

Autism Society of America
Position Paper
on
The National Crisis in Adult Services
for
Individuals with Autism

A CALL TO ACTION

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Summary

The critical shortage of services for adults with autism is a daily hardship for tens of thousands of families in the U.S. who struggle to provide a meaningful and productive life for their loved one who has aged-out of school. Since 1975 when the Education for All Handicapped Act (now Individuals with Disabilities Education Act, I.D.E.A.) mandated a free and appropriate education for children with disabilities, parents took for granted their child had a firm and Congressionally mandated right to services. Many are stunned to learn that when their child leaves school, the mandate for services ceases.

There is now a national crisis in services for adults with developmental disabilities, especially residential services, and especially for those with autism. The most critical issue is woefully inadequate funding. We cannot allow another generation of our adult children to go without the vital services that any humane society knows is necessary for a life of dignity and worth.

This paper presents some strong recommendations and a call to action.

Introduction

Only slightly more than two decades ago these aged-out-of-school adult dependent children would have been cared for by a stay-at-home mother or other female relative. Today, however, these traditional caretakers are in the work force, contributing to the current norm of the two-income household. This trend has now merged with another: the expectation of parents whose children have been in special education all their school lives (through age 22) that society will also assist them with adult services as was done, since 1975, with educational services. Their children had a Congressionally mandated right to public education, and a strongly worded legislative support of a right to file grievances if parents felt they were not getting a free and appropriate public education.

These students leaving school no longer have a mandated right to services. Their parents now face several different and complicated systems, such as vocational rehabilitation, public and private agencies providing a variety of funding and services, the latter typically not addressing the needs of their children. Even more daunting is the intricate and cumbersome Medicaid system which is usually their only hope for assistance. Some lucky families will have a good case manager whose case load allows more help than a few phone calls. In almost all cases, meaningful case management services come only if an individual can get funding from a Medicaid Waiver slot. (More on this later.)

But for individuals with autism, it is not a matter of only referral. Often there is no appropriate program (especially residential) to refer **to** anywhere nearby, or even in a contiguous state.

There are roughly 25 agencies* in the U. S. who have highly specialized programs (especially residential) for adults with autism. These community agencies are committed to serving this population, but inadequate Medicaid reimbursement rates and resulting low salaries cause high staff turnover rates. Providing quality services is a daily struggle. Expanding to include more clients is difficult to impossible. Agencies report a constant stream of calls from parents crying (sometimes literally) for help for their child.

Unlike the nation's educational system, where daily, hands-on special education services are provided by teachers with university degrees in the field, no equivalent professional, hands-on staff with pre-service training is readily available in the autism field. Those few degreed staff have typically started working at an autism agency during their college years and stayed on after graduation until they can find a better paying job or move up in the agency.

A few universities around the U.S. offer even one course in autism. Only five, at this writing, offer more than one, such as "Introduction to Autism," or "Classroom Strategies in Autism." One state, West Virginia, offers a summer course for autism mentors (autism classroom aides). No undergraduate degree in autism is yet available, to the knowledge of this author.

As though things are not bad enough, all indications are that the prevalence of autism, especially among children, is on the rise. The California Developmental Services System reported (Kleffman, S., 2001) that during the 88 days from January 4, 2001 to April 3, 2001, 760

* The National Association of Residential Providers for Adults with Autism (NARPAA), founded in January 2002, comprises most of the U.S. agencies providing these services. For information, go to www.NARPAA.org.

new cases were professionally diagnosed with DSM IV* autism. These new cases represent an increase of 107 more children than reported in the previous record high for a quarter. The report states that:

Autism now accounts for an unbelievable 37% of all the new cases coming into the California Developmental Services System ... These reports do not include any autism spectrum disorder such as PDD, NOS, Asperger's, Rett, Fragile X ... [usually stated as PDD-NOS].

Until the early 1990s, autism was said to be a rare disorder, approximately 4 per 10,000, or 1:2500.

A study by the Centers for Disease Control and Prevention (CDC, February 9, 2007) reports a prevalence rate of 1:150; **however**, it counted **only** children aged 8 years.

For adults with autism, we still have no official prevalence rates. (See Epilogue for more discussion.)

This growing number of individuals with a devastating and crippling disorder is no less than a public health crisis which needs immediate and serious attention at the highest levels of government and society.

Historical Background

Before we can propose a solution to the problems, it is important to understand how much has been accomplished in the past and what the present situation looks like.

Throughout the country, adult services for individuals with developmental disabilities (DD) are funded mainly by the Medicaid** Home and Community-Based (HCB) Waiver program, which provides federal funds to states, with a state match. The ratio of match depends on the economy of each state. In West Virginia, for instance, the match is approximately 25 cents in state funds for every 75 cents of federal funds. In New York, the match is near 50 cents state funds to 50 cents of federal funds.

* *The Diagnostic and Statistical Manual* is published by the American Psychiatric Association and has become the standard document to define autism and other mental disorders. This is their fourth edition.

** Medicaid is Title XIX of the Federal Social Security Act.

The term “Waiver” came about in 1981 when the HCB Waiver was authorized by Congress as the result of a strong and nationwide movement for community-based services. This legislation followed a decade-long series of high profile and successful class-action court cases against mental institutions, beginning with the impact of Wyatt V. Stickney (1972), in Alabama. A patient named Wyatt died after attendants deliberately inserted so much fluid (via enemas) into his intestines that they ruptured. The case alerted the nation to the ongoing and egregious violations of civil liberties taking place in many state (and other) mental facilities. This effort was also supported by the tireless advocacy of parents and their professional colleagues in the field of developmental disabilities, as well as many young lawyers who threw themselves into winning these landmark court cases.

Prior to the 1980s, state and federal funds for individuals with DD went only to state institutions (mainly state “hospitals” for mentally ill or impaired). If a family requested assistance, their only choice was placing their loved one in a state institution. There were almost no community services except a few private schools or day programs for individuals with mental retardation. The staff were not trained or experienced in working with the unusual (and often severe) behaviors and highly challenging learning styles of people with an autism diagnosis. Spaces were limited and anyone presenting with a diagnosis of autism was often not welcomed, or refused admission.

In 1974 a directory of services was published by the National Institute of Mental Health (NIMH) entitled *U. S. Facilities and Programs for Children with Severe Mental Illnesses - A Directory*, 1974. (See References.) The following excerpts from the preface demonstrate the state of affairs (p. v):

There is a rising social consciousness about the strange, tragic and severely handicapping mental illness [autism was then still classified as a mental illness] of early childhood. But there are still pitifully few services (and still fewer appropriate services) available anywhere at any price.

and

Although the growing list of facilities is heartening, we caution parents to read the entries carefully. If, for instance; a child’s label is autistic, he may not be eligible--even in many state mental hospitals with a children's unit; or, even if eligible, there might be a quota for children with this diagnosis.

The 1977 edition of the directory noted (p. v):

The major change is for a happy reason. Public school programs are proliferating ... While it is true there are ... few such programs in the country, the sudden growth from zero a few years ago to 40 new classes this year in Ohio alone is exciting.

And importantly,

Unfortunately, there is yet no official way to evaluate the programs in this directory. Parents (and a growing number of caring professionals) are still very much on their own to make judgments about the quality of a specific facility.

This last issue--evaluating a facility--will be discussed later in this paper.

When federal Medicaid monies became available to serve people with DD in institutions, many states “Medicaid” these hospitals* by setting up services which would meet the new federal guidelines. No longer would these funds support only custodial care. “Active treatment” became a top criterion for programs. There was a new designation called Intermediate Care Facility for the Mentally Retarded (ICF/MR). Before that, federal funding to states had been provided for individuals without mental retardation in skilled nursing facilities, called Intermediate Care Facility/Skilled Nursing Facility (ICF /SNF). The main criterion for services was that without them the individual was at risk of institutionalization.

Much of the bias one hears, even today, against ICFs and group homes, was generated by the development in the 1980s of large ICFs/MR, (congregate settings) housing several hundred or more residents. Some, called “group homes,” housed 20 or more. These days an increasing number of providers already operate small (three person) group homes, but the stigma is hard to shake.

Because these ICFs/MR were first set up at state hospitals and are (or were) in large institutions, they were based on a medical model, which typically have on-staff physicians and nurses, occupational therapists, physical therapists, sometimes even dentists. This explains the requirement in Medicaid's Home and Community Based Waiver program to have these professionals attending Individualized Program Plan (IPP) meetings and signing the sign-off sheet as though they were down the hall and available for meetings. In a truly community-based program, clients are served by health professionals in the same way as people without disabilities are served--at professionals' private offices, scattered around our communities.

In order for a state to receive federal HCB Waiver funds, it must provide the federal Health Care Finance Administration (HCFA) with an acceptable state plan. These plans vary from state to state, so it is important that families, professionals and advocates know what is in their own state plan, which is public information. Once HCFA approves the plan, the state must apply for a renewal periodically (e.g., every 3-5 years). Amendments can be requested at any time.

As the community integration movement grew, Congress was asked to waive some of the Medicaid funds going only to state institutions so that services could begin in community-based settings. That Waiver legislation passed in 1981 and the program has grown exponentially since then. In fact, at least nine states--Alaska, Hawaii, New Mexico, West Virginia, New Hampshire, Vermont, Rhode Island, District of Columbia, Minnesota-- have closed down all their institutions for people with DD (Braddock, 1998), almost always as a result of successful consumer-driven class action court cases. Community integration is firmly in place and seems here to stay.

* The term “hospital” was deemed a more politically correct term than “asylum” or “home for incurables,” as was common before c. 1950.

At first the HCB Waiver was available only to individuals who were in institutions so they could return to their communities. The first group to receive these funds was patients with “breathing problems.” Later, people with physical disabilities were included. In 1987, the funds were opened to people with mental retardation, and shortly thereafter to all with developmental disabilities, whether or not they had ever been in an institution. Again, the main criterion for eligibility was risk of institutionalization if they did not get these services. Also, an individual must require the intensity of training and support that is received in an ICF/MR setting.

Today the major funding source for DD services in community-based settings comes from the Medicaid HCB Waiver program. Depending on a state’s plan, the funding is based on consumer medical needs (not family income*), provides individual case management, promotes choice, mandates careful documentation, provides most medical costs (via a Medicaid card), covers **residential** costs as well as in-home training and/or respite, and makes parents/guardians an equal member of the Interdisciplinary Team (IDT), which develops the Individualized Program Plan (IPP).

BUT, unlike the mandatory services under I.D.E.A.**, the Waiver is funded for only a limited number of eligible individuals, so **eligibility does not provide entitlement**.

States now have embarrassingly long waiting lists. It is not unusual for heavily populated states to have 15-20,000. Too often, there is little or no reasonable movement toward additional Waiver slots for funding the needed services. One state recently froze all ICF/MR and Waiver funding for several years, which spawned a class-action court case against it. The state’s Department of Health and Human Resources and many other states are in litigation, a major issue being entitlement and lack of movement of people off waiting lists into community services.

Advocates in some states boast having closed all their DD institutions, and though that was a historic, good, and important accomplishment, many of these advocates dropped out of the picture after their victory and did not keep pressures on federal and state lawmakers and agencies to provide permanent and adequate funding for community services. With the safety net of institutions gone (such as they were/are), these and other states often have no real crisis services. When a family can no longer handle their relative at home (for example, because of no or inappropriate services, divorce, death of a spouse, illness, old age), negative behavior escalates, people and property get damaged, the use of psychotropic drugs increases and, not uncommonly, physical restraints are used. At this stage, clients--especially those with autism--are too often abused and injured. Some have died.

* For Medicaid services, a consumer--of any age--may not have an annual income over \$2,000.

** The original legislation in 1975 was titled “Education for All Handicapped Act.” In 1991, the name was changed to “Individuals with Disabilities Education Act, (I.D.E.A).”

In a behavioral, out-of-control crisis, individuals--including children--with autism can be scary. Without well trained, experienced staff or caretakers, the situation can quickly grow into a full blown confrontation.

Typically, the person with autism loses. Because half of individuals with classic autism* do not speak or have limited language, they cannot express themselves in ordinary ways. The constant high level of anxiety so characteristic of autism makes "getting the words out" even harder in tense situations. An experienced staff or caretaker would be more likely to recognize the source of the problem and know how to help the client to get himself back under control.

Here's an example, compiled from several articles in various publications in Nashville, Tennessee. (See E-mail References.)

In April, 2000, an agency providing HCB services to individuals with DD assigned a new staff to a 32-year-old, nonverbal man with autism. This new staff, a woman with a three year old, had been recruited and hired with the understanding that she could take her child along when she took the client on community outings. There had been some brief training in which she was told that if the client got upset (he had had aggressive episodes in the past which were noted in his record), the "treatment" was to take him for a walk.

On the second outing with the client, she took him and her child to a mall store where the client became agitated. (It is well known among people who know autism that hypersensitive hearing and anxiety around crowds or noise is common in autism. His record noted that crowds bothered him.) The staff was able to get the client back to her van. When he started hitting her child, she put him out of the van and locked the doors, but he began to pound on the vehicle. Now panicked, and unable to reach her supervisor, she called 911.

The police came, and during their effort to restrain the client, he hit an officer. He was then handcuffed and prone on the parking lot. He vomited, stopped breathing, and died. The cause of death was described as "situational asphyxia." The coroner's office said he died from a heart condition. (A class action court case, filed by his parents, is in progress.)

The News Channel 5.com (May, 2000, Nashville) report says:

(The client) often spent weekends with his sister, who lives in Nashville, and was able to sit in church on Sundays without much fidgeting, his father said.

* Individuals with less disabling Asperger's Syndrome are more able to fit into normal society. Their language skills are relatively good and their social deficits not as severe. Because they are not as recognizable as classic cases, many do not get a diagnosis of autism until later years. Most need considerable support, however.

A health reporter for The Tennessean, writes (Snyder, 5-7-00):

To some experts, (the client's) death illustrates the need for more careful monitoring and training to caregivers.

The Metro Police Department does not train its officers on how to deal with autistic people. Advocates for autism sufferers said (the client) might be alive today if officers received autism training.

Parents hearing stories like this know all too well how easily the anxiety in their child (especially their adult child) can escalate and how quickly unknowing caregivers will resort **first** to the most dangerous interventions. These parents, knowing that few appropriate services exist, are desperate to find a provider who has expertise in working with their son or daughter. It is not uncommon to find there is not one such provider in their state.

Providers, particularly of autism-specific services, have extremely limited financial* ability to develop appropriate long-term or crisis programs, which are expensive. Few families can afford these high cost services. And no insurance company covers the five-to-six figure annual expenses of long-term care. Medicaid Waiver is by far the major funding source, but the amount is woefully inadequate to serve most people with autism who need it.

Parents are desperate. Aging caretakers (often single mothers, often living alone with their middle-aged child), knowing how difficult it is to adequately care for an adult with autism, are often prisoners in their own homes, with little or no relief in sight. They know how easy it would be for untrained staff to be upset at the highly unusual behavior and poor communication skills of their son or daughter, and how easily abuse can occur. They are leery about placement with a provider if they can't really trust the staff with their loved one--especially if there is no one specifically trained and experienced in autism. After aging out of school, adult sons and daughters with autism typically either sit at home (and need a caretaker) with no programs, or participate in those which poorly serve their unique needs.

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Providers of DD services nationwide are currently experiencing a critical shortage of staff, due largely to low reimbursement Medicaid rates. Several states are in litigation about low pay for direct care staff. Other states' legislatures have in the last few years appropriated funds specifically for direct care staff.

Another major problem for individuals with autism (who usually qualify as eligible* for Waiver), is that typically ICFs/MR and group homes in the U.S. are programmatically and structurally designed for individuals with mental retardation, and **not** for autism. Most of these services do not have staff trained and experienced in autism and are generally at a loss when trying to handle the unusual language, cognitive, behavioral and social deficits of autism. If staff are ignorant of successful ways of dealing with these deficits, behavior problems are likely to be dealt with in a punitive manner which can quickly become severe and dangerous--even lethal, as seen above. It is at that point that parents are often called to come get their child or adult because "he doesn't fit our program."

Once enrolled in the Medicaid HCB Waiver, the guidelines provide basically a zero-reject service, but if a client is out of control, an understaffed agency not skilled in working with autism's severe behaviors can discharge a person who presents a significant challenge. ("He is a danger to himself or others," or "Our program is not set up to treat his condition.") It is easier and less expensive to discharge the hard-to-manage client than to retrain, supervise, monitor and support staff for people with autism.

Reimbursement rates are typically low, so providers naturally gravitate to serving clients with less intensive needs than those with autism. When rates are the same for all clients, it makes more business sense for providers to have 1 staff to 4 clients than 1 staff to 1 client, as is needed so often when the diagnosis is autism and a highly individualized program is critical. This is especially true for residential programs, where a client's family can't as easily be called to come get their son or daughter who is "acting up" as happens in some day programs and schools when the client/student is still living at home, close by.

In addition to low reimbursement, today's economic climate with its low unemployment makes it extremely difficult for providers to recruit and retain quality direct care staff. High turnover in direct care staff is a worrisome current trend throughout the United States. One large northeastern state recently reported a rate of 80 percent. This in turn drives up costs for recruiting,

* Currently, individuals with Asperger's, who may also have a diagnosis of Pervasive Developmental Disability (PDD), have a difficult time qualifying for the Medicaid HCB Waiver. They typically have relatively good speech and more social skills than classic cases of autism, which may make them ineligible because they may not meet the Medicaid HCB Waiver criteria for ICF/MR level of care.

hiring and training for which agencies get no* reimbursement. The constant changing of a large percent of staff is disturbing and can be destabilizing, especially for individuals with autism who have a high need for a consistent and predictable environment and staff who understand their individual blend of peculiar characteristics. Without proper supports, people with autism may not continue their personal growth--or worse, may lose the skills they and their caretakers have worked so hard to acquire.

Principles for Service Provision

In order to increase quality and quantity of post-school adult services in the major life areas, these individuals must have supports which:

1. Treat all clients with dignity and respect.
2. Provide for the health** and safety of clients, contribute to their well-being and happiness, inspire personal growth, and recognize the uniqueness of autism. In addition, these supports offer diverse and individualized choices in areas such as spiritual, recreational and social activities.
3. Make all caretakers, including providers, advocates and family members, accountable.
4. Provide access to the most normal and the least restrictive social and physical environments consistent with her or his needs.
5. Provide opportunities to pursue meaningful employment, which would include access to job coaches as needed.
6. Provide services in individuals' communities-- including rural community settings, such as farms, ranches--in order to continue and nurture family and community ties.
7. Base progress on outcomes, such as defined by the Accreditation Council. (See appendix.)

* The HCB Waiver does reimburse costs when staff is given client-specific training, usually after the basic training.

** Health services would include not only primary health care but so-called ancillary services such as behavior support, OT, PT, or speech therapy, which are often basic needs in autism.

8. Support families as they face autism's unique challenges and help them define their new role when their child transitions into adult services.
9. Promote autism-specific pre-service education with appropriate training for professionals and para-professionals for **adult** services, especially in community settings.
10. Promote community awareness and education about Autism Spectrum Disorders.
11. Promote research into service provision to identify long-term, comprehensive (especially residential, 24-hour) programs which make significant progress with adults, and why. Then, disseminate the information and provide funds for training nationwide.
12. Have adequate funding so the above can be accomplished for all adults with autism, not just the few who are fortunate enough to make the list of approved Waiver slots. (For example, make Medicaid HCB Waiver an **entitlement** to services.)
13. Consistently provide services based on best practices.
14. Provide a system of accreditation which acknowledges the intense and long-term effort needed to provide quality, autism-specific services and outcomes.

Needs and Recommendations

I. Residential

By far, most individuals with autism live at home with their families who, typically, want them there as long as possible or feasible. The following are some of the main ways residential services can be provided.

A. In-home support

1. Assist families who want to keep their adult son or daughter at home. Depending on need, services would include activities such as:
 - a. Training clients in self-help skills which would include toileting, shaving, personal hygiene, showering, making the bed, dressing, preparing meals or doing household tasks before leaving home for the day, or assisting them with these activities when they return home from employment, day programs or other daytime activities. In the HCB Waiver program, training in these self-help skills is called "residential habilitation."

- b. Accompanying client and training during community activities like grocery shopping, banking, buying clothes, walking, bicycle safety, going to the library or attending religious services, and other activities to increase adaptive behavior skills. The Waiver program calls these activities “day habilitation.”
- c. Respite for the family, in-home or out-of-home so they can have some time, for example, with their other children or family members, or have dinner with friends, go to a movie, go on a trip. Some families use respite services for events such as surgery or childbirth. In most states the HCB Waiver program provides respite, usually the most sought-after service requested by parents and families.
- d. Companion attendants for those such as individuals with Asperger’s who usually don’t need intensive care, but need a support person for some parts of their lives. This might include help in learning household skills for independent living or helping with relationships. These might also include learning how to be interviewed or interacting appropriately with housemates, fellow students, neighbors, employers or family. Some need attendants* in order to take technical, vocational, or higher education classes. This could include help with class schedules, taking notes, or negotiation with instructors for homework assignments or test taking.

B. Out-of-home placement, 24-hour care.

These services should be in the least restrictive settings which are feasible for normal community life--which could include farm or ranch settings.

- 1. Group homes of four or less with adequate number of staff who are well-trained, supervised, monitored and supported.
- 2. Apartments, or condos, with support staff as needed, including appropriate monitoring and support of staff by well-trained, experienced supervisors.
- 3. Access to home financing for individuals (or their families) who choose to live in their own home.

II. Vocational/Supported Employment

People with autism don’t need wheelchairs, artificial legs, or a guide dog. Their prosthesis is people. Many--even most--need job coaches in order to be employed in integrated work settings. Staying on task, having appropriate work-related behavior (not making loud yawning noises, responding properly when approached by others, not spending 20 minutes in the restroom washing hands because of obsessive/compulsive behaviors, not engaging in loud

* Other terms are “mentor,” “companion,” “resource,” or “aide.”

self-talk, managing anxiety) are typically the major issues with which a well-trained job coach can assist someone with autism or Asperger's to become a good employee. Once they are comfortable in the job, they often receive accolades from employers.

It is important that clients' interests are taken into consideration when looking for employment. For instance, someone fascinated with numbers and who can quickly spot a one-digit mistake on a page full of numbers might make an excellent data entry employee at a bank or a finance department. Someone with perfect pitch might be a piano tuner. Someone who is nonverbal and likes trains might work at a train station.

- A. Job coach services, also called supported employment, must continue as long as needed, must be highly individualized, and not restricted to a specific job or location. Some states' Division of Rehabilitation provides time-limited services. These services are also available under the HCB Waiver, but Waiver is not yet an entitlement and may not be included in a state's plan.
- B. Job-finding services must be an integral part of supported employment services.

III. Case Management or Service Coordination *

This service provides linkage and referral as well as assistance to clients and families which ensure accessibility to needed supports. It focuses on activities which establish and monitor life-long services. It provides accountability and continuity of services which promote meaningful choices, in a community-integrated environment.

- A. Major responsibilities of the case manager include:
 - 1. Assessment
 - 2. Linkage and Referral
 - 3. Advocacy
 - 4. Service Planning
 - 5. Monitoring quality of life, health and safety
 - 6. Crisis response planning
 - 7. Providing clients, their families and/or their legal representatives with information about their rights and responsibilities

* These terms are currently used synonymously, but the latter is considered by some to be more politically correct. The first term will be used in this paper.

B. Responsibilities of the Case Management Agency

1. Provide a reasonable case load* so case managers can do their jobs adequately.

In autism, service needs are often intense, therefore a knowledgeable, accessible case manager is critical to helping clients and their families with appropriate service provision.

IV. Accreditation

There needs to be a program of accreditation which is sensitive to, and knowledgeable about the special issues facing providers of autism-specific services to adults with autism--especially residential services.

Families or legal representatives want a national, rigorous and appropriately qualified standard of service that will assist them in judging the quality of programs in which they place their loved ones.

These days, parents with adult children have very little choice of providers--appropriate or otherwise. Because of the need for intense staffing and accompanying high costs of programs, multiple choices are not likely to be available to most families in the immediate future.

But, a nationally recognized set of standards** designed specifically for this population would go a long way to help parents know what to look for and provide focus for their (and their professional colleagues') advocacy efforts.

Also, specially developed standards of accreditation for autism would assist state and federal government agencies (as well as legislative and judicial entities, caretakers and service providers) to establish guidelines, regulations, and levels of funding necessary to provide appropriate services to adults with autism.

Epilogue

The Autism Society of America, in recognition of the critical shortage of services for post-school adults with autism, adopted this position paper in 2001 during their annual meeting in Pittsburgh, PA.

You are reading an updated version prepared in May 2007.

* Providers of case management services for people with DD typically depend solely on their state's MR/DD Medicaid funding. This brings us back to Item #12 under "Principles of Service Provision" (p .11) which addresses adequate funding.

** See Standards of the National Association of Residential Providers for Adults with Autism at www.NARPAA.org.

Considering that most of these adult individuals are living in their family homes and assuming that approximately three-to-four family members are significantly affected (including, for example, not being able to work--or missing work--because of caretaking responsibilities) by their relative's autism, we are speaking of a large number of citizens.

The only current official figures on population of people with autism are for **children**.

The U.S. Centers for Disease Control and Prevention (CDC MMWR, February 9, 2007) reported the "...approximate average of one child in every 150 is the prevalence among **children** (emphasis added) aged 8 with a diagnosis of Autism Spectrum Disorder (ASD)." These children were born between 1992 and 1994. Based on research at 14 sites in the U.S. the report says, "This ASD prevalence data...provides the most complete information on the prevalence of ASD in the United States to date."

These children will be 22-year-old adults in 2014 and 2016. Based on Census Bureau population predictions*, there will be (assuming the 1:150 prevalence rate does not go up or down), approximately 1,495,264 adults with autism in the United States.**

Since there is no such current prevalence study for **adults** with autism, for them we are left to extrapolate. However, we have only to add the 8-year-olds in the 2007 study to the many uncounted thousands who are adults now. The figure--and cost to society--is staggering.

In numerous studies comparing levels of stress in families caring for individuals with a variety of developmental disabilities, autism invariably ranks highest, or very high, as a stressor. Many families and caretakers are often at a breaking point. They are typically faced with round-the-clock, 24/7, eyes-on, lifetime vigilance for most adults*** with autism.

Because most (three out of four) individuals with this disorder are male, they are often quite strong, as well as aggressive, especially if there is no ongoing appropriate behavioral training and support. This is not to underestimate the strength and aggression of adult females when they are anxious and/or out of control.

Also, once these family caretakers can no longer function, then what? Reverse the years-long, hard-won deinstitutionalization trend which began in the early 1980s? Build new and larger institutions?

What David Braddock (1999) wrote remains true today:

It is an unfortunate reality that many families' caretakers must die before the disabled relative for whom they are caring can receive service from publicly financed institutions. (p.60)

* Source: U.S. Census Bureau, 2004, "U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin," <http://www.census.gov/ipc/www/usinterimproj/>.

** It is generally believed the rise in diagnosed cases of **children** began in the late 1980s and early 1990s.

*** Individuals with Asperger's Syndrome, the higher-functioning end of the Autism Spectrum Disorder, typically do not need eyes-on care, but most do need significant support to negotiate their social and employment world.

Our nation has done well and can be proud of what we have accomplished in the field of education for disabled children under school age (22). There are still many problems to be addressed, but it basically a good system.

Now, however, we must address the severe shortage of services to adults--and their caretakers--in this country. It is a national crisis. It will take an immense effort, at a high cost--of funds and human energy--to fix what is so poignantly wrong. It can be done.

Dr. Eric Schopler* once said that a nation has three choices:

1. Do what's right. (Provide appropriate services.)
2. Do as little as we can get by with. (Custodial care.)
3. Do what Hitler did. (Dig a big ditch.)

As parents, families, and professionals in this field, do we have the will to do the first?

If so, we must build on what we already have, which is more than any nation in the world, and continue to work for what is right, laboring into the night, if necessary.

THE END

* Founder of TEACCH in North Carolina; indefatigable and lifelong advocate for people with autism and their families; one of the most prominent professionals in the autism field, beginning in the early years. He died in July, 2006.

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for
2001 Original Paper

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Glossary

ASA	Autism Society of America
ASD	Autism Spectrum Disorder
Asperger's	One of the ASD, typically with less severe life-threatening characteristics. Named for Hans Asperger of Germany who wrote about it in 1944, one year after the first description by Leo Kanner, 1943.
Case Management/ Service Coordination	A professional who assists parents/families/clients in finding appropriate services and helps with follow-ups.
DD	Developmental Disability or Disorder
DSM IV	Diagnostic and Statistical Manual, Fourth Edition Published by the American Psychiatric Association
EHA	Education of the Handicapped Act, Public Law 94-142, mandating free and appropriate public education of students with disabilities
HCB	Home and Community Based
HCFA	Health Care Finance Administration, the federal office that oversees Medicaid
ICF/MR	Intermediate Care Facility (for the) Mentally Retarded
IDEA	Individuals with Disabilities Education Act, the new name given to EHA, in 1991
IPP	Individualized Program Plan
LOC	Level of Care
OT	Occupational Therapy (or Therapist)
PDD	Pervasive Developmental Disorders, an autistic-like category, on the autism spectrum, not as severe as classic autism, usually used for children.
PT	Physical Therapy (or Therapist)
Waiver	A Medicaid program established by Congress in 1981 to waive some of the federal Medicaid funds going only to state institutions and make the money available for community-integrated programs.

Autism Society of America
Plan of Action to Address
The National Crisis in Adult Services
For Individuals with Autism

July 2001

Adopted July 17, 2001 by ASA Board of Directors.
Adopted July 20, 2001 by Membership at ASA Annual Meeting (San Diego, CA)

1. Establish an entitlement to free and appropriate services to adults with developmental disabilities (DD), especially those with autism, in the least restrictive, community-based setting.

Begin initial funding and services for those most in need, especially those at risk of losing current residential or program placement.

2. Fund and implement adequate research to identify and disseminate information about current best practices. Develop a national and enforceable standard for government-supported services.
3. Establish, nationwide, new funding for appropriate pre-service and in-service training for professional as well as direct care staff.

Enhance funding levels of pioneer agencies currently recognized for providing appropriate services and training.

4. Establish choice of services:

Residential

Services in natural family home (day or residential habilitation)

Services out of home (24 hour)

Small (e.g., three-person) group homes, apartments, or condos

Clients' own homes, apartments, condos, etc.

Respite

In home/Out of home

Case Management

Supported employment

Crisis services

Family support

5. Establish choice of service providers.
6. Establish accreditation of autism-specific services (day and residential) for adults with autism.