
The New Jersey Center
for Outreach and Services
for the Autism Community (COSAC)

**Meeting the Needs
of Adults with Autism:**

A BLUEPRINT FOR THE FUTURE

October 2006

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Introduction

For most parents, their child's 21st birthday is a time for celebration and launching them into a meaningful adulthood. This is not the case, however, for most parents of young adults with autism. As the entitlement to an appropriate school program comes to a close at age 21, young adults with autism are still in desperate need of highly specialized, intensive supports to live, work and enjoy life in the community safe from harm. Many adults with autism have needs that far exceed the resources available to them. New Jersey's service system for adults with developmental disabilities has not been responsive to the critical needs of adults with autism.

Adults with autism and their families are in crisis.

Sam is a 34-year-old New Jersey resident with autism who needs a place to live. For the last 14 years, he has been on the state's waiting list for residential services. His aging parents are desperately trying to plan a future for him when they are gone.

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Jeanne is a 21-year-old woman with autism. For 18 years, she attended a school program where she learned important life skills. But now that she has graduated, and for the foreseeable future, she spends her days idly sitting at home. Even worse, she now has frequent outbursts of self injury, biting her arms and hands. She has begun to throw things and has destroyed property and broken windows, all behaviors that did not occur while she was in her school program. Because Jeanne has no place to go during the day, her mother left her job to stay home to care for Jeanne, leaving the family on one income.

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Matthew is a young man with autism who has excellent computer skills and a strong work ethic. Because of his significant social and communication deficits, he is not able to secure a job. He needs specific work-site supports, but the waiting list for those services is long. He has been in several other programs for adults with disabilities, but they were not appropriate for him. He is now home with his parents.

These scenarios typify the state of life for many New Jersey adults with autism and their families. This report details the recommendations necessary to address the many unique and unmet needs of this population.

Executive Summary

According to the New Jersey Division of Developmental Disabilities, “the number of people with autism or a related disorder who are eligible for Division services in a community setting has increased 186% since 1999, increasing from 2,108 in 1999 to 6,021 people in 2006.”

The service system for adults with autism in New Jersey is in crisis. It is unable to respond to the current need. Immediate and proactive steps must be taken. According to the New Jersey Division of Developmental Disabilities, there has been a 186% increase in the number of people with autism applying for services since 1999.

On April 27, COSAC convened an historic gathering of more than 50 stakeholders from the public and private sector including parents, service providers, planners and others to develop a blueprint to help guide the State of New Jersey in serving adults with autism. The group generated nearly 30 findings and more than 80 specific recommendations.

Findings fell primarily in five key areas:

1. Planning: The State of New Jersey needs a proactive strategy to meet the needs of an increasing number of adults with autism.

2. Funding: Local, state and federal funding sources must be maximized. Fiscal support for services must be flexible, sustainable and diversified. Funding levels for programs and mechanisms for the assessment of individual funding must adequately consider the unique, complex and shifting needs of adults with autism.

3. Service Delivery System: The adult service system must be integrated, seamless and transparent to users; it must encourage decision-making on the part of families and consumers. The State of New Jersey must establish a system for the coordination and dissemination of accurate information on the support needs of adults with autism.

4. Staffing: Adequate numbers of direct care staff who are well-trained and familiar with behavioral teaching is essential.

5. Specialized Services: There is an urgent need to develop more specialized services for adults with autism in all areas of the service delivery system including: in-home and family support; day programs and job supports; and out-of-home residential supports.

New Jersey's autism community envisions a future in which adults with autism and their families can choose supports and services from an array of appropriate options. These must be diversified and designed to ensure opportunities for employment, social relationships and independence. The greater challenge lies in creating a comprehensive and seamless statewide system that allows for local control, transparency and customization.

With this report, New Jersey has a road map to the future. Now, leaders in government and the greater autism community must move the service system forward – not only to meet the needs of thousands of adults with autism currently in need of services – but for the tens of thousands of infants, toddlers and children with autism now known to the system who one day will become adults with autism.

The Division of Developmental Disabilities (DDD) reports that more than 80% of the people with autism who have applied for services are under 22 years of age. Most are in an educational entitlement and primarily receive family support services from DDD (e.g., some form of respite or cash subsidy).

New Jersey Department of Education data show a 183% increase from 1999 to 2005 in the number of students with autism age 3 -21 who are eligible for special education services.

In that time, the number of students with autism has tripled, from 2,355 in 1999 to 6,665 in 2005.

Meeting the Needs of Adults with Autism: A Blueprint for the Future

One in three of the children on DDD's caseload living at home has autism or an autism related disorder.

DDD serves 6,021 individuals with autism - less than 13% of these individuals currently attend day programs; nearly 89% live at home with families.

Autism spectrum disorders (ASD) are the fastest growing developmental disabilities in the United States. They are now more common than Down Syndrome, cerebral palsy, hearing loss and visual impairment.

According to the Autism Society of America, autism is increasing at a rate of 10-17% a year. Once thought to be "rare," The Centers for Disease Control and Prevention now recognize that ASD affect one in every 166 individuals. This is approximately tenfold the prevalence estimated *just* ten to fifteen years ago.

Like the rest of the nation, New Jersey is at a critical juncture. An increasing number of adults with autism and related disorders is entering our state's service system, which already is overwhelmed by the number of people in need of services. Families are discouraged and angry to find waiting lists and inadequate services. Providers are struggling to meet an ever-increasing demand for service that exceeds the public resources to pay for them. Simultaneously, New Jersey faces unprecedented budget shortfalls, and a new generation of graduates with autism is preparing to exit the school system.

For many years, it was presumed that adults with autism could be served by programs created for people with intellectual disabilities, without regard for the unique environmental, behavioral, communication and sensory considerations that make autism a distinct condition. After years of unsuccessful efforts, it is now widely accepted that adults with autism require highly specialized supports delivered in a consistent, predictable manner.

Government programs create both services and barriers to services. While ever-evolving public programs and initiatives have introduced a new range of services and supports, they also have resulted in elaborate administrative systems and infrastructures that are difficult to negotiate and that often conflict with one another.

SUMMARY OF PROCESS

In 2004, the New Jersey Center for Outreach and Services for the Autism Community (COSAC) established the Adult Resources Initiative. Its mission is to help families and professionals understand and access the adult service system, support the creation of jobs and employment opportunities for adults, and advocate for appropriate, comprehensive adult services.

On April 27, 2006, COSAC's Adult Resources Initiative convened a notable gathering of more than 50 individuals to deliberate the service needs of adults with autism and then, identify the steps to move forward. Participants at the day-long forum worked in facilitated groups, each focusing on one of four specific areas of adult services: in-home and community-based supports; residential services and supports; employment supports; and adult day services. Each group responded to a common set of questions, and was asked to discuss the following: funding; legislative and regulatory issues; transportation; information and referral needs; and program development.

This report documents the consensus of the autism community around key areas of service delivery and defines a proactive agenda.

The following "Core Beliefs" are the foundation of this report:

1. People with autism are valuable. They are important members of their families, good employees, colleagues, classmates and friends, and play important roles in the communities in which they live, play and worship.
2. The service system for adults with autism is in crisis. It is unable to respond to the current need. Immediate and proactive steps must be taken to improve it.
3. Adults with autism should have every opportunity to live and work in the communities they choose, with supports and services they and/or their families select and control.
4. Adults with autism have a unique and complex constellation of needs, distinct from those individuals with intellectual disabilities, in the areas of receptive and expressive communication, social skills, behavior and sensory issues, and environmental needs.
5. Autism is a spectrum disorder and the full range of its functional abilities and limitations must be considered when planning services and supports. Those with the capacity for more self-direction must be afforded the opportunity to build on individual strengths to maximize independence.
6. Families, a vital part of the service system, have different needs, expectations, resources, values, and priorities, which must be honored in the service delivery process.

Meeting the Needs of Adults with Autism: A Blueprint for the Future

New Jersey's autism community envisions a future for adults with autism in which they and their families can choose services and supports from an array of appropriate options, that will allow them to build and maintain a meaningful life in the community, with opportunities for employment, social relationships and independence.

The challenge is to create a seamless and comprehensive statewide system that:

- offers clinically-appropriate services for adults with autism;
- allows control and decision-making on the part of families; and,
- can be customized to meet the identified needs of each individual during his or her lifespan.

FINDINGS & RECOMMENDATIONS

The following findings and recommendations were identified by two or more of the work groups and were common to all service delivery areas. They apply to all aspects of the current service delivery system for adults with autism.

FINDING: The State of New Jersey lacks a proactive strategy to meet the needs of an increasing number of adults with autism.

RECOMMENDATIONS:

- The State of New Jersey should establish a Governor's Task Force to develop a statewide plan of action to address the needs of adults with autism.
- Identify and promote best practices, policy initiatives and service delivery models successfully employed within New Jersey and in other states and countries.

FINDING: Present funding levels for programs, and mechanisms for assessing levels of individual funding, do not adequately consider the unique, complex and shifting needs of adults with autism.

RECOMMENDATIONS:

- The Department of Human Services must work with leaders in the autism community to develop and implement a clinically-validated, science-based assessment tool to gauge the preferences, strengths and support needs of individual adults with autism, and guide the allocation of public funding. Such an assessment must include collateral information collected from relevant stakeholders in the individual's life, direct observation and a review of appropriate records.
- The Division of Developmental Disabilities must ensure that the level of public funding for each individual with autism is based on specific, identified needs, and reflects a consideration of the person's behavior, social, communication and personal care skills, and capacity for independence.
- The autism community should advocate for a lifelong entitlement for services for adults with autism.
- The State of New Jersey must plan for the pending crisis related to the lack of services and supports for senior citizens with autism.

FINDING: The adult service system is highly fragmented. It is confusing to families and consumers, and limits their decision-making.

RECOMMENDATIONS:

- New Jersey must establish a single point of entry into the adult service system, which cuts across arbitrary Department lines.
- Funding must be portable across service lines and allowed to follow the individual as soon as an adult with autism becomes eligible for support services, and an appropriate level of public support has been determined.
- The support needs of an adult with autism are subject to change during the lifespan so the level of public fiscal support must periodically be reassessed.
- Policy makers must carefully consider new and existing public programs to ensure greater transparency and ease of use.
- DDD must examine decision-making at every level to ensure that families and adults with autism have more control over services and more discretion over use of resources.

FINDING: Funding for services must be flexible, sustainable and diversified. Funding solutions must consider all available sources, make better use of non-traditional resources, encourage efficiencies and cost-sharing, and allow personal contributions in a way that does not jeopardize eligibility for other services and benefits. Programs that exclusively rely on public funding are not a sustainable solution to the funding crisis.

RECOMMENDATIONS:

- Government must recognize the financial burden that families caring for a child with autism face by establishing tax credits, tax-exempt savings plans and other vehicles that would facilitate a family's contribution to the cost of services.
- Companies should establish options for pre-tax contributions to "cafeteria-style" benefits plans that would allow families to save for expenses related to caring for a child with autism.
- New Jersey should expand the availability of "Community Trusts," which allow families and/or individuals with autism to pool resources and save money for the future.

- Public programs such as food stamps, Women Infants and Children (WIC), Section 8 Housing, Social Security benefits and others must routinely be considered when determining a budget for individual supports.
- The autism community should solicit support from businesses in the form of grants, internships and in-kind contributions.

FINDING: State and federal funding sources are not being maximized.

RECOMMENDATIONS:

- New Jersey should explore a more flexible use of Medicaid funding under waiver services and optional state plan services.
- The new state Department of Children and Families should play a role in funding parent education and support services for families caring for a child or young adult with autism.

FINDING: New Jersey's service system does not address the fluid needs of adults with autism or their families.

RECOMMENDATION:

- New Jersey should explore models for wrap-around services that offer more seamless care and support across all areas of a person's life.

FINDING: New Jersey lacks an adequate number of well-trained, direct care professionals.

RECOMMENDATIONS:

- New Jersey should establish a statewide, comprehensive training program designed to prepare professionals to effectively serve adults on the autism spectrum.
- New Jersey institutions of higher education should establish a college-level curriculum for "Community/Life Coach" direct care professionals with measurable standards in areas such as safety skills, assessment and interventions for challenging behavior, crisis intervention, community integration and general knowledge of autism spectrum disorders.

- Two and four year colleges should work with families and providers to offer supervised, direct care practicum experience for students who plan to work with adults with autism.
- New Jersey's autism community should advocate for a state-endorsed training/certification program that includes specific training in the principles of Applied Behavior Analysis for direct care professionals.
- Advanced-level training programs should be offered to parents caring for an adult with autism so that, if they choose to, they may train and supervise caregivers for their adult child.
- Leaders in New Jersey government must work with the autism community to ensure that direct care professionals are paid a competitive living wage and offered complete benefits packages.

FINDING: New Jersey is home to “Pockets of Excellence.”

RECOMMENDATIONS:

- New Jersey's autism community should establish an ongoing forum for researchers, academics, providers, families, policy makers, and clinicians to confer and share best practices.
- Institutions of higher learning should develop and promote supervised training opportunities for professionals who plan to work with adults with autism.
- Leaders in New Jersey's autism community should develop a “Best Practices” report to help shape the development of high-quality adult services.

FINDING: New Jersey lacks a system for the coordination and dissemination of accurate information on services and supports for adults with autism.

RECOMMENDATIONS:

- New Jersey should create a one-stop clearinghouse for information from which residents can obtain accurate, up-to-date information, as well as secure assistance navigating our state's multifaceted service system.
- The autism community should develop and distribute measurable quality indicators for services used by adults on the autism spectrum so families can make educated choices about appropriate services.

- The Division of Developmental Disabilities should explore the benefits of regional case management units with demonstrated expertise in autism, either as a consultative support to existing case managers, or as a direct service to adults with autism and their families.

FINDING: While significant improvements have been made in the education of students with autism, graduates continue to exit school ill-prepared for adult life, and lack necessary connections to adult services.

RECOMMENDATIONS:

- The New Jersey Department of Education (NJDOE), with assistance from leaders in the autism community, should develop and disseminate a model “Summary of Performance” (as now required under the Individuals with Disabilities Education Act of 2004) specifically for students with autism to be used by schools to help facilitate their eligibility for the post-secondary services they are likely to need as adults.
- As part of the transition-planning process, the NJDOE should require school districts to make parents aware of the shift from “entitlement for services” under IDEA to “eligibility for services” that occurs when students exit the school system.
- The NJDOE should require that all students with an autism spectrum disorder who are likely to need adult services are registered with DDD prior to graduation.

FINDING: Lack of transportation services is a barrier to community integration, employment, and access to specialized services for adults with autism.

RECOMMENDATIONS:

- Services such as senior citizen transportation; private van and bus routes; school buses; public transportation; and corporate car and van pools must be accessed and used more flexibly to maximize existing resources.
- County governments should examine para-transit services to maximize efficiency and better meet the needs of consumers across county lines.
- The State of New Jersey should encourage the development of housing and day programs for adults with autism in proximity to commerce and municipal centers in order to take advantage of existing transportation infrastructures.
- Businesses should offer specific benefits to employees who formally assist adults with autism in the work place.

FINDING: Public employees and volunteers lack the information they need to appropriately serve residents with autism.

RECOMMENDATIONS:

- New Jersey should develop an educational campaign to provide public employees and emergency services personnel with a realistic picture of the strengths, limitations and challenges of adults with autism.
- New Jersey should initiate a hotline tied to the “NJ-211” system that would access counselors with expertise in autism who could assist law enforcement, EMTs, fire department personnel and others.

In addition to the aforementioned recommendations, which cut across service areas, the following are findings and recommendations that pertain to specific segments of the adult service system:

IN-HOME AND COMMUNITY-BASED SUPPORTS

Most adults with autism in New Jersey are living at home with their parents. From a public policy perspective, this may be the most cost-effective way for an adult with autism to live in the community.

Families, however, cannot be expected to provide full-time care. In-home and community supports, as well as employment-related supports, must be expanded, not only to reduce caregiver stress and the possibility of abuse or neglect, but to increase the integration of adults with autism into our communities, and enhance their social relationships.

Many families face lifelong, intensive caregiving responsibilities. Some report having to leave work and stay home in order to care for their adult son or daughter with autism, putting the family at an additional financial disadvantage. Many have never had a vacation away from their family member with autism.

Despite promising family support legislation passed in 1993, the availability of family support services in New Jersey is severely limited. Currently, services include in-home and out-of-home respite care provided by agencies under contract with DDD, and/or a periodic cash subsidy. These supports are limited and their availability varies by region.

FINDING: Families cannot be expected to provide full-time care for adults with autism without a reprieve, and without the clinical support and training resources typically afforded to paid caregivers.

RECOMMENDATIONS:

- Help reduce caregiver stress by establishing a support group for parents of adults with autism in each county.
- Make better use of the internet as a vehicle to connect parents of adults with autism to local services and with one another through chat rooms, list serves and electronic publications.
- Expand support services for parents of adults so they may experience an extended “vacation” from caregiving responsibilities.
- Establish a community support hotline, similar to that which is now available through the Children’s Mental Health Initiative, in which county or regionally-based emergency response teams can be dispatched to help families deal with crises.

- Establish a non-emergency call center to provide general information, referral, support and consultation for families caring for an adult with autism at home.
- Provide workshops, consultation services and other programs specifically designed to support parents caring for adults with autism at home.

FINDING: Adults with autism and their families need seamless support.

RECOMMENDATION:

- Explore the concept of “life coach” services to facilitate community integration and access for adults with autism.

FINDING: Families participating in New Jersey’s Real Life Choices Initiative are overwhelmed by responsibilities associated with planning and coordinating services. In fact, many function as case managers, emergency staff back-up, care coordinators and trainers, and without compensation.

RECOMMENDATIONS:

- Parents engaged in the traditionally professional functions of case managers, support coordinators, staff trainers, and job developers should be offered appropriate training, support and compensation for those functions.
- Parents who elect not to perform these functions, or are unable to do so, should have the option to access “Service & Benefit Coordinators” at no charge. These coordinators could hire, train, manage and coordinate staff, as well as help ensure services and supports for which an adult with autism may be eligible are maximized.

ADULT DAY SERVICES

Once viewed as a custodial, center-based service, the role of day programs for adults with developmental disabilities has evolved to include more community-based activities designed to foster independence and promote integration.

Adult day programs are best viewed as a “transitional service” designed to build skills that can lead to more inclusive opportunities for adults with autism. As such, they should offer participants opportunities for volunteerism, job sampling and leisure activities in the community, as well as support for continuing education.

Day services are a vital component of the service system for adults with autism because they offer a “safety net” for individuals who, occasionally, are not engaged in activities in the community, or whose behavioral profile is such that full-day, community-based programming is not appropriate.

Well-qualified staff are vital to the success of adults with autism in a day program. Like their counterparts in special education, staff working with adults with autism must be well trained in the principles of Applied Behavior Analysis and receive ongoing clinical supervision from credentialed professionals. Most successful programs for adults with autism retain low staff ratios of 1:1, 1:2 and 1:3.

FINDING: There is a lack of appropriate day services for adults with autism.

RECOMMENDATIONS:

- The State of New Jersey should create incentives for providers and businesses that seek to develop innovative day services designed to serve adults with autism.
- New Jersey should establish a statewide mechanism to deliver consultation services to providers who want to develop day services for adults with autism.
- New Jersey should design a comprehensive, standardized training program, which can be used by community providers to prepare and train staff to work in day programs for adults with autism.

FINDING: Day program services have limited operating hours, leaving large gaps in support and services.

RECOMMENDATION:

- Day programs should have longer and more flexible hours of operation and offer “drop in” services to better meet the needs of consumers and families.

COMPETITIVE AND SUPPORTED EMPLOYMENT

At a time when unemployment is near its lowest level in decades, adults with autism are chronically unemployed or underemployed. Many families report that when their son or daughter graduates, he/she has no place to go.

New Jersey currently uses several models to support the employment of adults with autism and other developmental disabilities, including competitive employment, job coaching, supported employment and sheltered employment programs.

Most funding for employment supports comes from the Division of Developmental Disabilities through contracts with community providers. Waiting lists for these services are long. Although the Department of Labor and Workforce Development's Division of Vocational Rehabilitation Services (DVRS) offers job supports, these supports are time-limited and generally cannot meet the full range of needs of adults with autism.

Adults with autism who earn wages are taxpayers and able to contribute to the cost of the support services they need.

Increasingly, major corporations are recognizing the contributions of people with disabilities and are recruiting and supporting them. New Jersey is home to several creative partnerships between autism service providers and businesses. These relationships have resulted in meaningful job experiences for adults with autism, and have allowed employers to fill positions that otherwise are difficult to fill.

FINDING: Potential employers often lack awareness of the benefits of hiring adults with autism.

RECOMMENDATIONS:

- The New Jersey Department of Labor and Workforce Development (NJDLWD), in consultation with the autism community, should create an educational campaign designed to promote the talents and resources available in the pool of employees with autism.
- The autism community should promote the use of “video resumes” for adults with autism who are seeking employment.

FINDING: Greater flexibility and creativity are needed when identifying work opportunities for adults with autism.

RECOMMENDATIONS:

- The autism community should promote “customized employment” and “job sharing” as effective methods for creating employment opportunities for adults with autism.
- Public funding must be made accessible for families and providers pursuing: non-traditional work; small businesses ownership; a cottage industry; or an entrepreneurial endeavor.
- Community service experiences, unpaid internships, apprenticeship programs and volunteer work must be leveraged as a means to develop job skills that could lead to paid employment.
- State, county and local government must assume a more assertive posture in recruiting adults with autism for both paid and unpaid work.
- The autism community should explore creative alternatives, such as farming and agricultural jobs, as an option for adults with autism.
- The New Jersey Department of Labor and Workforce Development (NJDLWD), in conjunction with leaders from the autism community, should educate Workforce Investment Boards (WIBs) and Business Leadership Networks (BLNs) about the labor resources that adults with autism can provide to local business and communities.
- New Jersey should establish a statewide clearinghouse that matches adults with autism to employers seeking to recruit them.

FINDING: Many students with autism leave school lacking “employability behaviors.”

RECOMMENDATIONS:

- The New Jersey Department of Education (NJDOE) should ensure that specific job-seeking skills, such as interview skills, are taught as part of the core curriculum.
- Youth with autism should secure a job while still in their educational entitlement, and have a job placement before graduation.

FINDING: There is a lack of well-trained, well-qualified, well-supervised professionals to provide job-coaching services.

RECOMMENDATIONS:

- The autism community should explore the benefits of a specific training/certification/accreditation program for the position of job coach and/or job developer.
- New Jersey's autism community should ensure the ongoing training and supervision of job coaches' activities to ensure best practices and problem-solving of difficult situations.

FINDING: Adults with autism who earn a wage and are able to save money are perceived to be at risk of losing the very benefits that allow them to work and live in the community.

RECOMMENDATIONS:

- The State of New Jersey must do more to educate families and providers about New Jersey's "Medicaid Buy-In" Program, which allows wage earners to continue to be eligible for Medicaid.
- Services should be developed in such a way that adults with autism do not lose existing benefits and supports because they are earning a wage.
- The New Jersey Departments of Human Services and Labor and Workforce Development should develop an interagency agreement to maximize New Jersey's work incentive option under Social Security and Medicaid.

FINDING: Businesses must be further encouraged to hire adults with autism.

RECOMMENDATIONS:

- State and federal government should offer tax credits and other incentives to businesses of all sizes that make an effort to employ numbers of adults with developmental disabilities.
- The provider community must remain cognizant of the currency of positive public relations, and ensure that businesses that employ adults with autism benefit from doing so.

FINDING: DVRS services, as currently structured, cannot be accessed by adults with autism, many of whom have functional limitations that require constant, long-term supports.

RECOMMENDATIONS:

- The Departments of Human Services and Labor and Workforce Development should revisit existing “Interagency Agreements” and revise them to ensure more seamless supports are delivered to adults with autism.

RESIDENTIAL SERVICES AND SUPPORTS

Adults with autism who are not living in their family's home need a range of residential options, each with appropriate supports.

Historically, group homes have been the option of choice for many families. Increasingly, however, adults with autism and their families want more typical housing options including apartments, condos, townhouses, and private homes.

Regardless of the housing option, highly specialized support services based on the needs of the adult(s) living there must be consistently provided. These services may include specialized behavioral, communication and social skills supports.

FINDING: Public support for residential services for adults with autism has not kept pace with the demand for services, and is not at a level that is appropriate to the intensive, multifaceted needs of adults with autism.

RECOMMENDATION:

- The State of New Jersey must assess its fiscal commitment to residential services for adults with autism and determine adequate levels of funding based on the history of actual costs.

FINDING: Funding for housing must be considered separately from funding for the residential support services needed by adults with autism.

RECOMMENDATIONS:

- The New Jersey Housing Trust Fund should be explored and evaluated as a vehicle for financing housing for adults with autism.
- The State of New Jersey should offer tax credits for builders who create or retrofit housing to meet the needs of adults with autism.
- Reverse mortgages and housing donated from private sources should be encouraged as a means to expand the availability of housing for adults with autism.

FINDING: Residential supports must include a wide array of non-traditional options for individuals and their families to consider.

RECOMMENDATIONS:

- New Jersey policy makers must encourage the use of flexible and creative support options including the use of roommates without disabilities who have specified duties; drop-in support; neighbor support; and individuals living with a host family.
- Farmstead options and other non-traditional housing options should be explored and expanded to meet demand.

Forum Participants

COSAC gratefully acknowledges the thoughtful participation of the following individuals in its April 27, 2006 Forum on Adult Services:

Lowell Ayre	Exec. Dir., Alliance for the Betterment of Citizens with Disabilities
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† Member of COSAC's Adult Resources Committee

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What is autism?

Autism is a lifelong developmental disability characterized by atypical, repetitive behaviors and deficits in social and communication skills. Autism is usually diagnosed during the first three years of life and is four to five times more prevalent in boys than in girls. It knows no racial, ethnic or social boundaries. Autism spectrum disorders range from a severe form, called autistic disorder, to a milder form, Asperger syndrome. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS). Other rare, very severe disorders that are included in the autism spectrum disorders are Rett syndrome and childhood disintegrative disorder.

Today's research suggests that autism spectrum disorders are a genetic disorder that is possibly triggered by environmental factors. There is no known cure for autism at this time.

For more information about autism spectrum disorders and the adult service system, or to request additional copies of this report contact:

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