offers an intensive 24-month residential program that teaches the individual to negotiate all aspects of independent living. Most students who graduate from our REACH Program remain in New Haven after graduation.   Residents live, with a roommate, in a typical community apartment and are provided instruction and support in all life areas including cooking, cleaning, budget and finances, social competence, accessing and maintaining employment, sexuality and community safety. Upon graduation Chapel Haven offers supported living services (see below) to individuals who opt to live nearby (REACH is being replicated in Tuscan, AZ).

3. College Support

A percentage of individuals with ASD will, after graduation from high school, attend college. These individuals, most of who will have an Asperger syndrome (AS) or high functioning autism (HFA) label will generally require some type of ongoing instruction or support in order to successfully navigate the social and academic demands of college life (Harpur, Lawlor, & Fitzgerald, 2004).   These individuals are no longer covered under IDEA because they have graduate out of the public school system. Colleges and universities are under no obligation to provide the array of services to which the individual might have been entitled and accustomed prior to his or her graduation. While little exists in terms of active supports at institutions of higher learning they are, however, bound by both ADA and Section 504 of the Vocational

Rehabilitation Act to make reasonable accommodations such that otherwise qualified students with disabilities are able to actively participate.

The **College Internship Program (CIP),** for example, based in Lee Massachusetts provides a year-round residential program which focuses on the development of the social, academic, career and life skills associated with success in college. Specific services offered include tutorials, counseling, an academic liaison, study halls, career counseling, social skills instruction, employment skills class, job coaching and internship/job support groups. Residential students receive life skills support such as one-on-one cooking and cleaning instruction, food shopping and menu planning. The CIP is an independent agency and is not directly affiliated with any one college or university. Other programs, such as the **Model College Program of the West Virginia Autism Training Center** are designed to support students enrolled at that college or university.

C. <u>Non-Transitional Models</u>

Non-transitional programs can be understood as those programs designed to provide more long-term residential services to the adult with ASD. While active instructional programming is provided, the individual is generally not expected to leave the program after a specified period of time.

1. <u>Supported Living</u>

Supported Living programs provide residential services to adults with developmental disabilities who are able to live in self-owned or leased homes in the community. Among the core tenets of supporting living are that 1) everyone, independent of current skills sets, can benefit from supported 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.

Since supported living is directed by the adult with ASD, the responsibilities of the professional staff are highly individualized. Duties may range from helping the individual hire/fire staff or chose a housemate (if desired), to assistance in completing many of the common activities of daily living to, ultimately, becoming an active and participating member of the community. Because these may be life-long issues, supported living is not considered a transitional service and, in fact, is intended to be flexible in its delivery of services across an individual's life. 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 suited for individuals with an established repertoire of life skills and those who do not engage in significant levels of challenging behavior.

Previously a provider of more typical group homes for adults with autism, **Jay Nolan Community Services** began transitioning all their residential services to supported living more than a decade ago. This involved a structural reorganization of the organization and a philosophical shift in how residential services were best provided. Despite the challenges, Jay Nolan Community Services has become a respected provider of supported living services and currently works to support over 90 adults with ASD and other developmental disabilities to live and work in, and around, Los Angeles.

2. Supervised Living

Supervised living is a residential model designed to provide services to individuals with ASD greater with greater oversight and direction than might be provided in a supported living context but less than group home living. In supervised living the homes may be self-owned or leased. Although individual residences may be small (generally no more than one or two adults with ASD per residence) there may be a number of such residences scattered throughout the

apartment building or housing complex allowing for greater staff accessibility oversight.

Fig 2. As one moves from a more congregate or institutional placement to supported living the degree of individualization and community integration increase significantly.

Notably, 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. Headquartered in Philadelphia, **Autism Living and Working (ALAW)** provides supervised living with home ownership opportunities to adults with autism in and around the Philadelphia, Pennsylvania area. Focusing on each individual's personal preferences, strengths, deficits, and sensory-motor requirements ALAW works to provide the necessary residential accommodations and vocational supports to enable the person to participate more fully in work and life in the community. All accommodations are specifically tailored to meet an individual's needs and preferences across their lifetime.

3. Group Homes

With the onset of deinstitutionalization came the movement of individuals with ASD and other developmental disabilities from large, congregate care facilities to smaller, more typical homes in the community. Group homes exist in every state. They are small, residential facilities (i.e., actual homes) located in the community and designed to serve children and adults with ASD, intellectual disabilities, or other chronic conditions. 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.

AdvoServ is one such provided of group home living for individuals with challenging behaviors. It runs state-of-the-art behaviorally-based group homes in New Jersey, Delaware, and Florida.

Group homes recently have come under some criticism for their supposed lack of individualized programming, limited access to the community 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 with 6-8 residents and toward the development of smaller residences with 2-3prople and 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, it has been noted that positive resident outcomes coupled with reduced costs "speaks well" of the Teaching Family Model when implemented correctly (Schneider, et al, 1982). While time consuming, the Teaching Family Model does represent a useful, and potentially effective model (Fixsen, et al, 2007). The **Princeton Child Development Institute's Family Focus** group homes for adolescents and adults with ASD are based upon the Teaching Family Model and their decades of data would appear to support this conclusion.

4. Farmstead Programs

A **Farmstead Programs** is a residential model set within the context of a working farm. While isolated by nature farmstead programs endeavor to meet the complex needs of adults with ASD and other developmental disabilities through the development of individually designed instructional programs focused on farm living. 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 work along with staff at tasks relevant to the care and maintenance of the grounds and the farm.   There is often little in the way of community integration or community based-instruction and life skill instruction is generally provided relevant only to those skills associated with life within the farmstead community.   **Bittersweet Farms**, in Whitehouse, Ohio was the first Farmstead Program for people with ASD established in the United States and remains the most widely recognized model for this, very specific, category of residential services.

5. Intermediate Care Facility – Mental Retardation (ICF-MR)

The **ICF-MR** is a large, congegate 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.

6. A Model for Independent Real Estate Development

Given the complexities involved in the development, maintenance and effective administration of community residential services a number of innovative businesses have been developed to target specific stages in this process. One such business, **Hallmark Community Solutions (HCS)** is an example of this entrepreneurial spirit in support of a tremendous community need.

The mission of HCS is to provide innovative solutions to many of the questions regarding real estate finance, home ownership and architectural design in a way that promotes a sustainable supply of high-quality housing for individuals with special needs. Currently, HCS serves as the master developer for the Bay Area Housing Plan (BAHP), a collaborative initiative to provide housing for 240 individuals slated to transition from a state developmental center to the community. **As the master developer, HCS is responsible to initially purchase and develop each property prior to entering into long term lease agreements with agencies charged with the actual provision of residential services.** Ultimately these properties will be transferred to nonprofit organizations and the active involvement of HCS will terminate.

D. Summary

There exist a number of viable models of residential models that may be considered appropriate for individuals with ASD. 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, 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.

VIII. LIFE IN THE COMMUNITY – ADDITIONAL CHALLENGES AND CONSIDERATIONS

Adulthood is defined by more than just where one works and 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 ASD the quality of life they so richly deserve. Underlying all these challenges however, is the central concept of community acceptance. We are fortunate at this time to have a greater level of autism awareness and understanding among the community than ever before. This awareness, however, is based more on the challenges presented by autism than it is on the potential of people with autism to be active, engaged, employed, and contributing members of their community. So while programs and services in each of the following areas should be considered essential for adults with ASD, so should the promotion of community awareness in each of these areas if increasingly greater levels of community integration are to be achieved.

A. 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 far more dangerous situations such as what to do when lost or during a fire.** Therefore, it is not surprising that individuals with ASD are far more likely to be victims of abuse and exploitation than are their typical peers (Mandell, et al, 2005; Koller, 2000). This issue requires significant instructional and programmatic attention.

A number of educational programs such as the **Apline Learning Group**, in Paramus, NJ; the **Princeton Child Development Institute** in Princeton, NJ; and the **Virginia Institute of Autism** in Charlottesville, VA. incorporate evidence-based safety training instruction (e.g., responding to being "lost", privacy in the bathroom, stranger/friend differential) in their curriculum. Alpine Learning Group, in particular, has published some of its findings (i.e., Taylor, et al, 2004) in the peer reviewed literature. Across the age and ability spectrum, however, this is an area of ASD intervention in need of significantly more research and professional attention.

B. Transportation

Perhaps the greatest, system-based challenge to community integration for adults with autism, whether for employment, leisure, or daily living is the lack of accessible transportation options. Outside of urban centers, opportunities to access mass transportation are limited or, as in often the case, nonexistent. As such, the majority of adults with ASD must rely on provider agencies, family members, or paid community helpers for transportation. Even in more urban areas where "accessible" transportation services may exist, these services are primarily designed to address the needs of the elderly or individuals with physical disabilities. For example, San Francisco's **Bay Area Rapid Transit (BART)** System lists the following accommodations on their website:

> *"If you are blind or vision-impaired:*
> > *-Textured rubber tiles along the length of BART train platforms warn passengers that they are close to the platform edge. These tiles can be detected with a cane or foot.*
> > *-Train Operators announce the name of the next station as well as instructions for transfers.*
> > *-Service animals are permitted in BART stations and on trains.*
>
> *If you are deaf or hearing-impaired:*
> > *-Changeable message signs on the platform announce the destination of each arriving train.*
> > *-There is at least one Telecommunications Device for the Deaf (TDD) in each BART station.*
>
> *If you use a wheelchair or have limited mobility:*
> > *-All BART stations have accessible elevator service to all levels.*
> > *-There is level boarding from the platform to all trains.*
> > *-All BART cars have space to accommodate wheelchair users.*
>
> *For all passengers:*
> > *-All BART stations have public and white courtesy telephones at all levels that connect directly to the Station Agent.*
> > *-All BART cars have designated priority seating near the doors for seniors and persons with disabilities."*

Source: (http://www.bart.gov/guide/accessibility/index.aspx)

Thus, while public transportation systems generally provide reasonable accommodations for riders with physical disabilities, there is generally little attention to the accommodations that might be considered reasonable and appropriate for individuals with autism. Such accommodations must, minimally, include the provision of ASD specific training for employees of public transportation systems.

Further complicating this issue is the simple fact that where public transportation may be available, effective travel training is rarely provided by schools or adult programs due to time constraints and concerns regarding liability and individual safety. In every state, however, programs do exist designed to address this issue in terms of

accessibility/accommodation, instruction, or both. For example SEEC, a nonprofit agency located in Silver Spring, Maryland, works to provide individuals with developmental disabilities access to community-based transportation. A community access specialist, employed by SEEC, works to coordinate individual access public transportation including Metro Access, Metro Bus, Metro Rail, and Ride On. In addition, SEEC conducts travel training and assists with ongoing services as necessary.

C. **Vacationing, Leisure, and Recreation**

The provision of age appropriate and enjoyable leisure and recreation activities to adults with ASD can be a particular challenge to both families and community service providers. Truly appropriate leisure/recreation – for any of us – is defined along a number of complementary parameters. These parameters include having choice in terms of **Activity** (What the individual chooses to do), **Location** (Where the individual can engage in the activity), **Access** (What barriers might prevent the individual from engaging in the activity), **Duration** (How long the individual is able to participate in the activity), **Time** (When the individual wants to engage in the activity), and **Partners** (With whom does the individual choose to engage with during the activity). Using the example of golf, for it be considered an appropriate leisure activity for an adult with ASD he or she would have to, minimally, want to golf, be able to get to the course, have a preferred tee-time, and play with known and liked people for just as long as they wanted. The fewer preferred options that are available, the less enjoyable the experience will be and the less it will function as leisure. Given all this it would seem the provision of true leisure/recreation experiences to adults with autism is a highly individualized, idiosyncratic, and evolving process and a particular challenge for service providers.

The **Abilis Community Network Services** in Greenwich, CT has a leisure/recreation program that works to address this specific challenge by offering a wide array of leisure/recreation choices to the adults with ASD and other developmental disabilities who they serve. Activities are designed to meet individual needs and interests and may include a variety of accessible, community-based activities including, small social groups when appropriate. Individuals are coached to plan their own schedule of activities which may range from more self-contained, group activities to highly integrated, individualized options. Support in the community is often provided by community volunteers and members of local civic groups are trained and asked to

include Abilis adults in their regular schedule of activities. In some cases, overnight to week-long vacations are also offered and professionally staffed by Abilis.

Vacations can be a stressful, challenging experience for many individuals with ASD due to changes in routines, lack of structure, sensory overload, or even limited access to preferred foods. However, if properly constructed vacations can also be a time of excitement, enjoyment and relaxation for the same individual. To address this specific need, a number of small businesses (e.g., **Travel with Autism, Inc**.) have begun to offer customized vacation packages designed to provide a positive vacation experience to the individual with ASD and their family. As a new concept, its success is yet to be determined but this would appear to be a potentially beneficial service.

D. <u>Communities of Faith</u>

For many families the inclusion of their child in their community of faith is an important and very personal goal. As each person with ASD becomes an adult and establishes an identity outside of his or her nuclear family access to worship services may be an important facet of life. Minimally, participation in a community of faith can also provide access to regularly scheduled and structured social events developed around a predictable set of activities 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 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. However, national programs and resources do exist including The **National Apostolate for Inclusion Ministry** (http://www.nafim.org/) and the **Division of Community and Congregational Supports at the Elizabeth M. Boggs Center on Developmental Disabilities** (http://rwjms2.umdnj.edu/boggscenter/index.htm) both of which offer print resources and additional assistance.

E. Health and Wellness

While little is known about the interaction of ASD and aging, it is generally accepted that adults with ASD 1) tend to be fairly poor self reporters when it comes to health issues, and 2) as a group tend to be fairly sedentary. As such, concerns related to the long term health and wellness of adults with ASD should be at the forefront of any discussion of appropriate services. **Beyond Boundaries Fitness** (http://www.autismfitness.com/) is a web-based organization dedicated to providing exercise and wellness strategies for individuals with ASD. The mission of Beyond Boundaries is to make the best science and practionary methods for developing lifelong fitness available to parents, educators, and professionals working with the individuals with ASD.

F. Sexuality Instruction

Individuals with ASD 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. The question no longer can be *if* sexuality education should be provided, but rather how it will be offered. Koller (2002)

Aprogram at the **Cody Center,** a division of the **Stony Brook University Medical Center**, offers sexuality education to individuals with ASDand other developmental disabilities, ages 12 years and up. As a function of age, needs, and individual ability level, instruction may be provided in any of the following areas: differentiating between public and private; modesty; puberty; grooming and hygiene; abuse prevention; social judgment and responsibility; personal boundaries; dating; love and intimacy; menstrual hygiene; masturbation; childbirth; sexual decision making skills; birth control; sexual orientation; and sexual health.   Parents of individuals with more significant cognitive challenges receive education in teaching their children about sexuality, particularly emphasizing protection against coercive sexual activity, pregnancy and sexually transmitted diseases.

G. First Responder Education/Training

According to Dennis Debbaudt, one of the nation's leading authorities on the issue, research indicates that individual's persons with developmental disabilities, including a rapidly rising population of people with ASD, are approximately seven times more likely to come in contact with law enforcement professionals and other first responders than their typical peers. As individuals with ASD are likely to respond to such contact in unexpected, idiosyncratic and, at times, potentially threatening ways the effective training of first responders is a primary concern.

Recognizing this need, a number of local chapters of the **Autism Society of America** have either developed, or helped to coordinate, first responder training for their local police, fire, and emergency medical personnel. **The Autism Program of Illinois** offers state-wide first responder training through their network of regional and centers. On a national level **Autism Speaks** is expected to have their "*First Responder Tool Kit*" available sometime in 2009. Currently, an excellent source of information and training materials for first responders, individuals with ASD and their families can be found at the **Autism Risk and Safety Management** website run by Dennis Debbaudt (http://www.autismriskmanagement.com/)

H. Involvement with the Criminal Justice System

Professionals have long been aware of high rates of learning and behavior disorders among incarcerated youth(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 professionals started to discuss the very real potential for individuals with ASDto 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.

"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."

While there currently appear to be no programs focusing on the specific needs of individuals with ASD as victims, witnesses, suspects, or defendants within the criminal justice system, the **ARC of the United States** has been at the forefront of this issue for a number of years. In addition, state and county ARCs generally have programs or services designed to meet the needs of individuals with developmental disabilities who become involved with the criminal justice system. The ARC of the United States publishes a guide to issues and advocacy within the criminal justice system which can be found at: http://www.arcofkingcounty.org/guide/library/arccj.pdf.

IX.   CONCLUSION

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.   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 fend for themselves.   This is completely unacceptable.

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 H. Humphrey said:

For generations of adults with ASD and their families, this is a test we cannot afford to fail.

X.   <u>REFERENCES</u>

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XI.   RESOURCE LIST

Contact information for the programs or services mentioned in this report is listed below. Please note that inclusion in this list or in the body of the report should in no way be construed as an endorsement of the program or agency.

Adult Day Program/Employment-related Programs

ARC of Bergen and Passaic Counties
223 Moore Avenue
Hackensack, NJ 07601
Telephone: (201) 343-0322
Fax: (201) 343-0401
Website: http://www.arcbergenpassaic.org/

The ARC of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
Telephone: (301) 565-3842
Fax: (301) 565-3843
Website: http://www.thearc.org/

Eden W.E.R.C.s
A Member of the Eden Family of Services
One Eden Way
Princeton, NJ 08540
Telephone: (609) 987-0099
Fax: (609) 987-0243
Website: http://www.edenservices.org/contact_mstr.html

Division TEACCH
Chapel Hill TEACCH Center
CB #6305
Chapel Hill, NC 27599-6305
Telephone: (919) 966-2174
Fax: (919) 966-4127
Website: http://www.teacch.com/supportedemployment.html

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Residential Services and Supports

AdvoServe
28308 Churchill-Smith Lane
Mount Dora, Florida 32757
Telephone: (352)-383-3685
Fax: (352)-735-0407
Website: http://www.advoserv.com/intro.html

Autism Living and Working
1528 Walnut Street, Suite 815
Philadelphia, PA 19102
Telephone: (267) 322-5800
Website: http://www.autismlivingworking.org/

Bittersweet Farms
12660 Archbold-Whitehouse Road
Whitehouse, OH 43571
Telephone (419) 875-6986
Fax: (419) 875-5593
Website: http://www.bittersweetfarms.org/

Coleman Institute for Cognitive Disabilities
University of Colorado
3825 Iris Avenue, Suite 200
Boulder, CO 80301
Telephone: (303) 492-0639
Fax: (303) 735-5643
Website: http://www.colemaninstitute.org/

College Internship Program
17 Main Street
Lee, MA 01238
Telephone: (877) 566-9247
Website: http://www.collegeinternshipprogram.com/

Hallmark Community Solutions
1242 Market Street, 3rd Floor
San Francisco, CA 94102
Telephone: (415) 863-3036
Fax: (415) 449-6488
Website: http://www.hallmarksolutions.org/

Jay Nolan Community Services
15501 San Fernando Mission Blvd, Suite 200
PO Box 9604
Mission Hills, CA 91346
Telephone: (818) 361-6400
Fax: (818) 365-0522
Website: http://www.jaynolan.org/

Kennedy Krieger Institute (Neurobehavioral Unit)
707 North Broadway
Baltimore, MD 21205
Telephone: (443) 923-9200
Website: http://www.kennedykrieger.org/

Model College Program West Virginia Autism Training Center at Marshall University
One John Marshall Drive
Huntington, WV 25755
Telephone: (304) 696-2332
Website: http://www.marshall.edu/coe/ATC/modelcollege.htm

National Association of Residential Providers of Adults with Autism (NARPAA)
Website: http://www.narpaa.org/index.html

Princeton Child Development Institute
300 Cold Soil Road
Princeton, NJ 08540
Telephone: (609) 924-6280
Fax: (609) 924-4119

The REACH Program at Chapel Haven
1040 Whalley Avenue
New Haven, CT 06515
Telephone: (203) 397-1714
Fax: (203) 392-3698
Website: http://chapelhaven.org/che/programs_life_skills.html

Trinity Services
100 North Gougar Road
Joliet, Illinois 60432

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Life in the Community

Abilis Community Network Services
50 Glenville Street
Greenwich, CT 06831
Telephone: (203) 531-1880
Fax: (203) 531-9367
Website: http://www.abilis.us/index.htm

Alpine Learning Group
777 Paramus Road
Paramus, NJ 07652
Telephone: 201-612-7800
Fax: 201-612-7710
Website: http://www.alpinelearninggroup.org/

Autism Risk and Safety Management
Website: http://www.autismriskmanagement.com/

Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
Telephone: (301) 657-0881
Website: http://www.autism-society.org/

Autism Speaks
2 Park Avenue
11th Floor
New York, NY 10016
Telephone: (212) 252-8584
Fax: (212) 252-8676
Website: http://www.autismspeaks.org/

Beyond Boundaries Fitness
Website: http://www.autismfitness.com/

Cody Center
5 Medical Drive
Port Jefferson Station, NY
Telephone: (631) 632-3070.
Website: http://www.stonybrookmedicalcenter.org/codycenter/

Easter Seals
233 South Wacker Drive, Suite 2400
Chicago, IL 60606
Telephone: (312) 726-6200 (voice)
Fax: (312) 726-1494
Website: http://www.easterseals.com/

New York Center for Autism
477 Madison Avenue, Suite 420
New York, NY 10022
Telephone: (212) 759-3775
Website: http://newyorkcenterforautism.com/

Organization for Autism Research
2000 N. 14th Street, Suite 710
Arlington, VA 22201
Telephone: (703) 243-9710
Fax: (703) 243-9751
Website: http://www.researchautism.org/

SEEC
8905 Fairview Rd, Suite 200
Silver Spring, Maryland 20910
Telephone: (301) 576-9000
Fax: (301) 576-9008
Website: http://www.seeconline.org/aboutSEEC.html

SARRC – Southwest Autism Research and Resource Center
300 North 18th Street
Phoenix, AZ 85006

The Autism Program of Illinois
Training Center at the University of Illinois Chicago
1747 W. Roosevelt Road, Room 155
Chicago, IL 60608
Telephone: (312) 413-4624
Website: http://www.theautismprogram.org/

The Daniel Jordan Fiddle Foundation
P.O. Box 1149
Ridgewood, New Jersey 07451-1149
Telephone: 201-444-4141
Toll Free: 877-444-1149
FAX: 775-243-9847
www.djfiddlefoundation.org

Travel with Autism, Inc.
Website: http://www.travelwithautism.com/

UM-NSU Center for Autism and Related Disorders
Website: www.umcard.org

Virginia Institute of Autism
1414 Westwood Road
Charlottesville, VA 22903
Telephone: (434) 923-8252
Website: http://www.viaschool.org/

XII. RESIDENTIAL SERVICES SUMMARY

Model	Base Unit of Service	Direct Care Staff:Adult Ratio	Integration	Individualization	Funding Source
Intensive Inpatient Behavioral	1 adult	Very High Comprehensive Team Approach	Low to none	High	DD, Medicaid, Private Insurance
Intensive Life Skills	1 adult	1:2-6	High	High	VR or Private Pay
College Support	2-6 adults	1:2-6	High	High	VR or Private Pay
Supported Living	1adult	1:1-6	High	High	DD or Self Determination
Supervised Living	2-4 adults	1:2-6	Moderate to High	Moderate to High	DD or Self Determination
Group Homes	4-10 adults	1:2	Moderate	Moderate	DD
Teaching Family Model	4-8 adults	1:2 with Teaching Parents	Moderate	Moderate to High	DD
Farmstead	30+ adults	1:10 and higher	Low to Moderate	Low to Moderate	DD
ICF-MR	12+ adults	1:4	Low	Low to Moderate	DD

XIII. EMPLOYMENT AND DAY SERVICES SUMMARY

Model	Base Unit of Service	Staff:Adult Ratio	Integration	Individualization	Primary Source
Customized Employment	1 adult	1:1 with rapid fading	High	High	Blended*
Individual Placement	1 adult	1:1 expected to be faded	High	High	VR and/or DD
Enclave/Cluster	2-6 adults	1: 2-6	Moderate	Moderate	DD
Mobile Crew	2-6 adults	1: 2-6	Moderate to Low	Moderate	DD
Entrepreneurial	Variable	1: number employed	Variable	High	Self Determination
Day Hab/Secure	15+ adults	1:4 and higher	Moderate to Low	Moderate	DD
Sheltered Workshop	30+ adults	1:10 and higher	Low	Low	Varies – VR/DD/ income

* Many customized employment outcomes are supported by blending multiple funding sources such as funding to purchase assistive technology with additional training and ongoing supports being paid for by Vocational Rehabilitation and from a Plan For Achieving Self Support (PASS).