

**Addressing
the Needs
of Adults
with Autism
Spectrum Disorder:**

Recommendations
for a Plan of Action
for the State of
New Jersey

**Adults with Autism Task Force
October 2009**

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JON S. CORZINE
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October 8, 2009

Honorable Jon S. Corzine
Governor
State of New Jersey

Honorable Richard J. Codey
New Jersey State Senate President

Honorable Joseph J. Roberts, Jr.
Speaker of the New Jersey General Assembly

Dear Governor Corzine, Senator Codey and Speaker Roberts:

On behalf of the New Jersey Adults with Autism Task Force, I am submitting the Task Force's report – a culmination of a year long process of study, evaluation, and findings. The members of the Task Force should be commended for their work. Each of the members committed countless hours to ensure that many viewpoints were considered – and their time and dedication to advance change on behalf of the Autism Spectrum Disorder (ASD) community is evident. I would also like to thank Deborah Cohen, Ph.D., who served as Chairperson-designate on my behalf.

The members of the Adults with Autism Task Force represented all areas and philosophies of the ASD community, thus enabling them to work through the challenging issues that accompany growing need. This fullness of representation produced a report that presents a broad range of recommendations aimed at filling gaps and meeting unmet need. In a desire to appropriately capture the depth of the group and the broad range of recommendations, this report offers the reader the views and perspectives as presented by the Task Force members themselves. Legislative support and predictable funding underlie many of the recommendations presented.

Autism is a lifelong disability and is the most common condition in a group of developmental disorders known as ASDs. Other ASDs include Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder Not Otherwise Specified. These disorders are characterized by limits in social interaction, verbal and nonverbal communication and unusual repetitive activities or severely limited interests.

This report provides an opportunity for the State to have a renewed focus, not only on ASD – but on the broad range issues that surround the entire disabilities community. I would like to thank the members for their tireless effort – not only as part of the Task Force – but also for those many thousands who they represent.

Sincerely,

Jennifer Velez
Commissioner

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The Adults with Autism Task Force wishes to express much appreciation to the parents and individuals who regularly attended meetings and actively contributed to the production of this report:

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Executive Summary

Public Law 2007, Chapter 173 establishes the “Adults with Autism Task Force.” The purpose of the Task Force is studying, evaluating and developing recommendations related to a specific plan of action to support and meet the needs of adults with Autism Spectrum Disorder (ASD) who are residents of New Jersey.

As mandated, the Task Force spent a year deliberating and considering the needs of adults with ASD. The activities included holding monthly meetings, establishing ten issue-specific sub-committees and collecting information through public participation that consisted of conducting an on-line survey (developed by the Task Force) and sponsoring six forums throughout the state. This report, entitled “**Addressing the Needs of Adults with Autism Spectrum Disorder: Recommendations for a Plan of Action for the State of New Jersey**,” puts forward a series of Task Force recommendations in a comprehensive manner based upon all the activities and results.

The foremost recommendation is: **the establishment of an Office of Autism Services (OAS) within the Department of Human Services, Division of Disability Services.** The Task Force rationale is that this state department already serves the adults. However, if deemed more appropriate and cost effective to have the OAS situated in another state department, other options may be feasible based upon existing expertise or commitment to serving adults with ASD.

The establishment of the OAS is fiscally and operationally the most efficient way to meet the needs of the 1 in 94 citizens in New Jersey with ASD. The OAS will provide a concentrated focus and responsibility for implementing the state strategic plan to address both existing adults with ASD and residents who now are children with ASD but soon will enter the adult service system.

The responsibilities of the OAS would include:

- Coordinating and promoting inter-agency collaboration of client-centered service delivery across the lifespan;
- Acting as a clearinghouse for state-wide resources, assessments and lifespan services;
- Serving as the designated lead ASD agency for New Jersey, as may be required to apply for federal funds;
- Pursuing grants and funding from for-profit, non-profit, corporate and governmental entities;
- Developing, managing and utilizing a comprehensive data system;
- Providing leadership and coordinating efforts to amend or enact legislation to benefit persons with ASD;
- Promoting, disseminating and coordinating best practices in the training of staff, and other supports, with respect to Autism Spectrum Disorder; and
- Promoting partnerships between state and local governments, along with for-profit and non-profit agencies, corporations, faith-based organizations, parents, persons with ASD and higher education institutions.

The Task Force also recommends: **the establishment of an Executive Oversight Committee (to work cooperatively with the Office of Autism Services)**. The purpose of the oversight committee will be to ensure that the recommendations, posited in the Task Force Report, are implemented effectively and made operational.

The Executive Oversight Committee, in addition, would work in cooperation with state departments and agencies, including the state Department of the Public Advocate, to ensure that state and federal laws regarding ASD are implemented effectively. The Executive Oversight Committee would be composed of representatives of the state agencies that are charged with and responsible for providing services to adults with ASD, as well as members of the Adults with Autism Task Force, other self-advocates and family members.

The Task Force, as part of its enabling legislation, is also mandated to provide a summary of legislative initiatives that would lead to a comprehensive system of services for adults with ASD. Along with the establishment of the OAS and the Executive Oversight Committee, the Task Force is recommending: **action of the legislature to address the specific needs and concerns of adults with ASD**. This action includes:

1. Establish a New Jersey Tax-Free Savings Account so that families can save for lifespan expenses relating to ASD. (See proposed federal legislation S493, which would establish such accounts based upon the 529 higher education tax free savings account model. NJBEST 529 College Savings Plan - New Jersey offers similar tax advantages to state residents.)
2. Amend New Jersey's Law Against Discrimination (LAD) specifically to prohibit discriminatory acts against persons with ASD and other developmental disabilities NJS 10:5-1, 10:5-3, 10:5-4-1 and 10:5-5(q) (See Appendix A).
3. Amend the Autism Registry legislation to include registering adults with ASD on an opt-in basis. A total of \$500,000 has been provided to the state Department of Health and Senior Services for an Autism Registry, for the reporting of diagnoses of autism. These funds will enhance the knowledge and understanding of ASD: both to plan better and provide for services to children and adults with ASD, and to analyze contributing factors to the cause of the increase in ASD. Adults with ASD can register themselves, or can be registered by health care and service providers.
4. Expand proposed legislation that urges the state Board of Education and the Commission on Higher Education to encourage the establishment of programs to provide student partners to students with ASD. Establish an adult peer mentor program with New Jersey's colleges and universities so that adults with ASD can benefit from support provided by mentors.

5. Expand proposed legislation to include ASD and Intellectual, and other developmental disabilities, in an awareness program for certain first responders to include:
 - a) New Jersey Department of Transportation Employees
 - b) Members of the State Bar Association and Judiciary
 - c) Day Program Staff*
 - d) Hospital Emergency Room and Medical Personnel
 - e) Residential Support Staff*

*Require certified training
6. Establish a tax-exemption for donation of homes to be used as residences for persons with ASD. This would enable families to participate in addressing the lack of accessible and affordable housing for adults.
7. Establish a state tax credit based on the federal Work Opportunity Tax Credit program.

The Task Force expressly recognizes that this report is being submitted during a period of great financial stress and uncertainty. To this point, the recommendations are put forward on both a short-term and long-term basis. The short-term actions generally require little or no new funds, but may require rebalancing of funds with the current service systems, in order to provide a higher quality of life to adults with ASD while attaining efficiencies in service delivery. The long-term recommendations often require legislation and a financial investment on the part of New Jersey.



44 Recommendations on the Needs of Adults with Autism in New Jersey

(Submitted by the Adults with Autism Task Force, August 2009)

- # 1: The establishment of an Office of Autism Services (OAS) within the Department of Human Services (DHS), Division of Disability Services (*This is the highest priority recommendation of the Adults with Autism Task Force*).
- # 2: Establish an Executive Oversight Board by Executive Order to ensure that the proposed recommendations are acted upon.
- # 3: Enact legislation to address the specific needs and concerns of adults with ASD.
- # 4: Develop a Student Bill of Rights.
- # 5: Establish a mandatory growth provision in the DHS Division of Developmental Disabilities' annual budget to ensure funding for students transitioning from school to adult life for each fiscal year.
- # 6: Require teachers and case managers involved in transition planning to attend training on transitioning students with Autism Spectrum Disorder (ASD), to be coordinated by the OAS in collaboration with the state Department of Education (DOE).
- # 7: Implement PL 2007, Chapter 171 in college and university curricula to train teachers and program coordinators in educational methods for teaching students with ASD.
- # 8: Increase educational opportunities for adults with ASD by expanding access to continuing educational opportunities on a credit or non-credit basis.
- # 9: Implement an ASD-specific training program, coordinated by the OAS, for Day Program professionals on the characteristics of ASD and effective interventions. Staff training programs should include consumer involvement to ensure self-determination and direction, and should be culturally appropriate. Provide Day Programs with staffing requirements based upon the needs of program participants.
- # 10: Expand the number of Day Programs for adults with ASD.
- # 11: Develop a model day program tailored to the needs of people with Asperger Syndrome or High Functioning Autism.
- # 12: Establish criteria and best practices for life-skills training for adults with ASD.

13: Allocate independent living funds received under the American Recovery and Reinvestment Act of 2009 (ARRA) for training and capacity improvement programs aimed at assisting Independent Living (IL) Centers to serve adults with ASD. This would be consistent with recognition of the availability of these funds and the goal of using these funds to serve additional consumers, especially populations that are unserved or underserved by IL programs in the state.

14: Increase efforts to educate employers about the positive aspects of hiring people with ASD.

15: Introduce legislation, similar to that under consideration in Massachusetts, to establish a tax credit for the employment of individuals with ASD, allowing employers to take a tax credit on a percentage of gross wages paid to employees with ASD.

16: Enhance the necessary support systems for adults with ASD to achieve employment success.

17: Expand innovative employment models such as work-cooperatives.

18: Provide autism-specific training to service providers of vocational services in both public and private organizations; offer autism-specific training that includes information about aspects and nature of autism as well as the varied assessments and services that would benefit this population.

19: Allocate a portion of New Jersey's ARRA funds to support vocational rehabilitation services for persons with ASD.

20: Continue exploration undertaken by the DHS Division of Developmental Disabilities (DHS-DDD) and the New Jersey Department of Labor and Workforce Development Division of Vocational Rehabilitation Services (DLWD-DVRS) to identify successful programs throughout the nation that offer creative use of long-term resources that promote natural supports in the workplace.

21: Educate the healthcare industry with regard to improving healthcare services and the healthcare experience for persons with ASD, through the development of best practice guidelines and by defining quality standards.

22: Develop a comprehensive existing database of all New Jersey healthcare providers who treat adults with ASD and make this information accessible to the broader community through existing entities such as NJHelps.org and the NJ 211 system.

23: Execute an interagency agreement between Department of Health and Senior Services (DHSS) and DHS to work together to assist people in understanding the healthcare services that are available; and if eligible, how to access Medicaid State Plan services and all other applicable state healthcare programs.

24: Educate people with ASD and their families about the governing authorities underlying their health plans so they can advocate more effectively for themselves or on behalf of a loved one.

25: Undertake an examination, by DHSS and DHS, to determine the commonalities between the long-term care needs of the aging population and individuals with developmental disabilities including autism.

26: Explore expanded partnerships with the federal government, and specifically the Center for Medicare and Medicaid Services (CMS), to maximize federal resources to serve adults with ASD, including enhanced services in the Medicaid State Plan.

27: Ensure the Dual Diagnosis Task Force proposed continuum of crisis response services addresses the needs of adults on the autism spectrum.

28: Re-organize and operationalize the Medicaid Waiver waiting lists, by county or region, in order to facilitate local long-term planning.

29: Provide ready information on available housing for people living with disabilities, including housing owned by DHS-DDD and resources available on a local level.

30: Create a grant award or pilot demonstration program for housing. Awards would be based on: 1) specific needs of the ASD population 2) ability to decrease service costs 3) community involvement 4) partnerships 5) sustainability, and 6) ability to be replicated. (During the current fiscal crisis, it is recommended that the State of New Jersey take a leadership role in conducting research, investigating the models and programs that are effective and efficient. Given the limited funds available under the Family Support Act, it is recommended that the State leverage those funds by using a portion to fund this program.)

31: Make alternative housing arrangements available to those who are waiting for their number “to come up” on the Priority Waiting List.

32: Increase and change how funds are distributed for housing and services.

33: Educate Superior Court judges about Autism Spectrum Disorder.

34: Create an ad campaign to focus on individuals and their varying strengths, challenges and abilities to highlight the diversity of the adult ASD community.

35: Sponsor roundtable discussions that include community partners (i.e, businesses, community organizations, ASD service providers and adults with ASD), to brainstorm for ways to engage adults with ASD in all aspects of community life, in collaboration with the New Jersey Chamber of Commerce.

- # 36:** Establish a peer mentoring program, in collaboration with New Jersey's state colleges and universities, for young adults and adults with ASD to gain invaluable support and guidance from their peers.
- # 37:** Establish a self-advocate awareness program geared to not-for-profit organizations; information could be circulated at symposiums and workshops provided by entities that serve not-for-profit organizations. The information for public presentations can be coordinated by the OAS.
- # 38:** Collaborate with existing entities to develop ideas as to how to further engage the members of these organizations in providing support for adults with ASD.
- # 39:** Completely implement, the recommendations of "*Meeting the Employment Transportation Needs of People with Disabilities in New Jersey*," published by the Alan M. Voorhees Transportation Center, Edward J. Bloustein School of Planning and Public Policy, Rutgers, The State University of New Jersey.
- # 40:** Include transportation as a critical component in developing and executing an Individual Education Plan (IEP), Individual Habilitation Plan (IHP), Essential Lifestyle Plan (ELP), or Individual Plan for Employment (IPE).
- # 41:** Establish a partnership between New Jersey AccessLink and regional providers to ensure that students with ASD who do travel to schools outside their service area receive appropriate training.
- # 42:** Investigate creative solutions to vehicle liability issues in order to facilitate greater coordination among community transit systems and lessen the duplication of routes and resources.
- # 43:** Adjust the New Jersey Casino Revenue Fund Advisory Commission's formula for para-transit aid to reflect the relevant county's population of seniors and persons with disabilities.
- # 44:** Train county-based offices on aging and other aging-related service providers regarding the needs of persons with ASD.

Brief Background on Autism Spectrum Disorder (ASD)

Over the past few years, much attention has been given to the growing number of young children who are being diagnosed as having an Autism Spectrum Disorder (ASD). The Centers for Disease Control and Prevention (CDC) has reported that 1 in 94 residents in New Jersey have an ASD (1). Sustained and focused attention on “early identification” and early intervention has resulted in public and private initiatives to increase awareness of autism in children, lower the age of diagnosis and improve the interventions and treatments provided to children.

Receiving much less attention, however, is the number of persons with ASD who are now or soon will be entering adulthood; *this number is steadily growing*. With improved health care and other services, the lifespan of persons with ASD is likely to increase, which will result in significant, accompanying increases in costs.

The purpose of the recommendations contained in this report is to provide guidance in the effective and efficient means of using the state’s resources to address, what has been characterized by experts as, a looming crisis for adults with autism that we are currently ill-prepared to handle. The current lack of supports and services has resulted in loss of productivity for adults with ASD as well as for their parents, siblings and children. A report by the Harvard School of Public Health indicates that the indirect costs, which are largely costs in lost productivity, are greater than the direct costs of support and services (2). This system failure is not only a waste of the potential of adults with ASD, it is also a waste of years of costly special education spent preparing these individuals for adult life.

Adults with ASD have the potential to lead fulfilling and active lives as participants in all aspects of community life. These adults want to be able to leave home and live in community settings, and they aspire, when appropriate, to attend college or continue to pursue avenues for life-long learning and personal growth. These adults are capable of acquiring skills that lead to suitable and sustainable opportunities for employment.

Adults with ASD also have a variety of interests and talents, and wish to pursue them through diverse and stimulating recreational endeavors that enhance their social lives. With the proper supports, all adults with ASD can lead fulfilling and well-rounded lives.

Signed into law by Governor Corzine in September, 2007, Public Law 2007, chapter 173 established the Adults with Autism Task Force. As stated in the legislation, “the purpose of the Task Force shall be to study and evaluate, and develop recommendations relating to, specific actionable measures to support and meet the needs of adults with autism who are residents of New Jersey, including, but not limited to, job training and placement, housing and long-term care. The recommendations shall comprise the basis for a comprehensive plan for meeting the needs of adults with autism, which the Task Force shall present to the Governor and Legislature. The Task Force shall report its findings and recommendations, along with any legislative bills that it desires to recommend for adoption, no later than 12 months after the initial meeting of the Task Force.”

The enabling legislation defined the membership by stipulating that the “Task Force shall consist of 13 members as follows: the Commissioners of Human Services, Health and Senior Services, Education, and Labor and Workforce Development, as well as the Chair of the Governor's Council for Medical Research and Treatment of Infantile Autism or their designees who shall serve ex-officio; and 8 public members who shall be appointed no later than 30 days after the signing of this legislation of which 6 shall be appointed by the Governor including one person upon the recommendation of the New Jersey Center for Outreach and Services for the Autism Community (now called Autism New Jersey), one person upon the recommendation of Autism Speaks, one person upon the recommendation of ASPEN, one person who is an adult with autism and two public members with demonstrated expertise in issues relating to the work of the Task Force; one person appointed by the President of the Senate; and one person appointed by the Assembly Speaker.”

The Adults with Autism Task Force first convened on June 19, 2008 and continued to meet monthly. After analyzing its priorities and the scope of work, the Task Force organized itself into subcommittees as a way to address each priority comprehensively. The additional representatives from the ASD Community provided their expertise by attending meetings and participating on the sub-committees, which included:

1. Transition from Educational Entitlement to Adult Life
2. Day Programs
3. Life Skills
4. Employment
5. Health Care
6. Housing
7. Legal Issues
8. Private Sector Engagement
9. Transportation
10. Survey Analyses

The deliberations of the sub-committees served as the basis for preparing the recommendations proposed by the Adults with Autism Task Force. In addition to working sub-committees, the Task Force undertook two initiatives for the purpose of gathering information about the needs of adults with ASD: developing and conducting a statewide, on-line survey of needs of adults with ASD, and sponsoring six public forums throughout the state.

The Task Force worked throughout the year collecting information, deliberating and considering the needs of adults with ASD. “*Addressing the Needs of Adults with Autism Spectrum Disorder: Recommendations for a Plan of Action for the State of New Jersey*” is a report of Task Force findings and recommendations to establish resources to handle the growing public health and cost of living needs of adults with ASD. The overall objective is to help adults with ASD to live an active, meaningful life here in New Jersey.

New Jersey Survey: What are the Needs of Adults with ASD?

The Adults with Autism Task Force adapted and expanded a survey, developed by a Florida-based autism organization called CARD, for use here in New Jersey. The survey was sent to numerous agencies for distribution to families through email notification and website placements. Additionally, the DHS Division of Developmental Disabilities mailed letters to 4,523 families served by the division, notifying them of the survey and how to access it on-line.

Over a five month period, a total of 1,077 individuals responded to the survey. The greatest number of respondents (89 percent) were parents, 7.6 percent were individuals with ASD, and the remaining 3.4 percent were guardians. Seventy percent of the respondents were parents (N=748) whose children were 21 years of age or younger, while 294 respondents were from parents or individuals with ASD who were 22 years of age or older. Thirty-five respondents did not provide the age of their children. The fact that parents whose children are still in school responded at such a high rate is indicative of the great concerns these families have for their future.

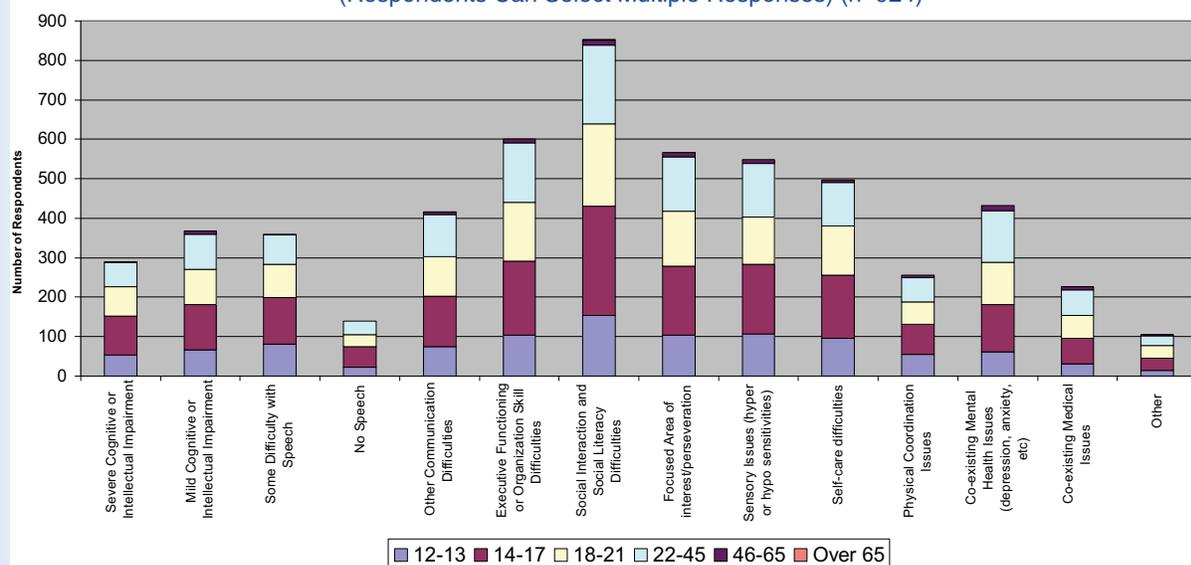
Research has demonstrated that individuals with ASD exhibit a broad range of behavioral characteristics and disabilities. The results of the New Jersey Survey document that this defining feature is prevalent among individuals with ASD or parents who responded.

The most commonly cited ASD-related impairments were:

- 1) Social Interaction and Social Literacy Difficulties - 92 %
- 2) Executive Functioning Difficulties - 63.3 %
- 3) Sensory Issues - 59.5 %
- 4) Self-care Difficulties - 53.7 %
- 5) Co-existing Mental Health Issues - 46.8 %
- 6) Communication Difficulties - 44.8 %

Table 1 - Summary of the broad range of impairments by age group.

What ASD-related impairments or other characteristics does the individual on the ASD spectrum experience? (Respondents Can Select Multiple Responses) (n=924)



Note: The range of the disability characteristics documents the requirement that service systems be responsive and appropriate to address these needs. Other survey findings will be discussed in association with particular recommendations presented in this report.

Public Forums: What are the Needs of Adults with ASD?

The Adults with Autism Task Force sponsored six public forums throughout the state to allow persons with ASD and their families to participate directly in the enunciation of their needs. To this end, the Task Force prepared a document that presented “preliminary” recommendations. The public forums were held:

March 14, 2009 – Bergen Community College
March 14, 2009 – Monmouth County Library in Manalapan
March 16, 2009 – Burlington County Library
March 16, 2009 – Cumberland County Library in Bridgeton
March 18, 2009 – Historic Court House in Flemington
March 21, 2009 – Hudson Community College in Jersey City

Approximately 80 persons testified at the forums, and an additional 70 individuals submitted written testimony. Six self-advocates with ASD presented testimony on their own behalf. In addition, most forums included individuals who attended to learn about the issues and express a sense of concern about the future; and some did not present testimony themselves.

To a great extent, the given testimony reinforced the findings of the survey and the preliminary recommendations developed by the Task Force. While specific concerns were voiced at each forum, the two most common themes related to the transition from school to adulthood and concern for the future of the adult with ASD having a place to live in the community.

Concerns were often expressed in relation to statements of fear as to what would happen when families were no longer able to care for their loved ones with ASD. Parents sought to present new models of community housing that they felt could address this need (See Appendix C).

During the public forums, the families also:

- Identified the need for day programs, social networks, training and employment opportunities, and transportation, which currently presented barriers to their adult child with ASD being integrated into community life.
- Reported on the financial hardships experienced while fulfilling the educational, medical and social needs of their children with ASD.
- Provided testimony regarding the additional challenges faced by families with a child with ASD who are of lower socio-economic circumstance and reside in the inner cities.
- Documented their dependence upon hospital emergency rooms as a medical home due to the dearth of physicians trained to treat persons with ASD in the cities.
- Expressed concern about the lack of appropriate housing, employment and social and long-term care services in the urban areas as well as the need for culturally appropriate services.



“I stand here today, as my son, who is now an adult, prepares to exit the educational system in just three short months and I am absolutely terrified of what our future holds... when I look out into the adult services world, what do I see? I see no funding, no services, no day programs, no supports for employment, no appropriate health services, no access to transportation and ridiculously long waiting lists for residential.”

- Mother of 21 year old adult with ASD

Statement of Problem

The most recent Center for Disease Control and Prevention (CDC) prevalence estimates for Autism Spectrum Disorder (ASD) is 6.7 per 1,000 (1 in 150). However, the prevalence in New Jersey is much greater with an estimate at 1 in 94 residents being affected. These estimates are more than ten-fold higher than just two decades ago, and raise urgent concerns about what the future holds for the increasing number of persons with ASD living in New Jersey.

The increasing number of children with ASD residing in the state is reflected in the growth of the need for special education services. According to the New Jersey Department of Education, Office of Special Education Programs, fewer than one percent of all children (N=509) receiving special education services in 1992 were diagnosed with ASD. Fifteen years later in 2007, there were 9,750 children or four percent of all children with a disability diagnosed with ASD.

If the current prevalence rate remains stable, each year New Jersey can expect a concurrent growth in the number of identified persons with ASD in need of some types of supportive services to function in the activities of adult life. If the prevalence continues to increase, the current service systems would be unable to function. It is imperative to have resources devoted to services and supports commensurate with this growing public health need.

Recent legislation has successfully laid the groundwork for a small part of the work that is ahead. The creation of the Adults with Autism Task Force and subsequent publication of this report have provided stakeholders and government agencies an opportunity to investigate the problems and promising practices existing throughout the state. The inclusion of ASD as a mandated reportable condition to the state Department of Health and Senior Services, Special Child Health Services Registry means that, over time, data on children under age 21 will be available to inform adult service agencies about the number of persons moving into adulthood who may need support and services. Support to public schools for ASD program expansion and advanced teacher training are aims to increase the capabilities of teachers to prepare their students with ASD, and to lead to adults with ASD being better prepared for life upon leaving the school system.

The Adults with Autism Task Force identified multiple failures of the current state-of-the-state when providing coordination and implementation of supports and services to meet the needs of adults with autism who live in New Jersey. The recommendations presented herein are intended to help correct some of these problems while providing guidance for development of a comprehensive system of services geared to adults with ASD. The Task Force recognizes that these recommendations are being made in times of difficult economic circumstances. With this in mind, the recommendations are given in short-term time periods with little or low costs associated and long-term time periods where funds will be required to achieve the recommended outcome.

Note: The recommendations made by the Task Force are directed to adults with ASD. However, many of the recommendations could be applicable to other disabilities.

List of Recommendations with Summaries

Recommendation #1: *The establishment of an Office of Autism Services (OAS) within the Department of Human Services (DHS), Division of Disability Services. (This is the highest priority recommendation of the Adults with Autism Task Force.)*

Problem Statement: Coordination and collaboration of information and services

Due to the availability of services through different New Jersey state government programs, accessing the information regarding the services is a significant and overwhelming challenge for constituents. When families or consumers enter the disabilities service system, they are confronted with an array of governmental and private service options. Each with a different entry and eligibility criteria, and also governed by different legislative mandates and funding sources. Those individuals charged with assisting families in the navigation of the service system (e.g., case managers) are limited by a lack of a centralized data system that can provide real-time information on program availability, eligibility criteria, waiting lists, costs and other factors that would indicate an appropriate service for a particular consumer.

A comprehensive system of information, referral and service delivery that can be accessed by families and consumers needs to be established through a collaborative effort. The need for this broad system is recognized at the federal level through the “Helping Hands for Autism Act of 2008,” which is now encompassed in The Autism Treatment Acceleration Act of 2009 [a bill co-sponsored by Senator Robert Menendez (NJ-D) and Representative Chris Smith (NJ-R)]. A coordination of efforts must be undertaken statewide, as well as between the state and federal government, to plan strategically for adults with ASD and to implement the recommendations of the Adults with Autism Task Force Report.

The Office of Autism Services

Purpose: The proposed Office of Autism Services (OAS) would provide a concentrated focus on addressing the needs and issues facing adults with ASD and their families. The OAS would take primary responsibility for crafting and implementing the state strategic plan to address both existing adults with ASD as well as the influx of residents who are now children with ASD but who will soon be adults with ASD entering the adult service system.

The Task Force recommends locating the OAS within the Department of Human Services, Division of Disability Services because this Division currently serves as the key information and assistance entity for all disability services. It is also proposed that the OAS evolve (within 18 months from inception) into a division, and that this office undertake efforts to employ persons with ASD within its workforce.

Responsibilities: The Office of Autism Services (OAS) would be responsible for:

- 1. Coordinating and promoting interagency collaboration of service delivery across the lifespan that is client-centered.** It would include a partnership of individuals with ASD, their families, schools and community organizations, as well as all state agencies that interact and provide services to persons with ASD.
- 2. Acting as a clearinghouse** regarding state-wide resources, assessments, lifespan services, waivers, health care, housing, transportation, employment, education and community supports for individuals with ASD.

3. **Serving as the designated lead autism agency for New Jersey.** As the Combating Autism Act (PL 109-461) required, the proposed Autism Treatment Acceleration Act of 2009 (H.R. 2413) is likely to require that states identify a single-state agency to serve as the lead agency to coordinate activities, research and services for Autism Spectrum Disorder.
4. **Developing, managing and utilizing a data system that would provide time sensitive information for the public, consumers and policy makers.** Currently, the Department of Human Services (DHS) funds a variety of efforts to provide information to individuals with ASD and their families. By combining these efforts into a single effort, the state could develop a robust system that can be utilized by individuals with ASD, their families and case managers. This would be an important tool for case managers and the DHS Division of Disability Services. The American Recovery and Reinvestment Act included \$100 billion in healthcare measures, of which \$19 million is intended for healthcare information technology. The Task Force recommends that these funds be examined as a possible source of funds to support the construction of a comprehensive database system for autism. Additionally, it is recommended that resources which otherwise would have been dedicated to duplicative services be realigned to fund the database system.
5. **Providing leadership and coordinating efforts to amend or enact legislation to benefit persons with ASD and these families.** Such legislative initiatives include:
 - A. Revising the legislative mandate for the Autism Surveillance Database to include persons older than 21 years of age;
 - B. Enacting legislation to establish a tax-exempt savings plan to provide for care and services for individuals with ASD; and,
 - C. Enacting legislation to allow the tax exempt donation of houses even in the event that a family member with ASD will not be residing there.
6. **Promoting, disseminating and coordinating best practices in the training of staff and other supports to people with autism as well as autism awareness training to community entities.** OAS can provide leadership in developing incentives for the delivery of quality support care for persons with ASD by working to elevate the prestige and importance of this work. These efforts would include improving the training programs and reimbursement for direct services staff and behavior specialists, and increasing the pay scale for those providing support to adults with ASD in employment and residential settings to a level competitive with alternative employment.
7. **Assisting individuals with ASD and their families to understand the range of available services across the lifespan and across agencies.** The OAS can play a critical role in assisting persons with ASD and families to become knowledgeable about the policies and planning processes that serve as the foundation to the service systems.
8. **Providing leadership in enacting legislation that would benefit individuals with ASD and their families.** Such initiatives could include working with the Governor and Legislature to establish a New Jersey Disability Savings Account, based on the federally-proposed Achieving a Better Life Experience Act. The act would encourage individuals with ASD and their families to save funds tax-free for disability related expenses.

9. **Act as the coordinating entity in pursuing grants and partnerships with non-state entities** that would include, but not be limited to, faith-based organizations, non-profit entities, for-profit corporations, local community groups, local and county governments and federal agencies.

The creation of an “Office of Autism” is not a new concept to state government. New Jersey would follow the lead of other states that have, in response to the growing number of citizens with autism, created similar entities. The states of Pennsylvania (Bureau of Autism Services), Massachusetts (Autism Spectrum Division) and Connecticut (Division of Autism Services) have successfully put into place centralized offices with purposes and intent similar to those proposed for New Jersey. California has added two additional autism specialty positions to each of the 21 Regional Centers serving their developmental disability population, expanding their workforce to coordinate better services and supports with the necessary expertise. It is noteworthy that the aforementioned states have found that the centralization of autism-related matters has increased both fiscal and managerial efficiency.

Recommendation #2: *Establish an Executive Oversight Board to ensure that the proposed recommendations are acted upon.*

The purpose of the Executive Oversight Board (EOB) would be to ensure the development of an implementation plan that puts into operation the recommendations, and maintains the Administration’s focus on the needs of adults with autism. The Task Force recommends the EOB be convened by the Governor and include key cabinet level representatives, including the Commissioners of Human Services, Education, Labor and Workforce Development, Community Affairs and Health and Senior Services; appointed members of the Adults with Autism Task Force as well as members of the public would be appointed by the Governor.

Recommendation #3: *Enact legislation to address the specific needs and concerns of adults with ASD.*

Problem Statement: Recent state legislation has improved a system that addresses children with ASD, but far less attention has been given to the needs of adults with ASD.

As described more fully in the Executive Summary (See Page 3), the Task Force recommends the legislation listed below to be enacted to address the needs of adults with ASD:

- Establish a New Jersey Tax-Free Savings Account so that families can save for lifespan expenses related to ASD.
- Amend New Jersey’s Law Against Discrimination (LAD) specifically to prohibit discriminatory acts against persons with ASD and other developmental disabilities.
- Amend the New Jersey Autism Registry legislation to include adults with ASD on an opt-in basis, and include the necessary privacy and information security protections.
- Expand proposed legislation that urges the state Board of Education and Commission on Higher Education to encourage the establishment of programs to provide student partners to students, to include adults with ASD.

- Expand proposed autism and intellectual, and other developmental disabilities awareness program legislation for certain first responders, to include other professionals.
- Establish a tax exemption for donation of homes to be used as a residences for persons with ASD.
- Explore state tax credit for employment of autistic adults.

If New Jersey lawmakers and governmental agencies are truly committed to protecting and assisting some of their most vulnerable citizens, a strategic plan commensurate with the enormous needs of the state will be implemented; and include the necessary resource commitments to ensure the state and local infrastructure is prepared.

Note: Each of the remaining recommendations, as proposed by sub-committees of the Task Force, will realize a greater opportunity for successful implementation with the establishment of an Office of Autism Services (OAS).

Transition from Education Entitlement to Adult Life

Recommendation #4: *Develop a Student Bill of Rights.*

Problem Statement: Many students in New Jersey with ASD are not prepared for life beyond school, and the testimony of families at the public forums of the Task Force reaffirms this fact. Few families (See Table 2) are confident that the transition plan for their child with ASD has been adequately established and that it will be effectively implemented.

Notably, one of the purposes of The Individuals with Disabilities Education Act of 2004 (IDEA) is to ensure that 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. School districts should be required by law to advise parents/guardians of all classified students with ASD regarding the students' legal rights with graduation, transitional and post-school services within 30 days of their 17th birthday; a statement of rights should be coordinated by OAS and provided to parents.

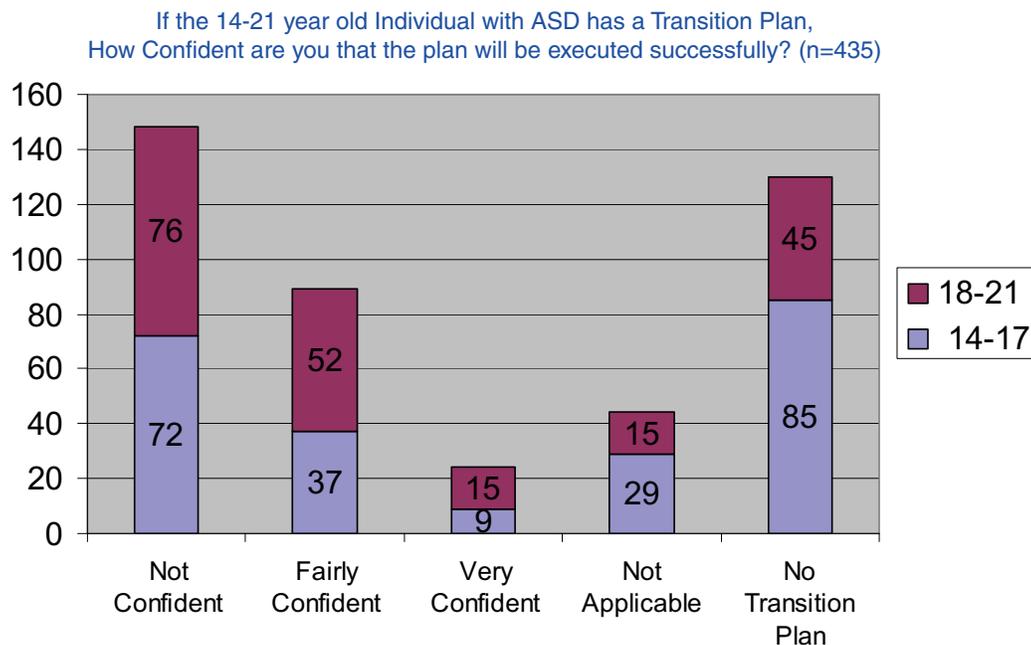
Clearer guidance is needed for all members of the Individual Education Plan (IEP) team in regards to defining appropriate goals and programs to meet those goals. Appropriate documents could include a Bill of Rights, a Parent Manual and updated Quality Indicators. The Bill of Rights for students with ASD could be modeled after the Student Bill of Rights developed by the Office of Special Education Programs.

The Bill of Rights should be a one or two-page information sheet clearly explaining to individuals with ASD and their families the requirements of the IEP with regards to transitioning from school to adult life, including but not exclusively their right to:

- Access to an autism specific expert
- Functional resume upon graduation
- Social skills training
- Information regarding higher education options

A Parent Manual, coordinated by the OAS, would include basic information on the transition process, including all the partners involved on the state level, the necessary items to have in place year-to-year in the transition process, important resources (including information about federal and state benefits) and contact information. Quality Indicators regarding training of transition personnel, appropriate program characteristics, effective instructional methods, effective family involvement and support, and effective program evaluations should be developed in cooperation with the state Department of Education and coordinated by OAS. The Quality Indicators should be reviewed from time to time to ensure relevance.

Table 2 - Summary of confidence in transition plan for adolescent with ASD.



Note: A separate transition plan is not required by state or federal regulations. Transition services are addressed in the IEP for students age 14 and older.

Recommendation #5: *Establish a mandatory growth provision in the DHS Division of Developmental Disabilities’ annual budget to ensure funding for students transitioning from school to adult life for each fiscal year.*

Problem Statement: Historically, available funds for transition are not announced until after the State adopts the budget on June 30. Without surety of funds during the transition process, which begins at age 14, successful transition is at risk.

Recommendation #6: *Require teachers and case managers involved in transition planning to attend training on transitioning students with ASD, to be coordinated by the OAS in collaboration with DOE.*

Problem Statement: Individuals with ASD and their parents look to teachers and case managers for guidance in preparing for transition. Many of these professionals are not specifically trained in addressing transition needs of youth with ASD.

Recommendation #7: Implement PL 2007, Chapter 171 in college and university curricula to train teachers and program coordinators in educational methods for teaching students with ASD.

Problem Statement: The DOE responded to public Law 2007, chapter 171 provides for instruction, in autism and other developmental disabilities awareness and methods of teaching students with such autism and other developmental disabilities, for candidates for teaching certificates, current teachers and paraprofessionals; this has not been implemented despite clear time deadlines.

The DOE responded to the requirements set forth in P.L. 2007, C. 171, Section 2, by incorporating the legislative requirements for autism, developmental disabilities awareness instruction, and teaching methods into the New Jersey Administrative Code 6A:9. Professional Licensure and Standards. The Professional Licensure and Standards regulations include the Professional Standards for Teachers and School Leaders at N.J.A.C. 6A:9-3.1. and requirements for the curriculum for teacher preparation programs at N.J.A.C. 6A:9-10.2.

These standards identify the knowledge, skills and dispositions that teachers need to practice responsibly, and are used in accreditation of preparation programs (N.J.A.C.:9-3.1(a),(c). In addition, there is a requirement that the professional component of the undergraduate program be aligned with the Professional Standards for Teachers, and provide students, normally beginning in the sophomore year, with practical experiences in an elementary, middle or secondary school setting (N.J.A.C.: 6A: 9-10.2(a) 4.

Through the administrative code changes, the department strengthened Standard Seven, Special Needs of the Professional Standards for Teachers, which states: "Teachers shall adapt and modify instruction to accommodate the special learning needs of all students." Standard Seven will be enhanced by incorporating the areas included in P.L. 2007, C. 171, Section 2, specifically:

- Characteristics of students with autism and developmental disabilities;
- Curriculum planning, curricular and instructional modification, adaptations and specialized strategies and techniques;
- Assistive technology; and
- Inclusive educational practices, including collaborative partnerships.

Through this revision, the DOE will implement the legislation in each of the 18 New Jersey institutions of higher education (IHE) that offers a teacher preparation program, thereby requiring all of the IHEs to incorporate the above listed areas into its sequence as required by N.J.A.C. 6A: 9-10.2(a) 4.

The DOE, Office of Special Education programs, has allocated funds for the 2009 - 2010 school year to support the implementation of this legislation by providing the opportunity for each IHE to enter into a grant agreement to purchase instructional resources (e.g, professional textbooks, videos, DVDs, etc.) that will support the implementation of the enhancements to Standard Seven. In addition, the department will seek input from each of the organizations specified in P.L. 2007, C. 171 regarding strategies for infusing the standards into the IHE curriculum and potential instructional resources.

Recommendation #8: Increase educational opportunities for adults with ASD by expanding access to continuing educational opportunities on a credit or non-credit basis.

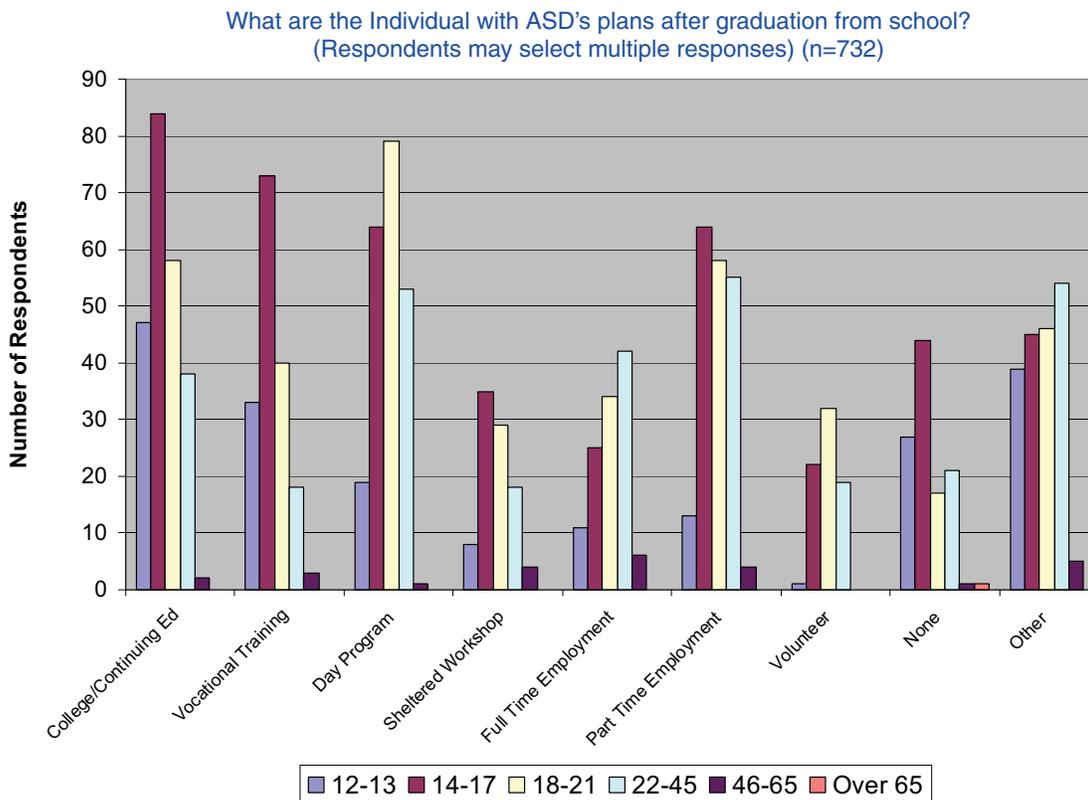
Problem Statement: Recent research suggests that neurological systems continue to develop until the mid-20s. As a result, individuals with ASD may have slower neurological development than neurotypical persons and may thus need a longer period for transition.

“He currently has an internship at a restaurant, and also interns at an Assisted Living home setting tables, and working in the office. He enjoys both of his internships, however, this will all come to an end upon graduation. I am in the process of trying to find a placement for him after graduation, and I can’t believe that we have worked so hard and his prospects are so limited. Waiting lists, waiting lists, waiting lists! This is exactly where I started back in 1990. The population of autistic individuals has soared, and yet the State has failed to prepare for it. Many programs were not designed to fit this type of individual, merely a “one size fits all.” Without the proper placement, anxiety will build, and behaviors will return. My son has acquired many capabilities, but also requires supports in the outside world. He does not pose a threat to anyone, but is innocent of what can happen to him. The funding is necessary to keep him a part of society, with individuals properly trained to integrate him in the real world.

My son will graduate in 2010, and can’t afford the setback of not having a place to go each day. Sitting in front of the television, playing videos, etc, by himself all day should not be his only option. Graduation will also mean I can no longer work, because I need to provide the necessary care for him. My son cannot be left alone. His communication abilities are such that he is not able to call for help, or know what to do in case of an injury, or emergency. This is very stressful. I cannot afford to retire in 2010.”

- Mother of a 20 year old son with ASD

Table 3 - Persons with ASD and their families show great interest in the broad range of opportunities for work environments.



Day Programs

The transition of students with ASD, from the educational system to participation in appropriate day programs, should be seamless, just as the transition from high school to college is for other students. Like other school age transition programs, a strong day program will contain a robust life skills module. It is paramount that the needs of the person with ASD determine the environment and nature of the services provided.

Recommendation #9: *Implement an ASD-specific training program, coordinated by the OAS, for Day Program professionals on the characteristics of ASD and effective interventions. Staff training programs should include consumer involvement to ensure self-determination and direction, and should be culturally appropriate. Provide Day Programs with staffing requirements based upon the needs of program participants.*

Problem Statement: Insufficient staff is not trained in appropriate ASD interventions, and the staffing ratios do not allow for meaningful and functional engagement.

Recommendation #10: *Expand the number of Day Programs for adults with ASD.*

Problem Statement: There are an inadequate number of Day Programs that address the needs of adults with ASD and those that do exist often do not offer the necessary skills training to promote the advancement of the adults with ASD being served.

These programs should be required to include a social skills training module with opportunities for natural reinforcement in the community. Pre-vocational skills building in areas such as good grooming, social skills, organization training, budgeting, workplace behavior and potential employment (e.g, basic computer applications or facilities) should be offered.

Recommendation #11: *Develop a model program tailored to the needs of people with Asperger Syndrome or High Functioning Autism.*

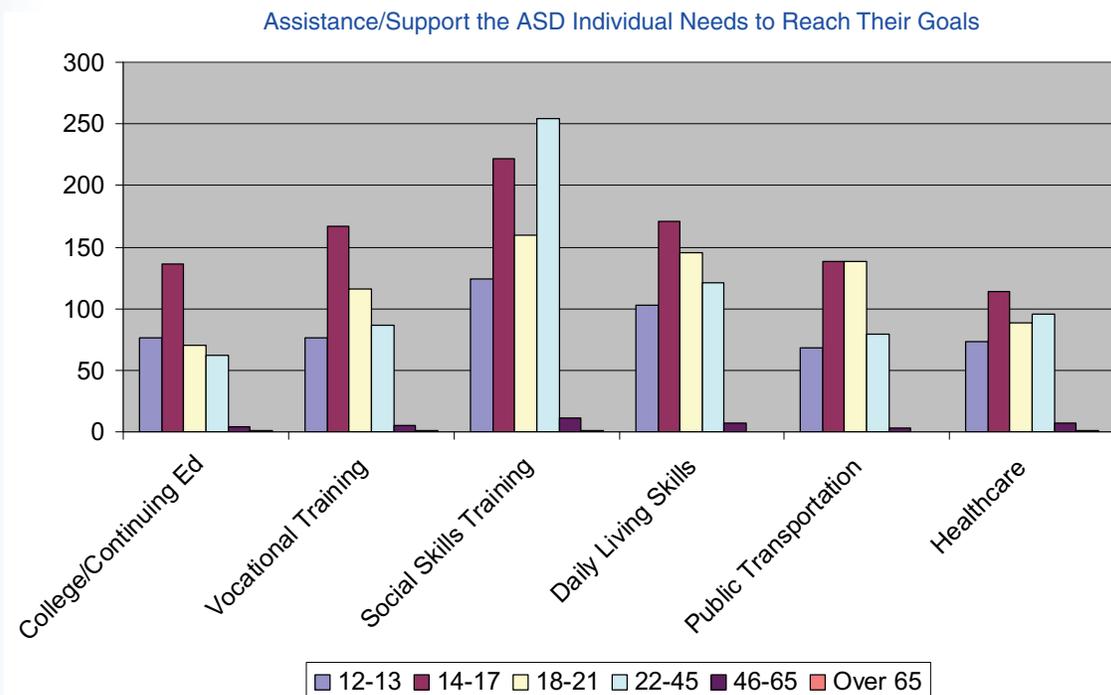
Problem Statement: The established Day Programs need to address the challenges of individuals with high functioning autism or Asperger Syndrome.

Although some of the program components would be similar to the traditional ASD Day Program, the level of instruction and degree of intensity would differ. The topics would include social skills training, pre-vocational skill development and exercise. A greater emphasis should be given to preparation for competitive employment, when appropriate.

Life Skills

Life skills include training across a broad range of categories. These skills include, but are not limited to, social skill development that enables individuals with ASD to interact effectively with others, to more functional skills, such as using transportation systems independently, to specific skills that are required to access higher education or competitive employment and advocacy. Table 4 (See Page 26) provides a summary of the assistance or supports that persons with ASD perceive to be fundamental to their achieving independence.

Table 4 - Summary of the assistance or supports that persons with ASD perceive to be fundamental to their achieving independence.



Recommendation #12: Establish criteria and best practices for life-skills training for adults with ASD.

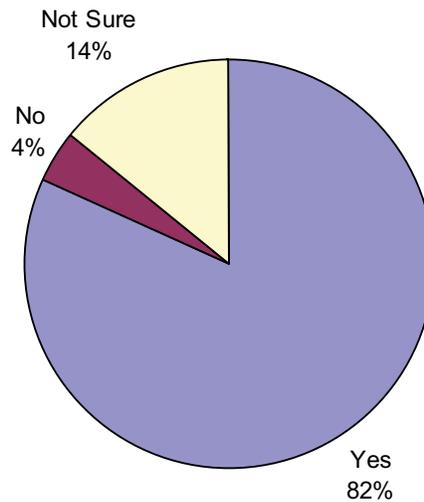
Problem Statement: Sufficient services are not available to foster independent living skills in adults with ASD.

Without appropriate services, many adults with ASD are not able to develop independent living skills and could require more intense and costly services. A life skills training program would teach and continue to reinforce social skills, workplace conduct, organizational skills, budgeting, transportation and personal health (including nutrition and fitness). The program would utilize a person-centered planning concept that uses both natural supports and formal community supports.

A life skills module as part of the transition curriculum is also recommended for students with ASD. As illustrated in the following Table 5, respondents identified training in social skills as their greatest need.

Table 5 - Respondents summary of the assistance or supports that persons with ASD perceive to be fundamental to their achieving independence.

Would Social Skills and Relationship Training Be Beneficial For Individuals with ASD? (n=816)

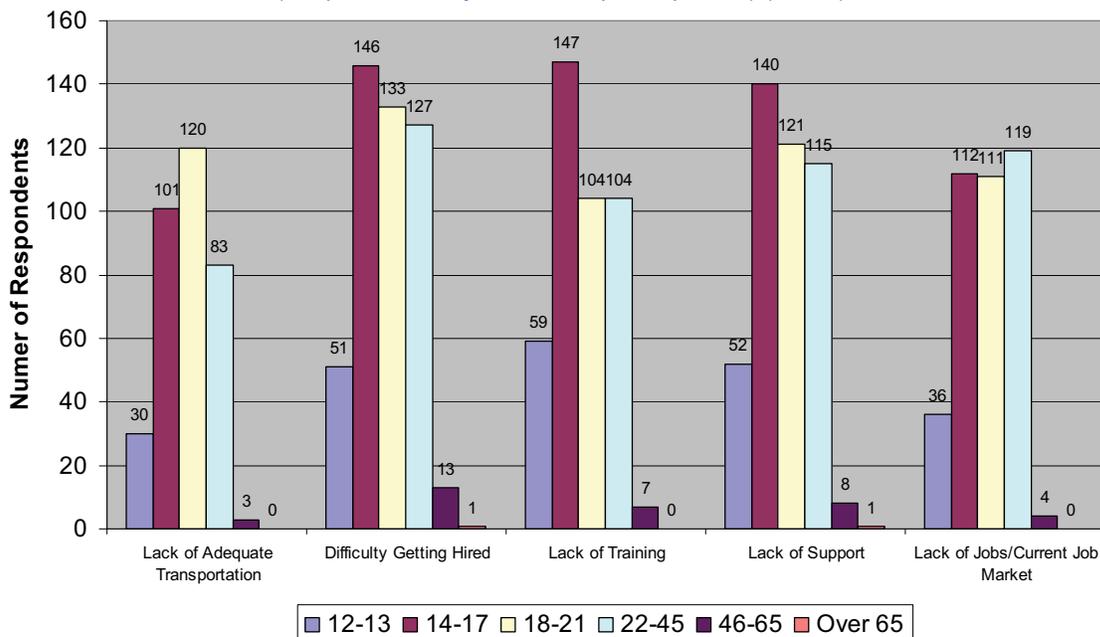


Recommendation #13: *Allocate independent living funds received under the American Recovery and Reinvestment Act of 2009 (ARRA) for training and capacity improvement programs aimed at assisting Independent Living (IL) Centers to serve adults with ASD. This would be consistent with recognition of the availability of these funds and the goal of using these funds to serve additional consumers, especially populations that are unserved or underserved by IL programs in the state.*

Problem: Funding for the implementation of appropriate and sufficient programs is scarce.

Table 6 - Persons with ASD perceive that they face numerous barriers to employment.

What are the barriers to employment for Individuals with ASD?
(Respondents may select multiple responses) (n=667)



EMPLOYMENT

Recommendation #14: *Increase efforts to educate employers about the positive aspects of hiring people with ASD.*

Problem Statement: Adults with ASD are under-represented in the workforce.

In-service trainings could be provided to the employers and employees of various companies and organizations. Education would include information about tax credits and “On-the-Job Training” funds offered in coordination with DLWD-DVRS. Training should also incorporate information about assistive technology, and the array of reasonable accommodations that could serve the employee with ASD.

Recommendation #15: *Introduce legislation, similar to that under consideration in Massachusetts, to establish a tax credit for the employment of individuals with ASD, allowing employers to take a tax credit on a percentage of gross wages paid to employees with ASD.*

Problem Statement: There are no state tax benefits for employers in New Jersey who hire adults with ASD.

Recommendation #16: *Enhance the necessary support systems for adults with ASD to achieve employment success.*

Problem Statement: Some individuals with ASD may need intensive supports, including job coaching, social skills and executive functioning training, over longer periods of time than what is typically offered.

It may be appropriate to examine this issue in pilot programs that study the appropriate levels of supports needed for certain individuals on the spectrum or, if feasible, to examine how best to structure and utilize job coaching as provided by existing service agencies. For individuals with ASD who could be successful in self-employment, there may be the need for specific supports to assist them with executive functioning issues such as organization. The supports may need to be explored within the scope of job coaching or through the assistance of volunteers such as retired business executives/personnel.

Recommendation #17: *Expand innovative employment models such as work-cooperatives.*

Problem Statement: There is a need for more structured work environments to help support individuals with ASD.

There may be the need to develop additional settings other than those already in existence in order to accommodate the needs of those on the autism spectrum who desire to work. These options could be proposed by a business leadership team, comprised of self-advocates, who could meet with local and regional businesses. This type of work environment could be added as a work component to other types of structured programs. The goal also could be achieved by private agencies developing small businesses or work co-operatives as a means of providing employment for individuals with ASD and generating income to sustain the business. It is also recommended that mechanisms for self-direction and self-determination in service delivery are incorporated into such programs.

Recommendation #18: *Provide autism-specific training to service providers of vocational services in both public and private organizations; offer autism-specific training that includes information about aspects and nature of autism as well as the varied assessments and services that would benefit this population.*

Problem Statement: New Jersey lacks ASD-specific training programs for employers and staff.

An example would be training in the use of augmentative communication devices and other assistive technology, since this may be a useful support in employment settings. Autism-specific training is currently being provided to New Jersey DVRS counselors and job coaches, and it is assumed that this also would be a viable training venue for other services providers. Individuals with ASD should be included in the provision of this training.

Recommendation #19: *Allocate a portion of New Jersey's ARRA funds to support vocational rehabilitation services for persons with ASD.*

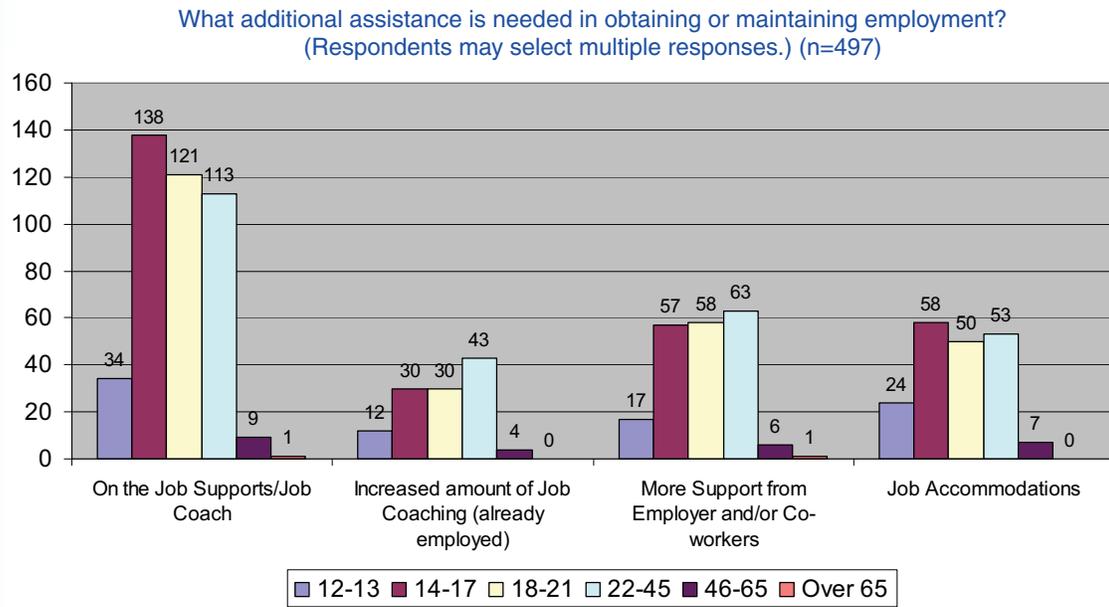
Problem Statement: There is no funding available to help create jobs for adults with ASD.

Creation of jobs for individuals with ASD is consistent with the purpose of the American Recovery and Reinvestment Act of 2009 (ARRA), which encourages states to spend funds to create new jobs and to do so in a fashion that will minimize the "funding cliff" created by the temporary nature of this additional funding. It is anticipated that New Jersey's vocational rehabilitation system will receive an additional \$9.4 million in funding under ARRA.

Recommendation #20: *Continue exploration undertaken by the DHS Division of Developmental Disabilities (DHS-DDD) and New Jersey Division of Vocational Rehabilitation Services (DVRS) to identify successful programs throughout the nation that offer creative use of long-term resources that promote natural supports in the workplace.*

Problem Statement: Current government funding does not identify specific employment services for people with ASD.

Table 7 - Summary of the support services that persons with ASD perceive will help them become successful in obtaining and maintaining their employment.



Healthcare

A transparent, accessible acute and long-term care (LTC) healthcare system in New Jersey needs to be available for all adults with ASD. Task Force Recommendations # 21 through #27 are framed by the knowledge that healthcare is one of the most critical issues facing the nation. We must ensure that people have access to, and understand how to access, the healthcare services they need when at all possible. Generic healthcare services and disability specific services should be used, but there also needs to be evidence-based autism specific interventions available to adults on the spectrum.

Recommendation #21: Educate people with ASD and their families about the governing authorities underlying their health plans so they can advocate more effectively for themselves or on behalf of a loved one.

Problem Statement: The healthcare industry is not completely educated about the health needs of persons with ASD, and best practice guidelines for providing health services are not available.

Under the leadership of OAS, DHSS and DHS should make these guidelines and quality standards material accessible to current consumers (of their services) and potential consumers through the DOE and Department of Children and Families (DCF). Training on these guidelines and quality standards should be available through medical and allied health professional continuing education programs. If existing guidelines and quality standards are not available, the Task Force recommends the Governor's Council for Medical Research and Treatment of Autism work to develop these materials.

Recommendation #22: *Develop a comprehensive existing database of all New Jersey healthcare providers who treat adults with ASD and make this information accessible to the broader community through existing entities such as, NJHelps.org and the NJ 211 system.*

Problem Statement: No comprehensive database of healthcare providers serving persons with ASD is currently available.

Particular focus should be placed on health care disparities faced by adults with ASD, and on race, gender, ethnicity, income and geographic disparities in autism diagnoses and services.

Recommendation #23: *Execute an interagency agreement between DHSS and DHS to work together to assist people in understanding the healthcare services that are available; and if eligible, how to access the Medicaid State Plan services and all other applicable state healthcare programs.*

Problem Statement: The service system is confusing.

Persons with ASD and their families are not educated about how to access Medicaid and other state healthcare programs. Eligibility criteria and availability information should be accessible to consumers and healthcare providers.

Recommendation #24: *Educate people with ASD and their families about the governing authorities underlying their health plans so they can advocate more effectively for themselves or on behalf of a loved one.*

Problem Statement: Persons with ASD and their families are not well-educated about the policies that govern the various health care programs.

Individuals should be made aware of state authority under the State Health Benefits Plan (SHBP), federal ERISA authority and Medicaid State Plan Services, including New Jersey's Medicaid Buy-in Program. A public awareness campaign would help the ASD community to understand SHBP rules. This could include Public Laws such as:

- Mental Health Parity
- P.L. 2005, Chapter 365 (where individuals can maintain a dependent's healthcare up to age 30)
- P.L. 2005, Ch 198 requires offering long-term care insurance to employees

Recommendation #25: *Undertake an examination, by DHSS and DHS, to determine the commonalities between the long-term care needs of the aging population and individuals with developmental disabilities, including autism.*

Problem Statement: Innovative mechanisms for supporting long-term services for persons with ASD have not been explored.

Ideas should be explored that would expand the pool of available resources by allowing for a combination of public/private financing of an individual's services. Alternatives could include purchasing long-term care with tax advantaged medical savings accounts and sliding scale fees. The Home and Community-Based Services (HCBS) Waiver* administered by the DHS, Division of Developmental Disabilities (Community Care Waiver) should be enhanced in order to meet the needs of adults with ASD in a flexible manner. The OAS should explore developing viable options through a commission on long-term care and the developmental disabilities community.

Recommendation #26: *Explore expanded partnerships with the federal government, and specifically the Center for Medicare and Medicaid Services (CMS), to maximize federal resources to serve adults with ASD, including enhanced services in the Medicaid State Plan.*

Problem Statement: Federal resources are not being maximized to support services for adults with ASD.

Recommendation #27: *Ensure the Dual Diagnosis Task Force proposed continuum of crisis response services addresses the needs of adults on the autism spectrum.*

Problem Statement: During crisis episodes, individuals on the autism spectrum with challenging behaviors or who also have mental health disorders often go to general hospital emergency rooms. These individuals and their families report that there are very few resources to address their needs.

In October, 2008, the Dual Diagnosis Task Force (DDTF), convened by Department of Human Services Commissioner Jennifer Velez, published its report entitled "Collaborating to Provide Supports and Services for Adults and Children with Co-Occurring Developmental Disorders and Mental Health/Behavioral Disorders." One of the priority recommendations was the development of a continuum of crisis response services including crisis prevention, mobile response, crisis beds and crisis stabilization services. As part of their Implementation Plan, the DDTF convened a Clinical Workgroup that will participate in defining the continuum of crisis response services that should be contained within the State's Medicaid Plan.

Note: The Department of Human Services (DHS) operates a Home and Community Based Services Waiver in accordance with federal regulations promulgated by the Centers for Medicare and Medicaid Services. The waiver, which has been in place since 1982, is commonly referred to as the Community Care Waiver (CCW) and allows the state to use Medicaid funding to pay for certain services provided to people living in the community, rather than in an institution. Most of these services are provided by contracts with social service agencies. Recently amended, the Department of Human Services, Division of Developmental Disabilities (DHS-DDD) will be able to bill the federal government for a portion of the cost of a number of services that currently are funded entirely by the state, including self-directed services, community transition services, support coordination, assistive technology devices and non-medical transportation needs. The DHS website, <http://www.state.nj.us/humanservices/>, provides additional information regarding this matter.

Housing

Persons with ASD, with the help of their families, the State of New Jersey and their community, can successfully transition into independent living in New Jersey. The process is clearly defined. Information is readily accessible. Persons with ASD and their families are fully capable of participating in a plan that will result with full integration into the community. Table 8 (See Page 33) displays the current living arrangement for individuals with ASD, while Table 9 (Same Page) shows the living arrangements those same individuals would prefer.

Recommendation #28: *Re-organize and operationalize the Medicaid Waiver waiting lists, by county or region, in order to facilitate local long-term planning.*

Problem Statement: The current system funnels everyone into a single point of service, creating a log-jam where few people are served in any year.

In addition, since there is little geographic consideration at the time a placement occurs, placements are often made away from an individual's natural support system. As illustrated in Table 9, (See Page 33) the greatest proportion of persons with ASD prefers to reside in housing that is independent from their parents.

Recommendation #29: *Provide ready information on available housing for people living with disabilities, including housing owned by the DHS-DDD and resources available on a local level.*

Problem Statement: Information regarding housing for the disabled is available at different places or is not available. Access to ready information is unclear and it does not allow for potential partnerships to rehabilitate, maintain and operate housing.

The Task Force recommends making ready information on available housing for the disabled, including both housing owned by the DHS-DDD and resources available on a local level. Technology platforms in which the state has already invested, such as the New Jersey Housing Resource Center, should be used. Information regarding DHS-DDD housing can be included by municipality or county and not by street address, if there is a concern that neighborhoods will respond negatively to DHS-DDD housing within their neighborhood. It is also recommended that DHS-DDD prepare a report that specifies the location, type and physical condition of the housing unit that would be shared with the Office of Autism Services.

Alternative housing arrangements should be made available to those who are waiting for their number to come up on the Priority Waiting List. Perhaps families could help contribute their own time and/or resources for these alternate options. Collaboration is needed between the various agencies (for example: DDD, HUD, County Assistance, Social Security, home health care agencies, private businesses) and the families to make independence possible earlier for the adult with autism. For example, perhaps families can contribute their own time toward the staffing requirements of supervised apartments. Again, alternatives should be explored while DDD's Priority Waiting List remains extraordinarily long.

- Mother of 20 year old adult with ASD

Recommendation #30: Create a grant award or pilot demonstration program for housing. Awards would be based on: 1) specific needs of the ASD population, 2) ability to decrease service costs 3) community involvement 4) partnerships 5) sustainability, and 6) ability to be replicated. During the current fiscal crisis, it is recommended that the State of New Jersey take a leadership role in conducting research, investigating the models and programs that are effective and efficient. Given the limited funds available under the Family Support Act, it is recommended that the State leverage those funds by using a portion to fund this program.

Problem Statement: The current waiting list for housing and services is in excess of 8,000 individuals. The DHS-DDD has been able to serve approximately 50 to 150 individuals a year, mostly on an emergent basis.

Most people on the list will not be able to be served. The current system amounts to putting the disabled person on a list and waiting; and does not allow for meaningful input from existing resources including parents, faith-based organizations, local government, educational institutions and profit/non-profit entities.

The cost of developing housing includes not only the purchase of the house, but also the operating costs and services necessary for independent living. During the current fiscal crisis, the State needs to conduct research and investigate models that will be more effective and efficient. It should be noted that housing models should be integrated and consistent with the Americans with Disabilities Act; and service provision models should be person-centered and self-directed.

Recommendation #31: Make alternative housing arrangements available to those who are waiting for their number “to come up” on the Priority Waiting List.

Problem: Adults with ASD are told they should expect to wait for many decades before their number comes up.

Programs that encourage contributions of time and/or resources are needed to implement these alternate options, which would require collaboration between the various agencies (for example: DHS-DDD, the U.S. Department of Housing and Urban Development (HUD), county assistance, U.S. Social Security Administration, home health care agencies, private businesses, etc.) and the families to make independence possible earlier for the adult with ASD.

Recommendation #32: Increase and change how funds are distributed for housing and services.

Problem Statement: The magnitude of the housing problem requires a fundamental change in how DHS-DDD addresses the issue. A significant portion of DHS-DDD’s budget is dedicated to the State’s seven developmental institutions. The State has also concluded that 81 percent of those in the developmental institutions are able to live in the community. It is the understanding of the Task Force that the cost of living in the community is approximately half of the cost of living in an institution. If savings could be obtained by transitioning the disabled out of the institution, while still providing a safe and successful life for those who would be transitioned, the Task Force supports closing a majority of the developmental institutions. This also would allow the DHS-DDD to develop community support programs.

In addition to changes in how DHS-DDD applies its budget, the overall budget for DHS-DDD must be increased. The Task Force recognizes that this would be difficult during the current fiscal crisis; but it also believes that a delay would only exacerbate the number of persons on the waiting list.

“My son has been on the DDD high priority waiting list since July of 2000. My latest records show that he is currently number XXX, with no prospect of substantial movement in the foreseeable future. The waiting list continues to grow and grow. While we are fortunate that my son is in a work program, both my son’s mother and I (both in our mid sixties) are deeply concerned for his future. My son needs a viable residential placement before the alternatives reach a problematic stage – not only for him, but as well for the State where the costs will grow substantially.”

- Father of 30 year old adult with ASD



Table 8 - Summary of Current Living Arrangements for Individuals with ASD.

What is the current living situation for the Individual with ASD? (n=785)

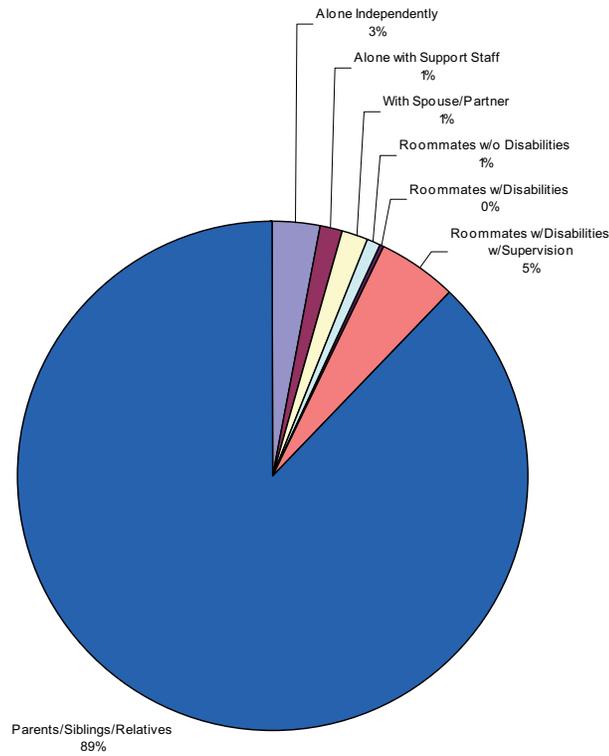
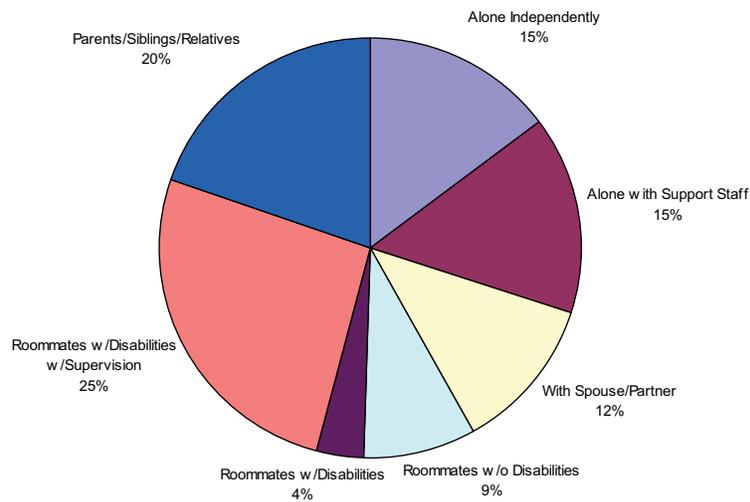


Table 9 - Living Situations Preferred by Individuals with ASD.

With whom does the ASD Individual wish to live? What is the preferred living situation? (n=785)

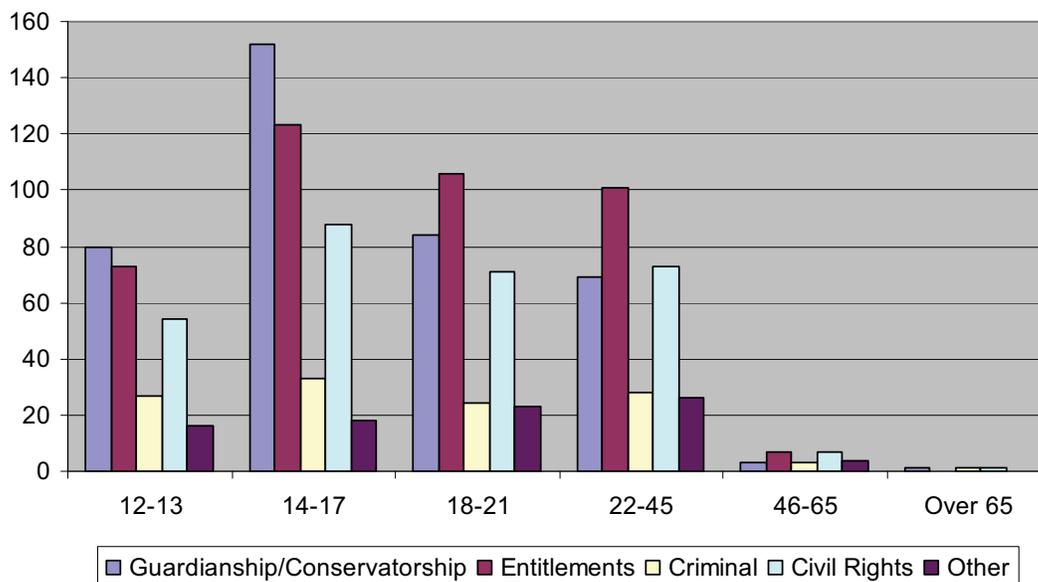


Legal Issues

Preliminary Note: The Adults with Autism Task Force has addressed and considered various law-related issues that appear in other sections of this report, such as the proposed amendments to New Jersey’s Law Against Discrimination, creation of a New Jersey Office of Autism Services, possible modifications to tax codes, methods of addressing transitional issues for high school students with ASD, etc. The Legal Issues section focuses specifically on New Jersey’s court system and the need for continuing judicial education on autism spectrum disorder.

Families encounter a myriad of legal issues as their child with ASD reaches adulthood. Consequently, guardianship for individuals with ASD who may need this protection and entitlement to adult services become tantamount. Table 10 provides a summary of these concerns.

Table 10 - Legal Issues of Concern for ASD Individuals.



Recommendation #33: Educate Superior Court judges about Autism Spectrum Disorder.

Problem Statement: In the past decade, the population of New Jersey residents diagnosed with ASD has grown substantially. As a result, it is logical and predictable to assume that there will be a growing increase of persons with ASD who are involved in, or the subject of, judicial proceedings including, but not limited to, proceedings in Family Court, Surrogate's Court and Criminal Court. It is therefore a matter of sound public policy to provide members of the judiciary with on-going judicial education about ASD.

In New Jersey's judicial system, Superior Court Judges often must address legal issues concerning persons who have ASD. Judges are often personally unfamiliar with ASD. In view of the growing number of persons diagnosed with ASD, it is in the public's interest for judges and attorneys to learn as much as possible about ASD as such education may significantly impact how cases are viewed by judges in matters involving persons with ASD. Education should be developed through such educational outlets as the Judicial College and other court-sponsored or supported programs.

Family Court:

- a) A high percentage of marriages end in divorce when the parties have a child with ASD. Thus, children with ASD are often the subject of court proceedings relating to custody, visitation schedules, support and funding of special needs.
- b) The court and counsel must advocate for the best interests of the child with ASD under **parents patriae jurisdiction**, so that the child may hopefully grow to be an adult who can be a functioning member of society.
- c) Accordingly, public policy supports the establishment of autism education for family court, in conjunction with the Judicial College through the Administrative Office of the Courts.

Surrogate's Court:

- a) Once an autistic child is over 18 years of age, he/she may possibly be the subject of a guardianship or conservatorship proceeding. Judges who preside in Surrogate's court will benefit from continuing education on ASD to help resolve the issues of (a) whether guardianship is required, and if so (b) who should be named guardian and the familiarity required of the guardian in regards to ASD.

Criminal Court:

- a) If a criminal defendant has ASD, the disorder may be relevant on the issues of criminal culpability as well as sentencing (rehabilitation, deterrence, etc). Accordingly, there is a public interest in judges having continuing education regarding ASD.

Note: See Appendix B for more details.

Private Sector Engagement

It is imperative that the public and private sectors forge a partnership to attain the goal of successfully integrating adults with ASD into community life. Private sector engagement includes the goals of: fostering awareness that ASD is a lifespan challenge; dialoging that focuses on strengths, talents and abilities while addressing challenges; and enhancing opportunities for adults to live, work and participate in recreational activities.

Recommendation #34: *Create an ad campaign to focus on individuals and their varying strengths, challenges and abilities to highlight the diversity of the adult ASD community.*

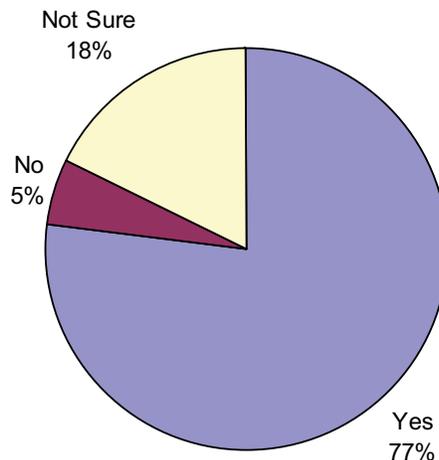
Problem Statement: The Task Force survey supports the view that a public service ad campaign is essential to creating accurate portrayals of adults with ASD.

The plan of action is for the OAS to work with the New Jersey Ad Club, the New Jersey Art Director's Club and The New Jersey Broadcasters Association to develop a pro bono public service media plan and public service ad campaign. There is already a mechanism in place for applying for such pro bono advertising with these organizations.

Overwhelmingly, individuals and families affected by ASD feel that the public has many misconceptions about adults with ASD (See Table 11). Many persons have a "Rain Man" image of adults with ASD, while others believe that adults with ASD are totally dependent people with few skills, talents or abilities to participate in community life. Still, others do not realize that ASD is a life-long challenge and that varying levels of support are needed for individuals to achieve their full potential for participation in society.

Table 11 - Summary regarding families affected by ASD feel that the public has many misconceptions about adults with ASD.

Do you think a public awareness campaign highlighting the strengths and talents of adults with ASD would enhance opportunities for community support and participation? (n=796)



Recommendation #35: *Sponsor roundtable discussions that include community partners (i.e., businesses, community organizations, ASD service providers and adults with ASD), to brainstorm for ways to engage adults with ASD in all aspects of community life, in collaboration with the New Jersey Chamber of Commerce.*

Problem Statement: Local and regional businesses and community organizations lack exposure to adults with ASD and thus do not know how to integrate these adults into business and community settings.

Roundtable discussions would sensitize and familiarize participants with one another in relations to the goal of fostering empathy and opportunities. Additionally, the New Jersey Chamber of Commerce sponsors an annual Disability in the Workplace Event, which the Chamber is proficient in organizing. It is recommended that this annual program be enhanced with a special week-long track for individuals with ASD. This event would also provide adults with ASD the chance to explore potential employment and recreational opportunities

Recommendation #36: *Establish a peer mentoring program, in collaboration with New Jersey's state colleges and universities, for young adults and adults with ASD to gain invaluable support and guidance from their peers.*

Problem Statement: Adults with ASD have little opportunity to engage with neuro-typical adult peers.

This model would build upon existing peer model programs that have been legislatively established in our state. Degree credit may be offered to the mentors in some cases. Moreover, it is within the current tenor of our state and national agendas to create community service opportunities for our young people. In addition, as part of this adult peer mentoring program, an expert-led autism awareness training session would be required of all peer mentors and could easily be facilitated at college and university settings. An important, existing and untapped resource for support and friendship for adults with ASD are the many young adults and adults attending New Jersey's colleges and universities.

Recommendation #37: *Establish a self-advocate awareness program geared to not-for-profit organizations; information could be circulated at symposiums and workshops provided by entities that serve not-for-profit organizations. The information for public presentations can be coordinated by the OAS.*

Problem Statement: Adults with ASD are not often asked to participate in the decision-making process of not-for-profit organizations that provide services to them.

Self-advocates have the capacity of contributing to the services system.

Recommendation #38: *Collaborate with existing entities to develop ideas as to how to further engage the members of these organizations in providing support for adults with ASD.*

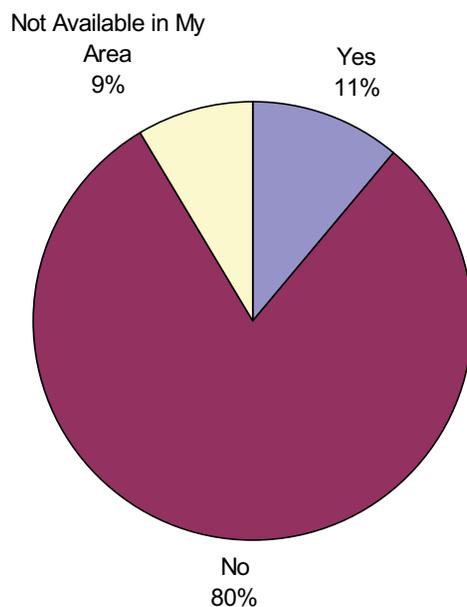
Problem Statement: Private sector partnerships are not maximized to enhance community participation of adults with ASD. Ideas for the development of such community service endeavors are limitless and could include such things as providing rides, adopting a group home and networking for adults with ASD.

Transportation

Public transportation is a critical component for community living for the majority of adults with ASD. In order to avoid institutionalized care, adults with ASD need to be able *to go to work, to go grocery shopping, and to be part of the greater community*. There is inadequate access to public transportation for persons with a developmental disability. As illustrated in Table 12, many adults and students with ASD are not educated in negotiating the state’s available, diverse and complex transportation systems. Similarly, transportation operators are not trained in working with individuals with ASD.

Table 12 - Perceptions of individuals with ASD about their ability to access public transportation.

Did the individual with ASD receive training on how to use public transportation? (n=787)



Recommendation #39: *Completely implement the recommendations of “Meeting the Employment Transportation Needs of People with Disabilities in New Jersey,” published by the Alan M. Voorhees Transportation Center, Edward J. Bloustein School of Planning and Public Policy, Rutgers, The State University of New Jersey.*

Problem Statement: The recommendations of the transportation report, entitled “Meeting the Employment Needs of People with Disabilities in New Jersey,” have not been fully implemented.

Recommendations regarding increased driver training, education in how best to interact with adults with ASD, and developing a concierge/brokerage service demonstration program (that can guide users through the different transportation systems) are of particular importance. It is recommended that these efforts would most efficiently be executed by capitalizing on the work being undertaken by the Council on Access and Mobility to inventory state and federal transportation funding sources, identify additional resources and study ways to improve the coordination of resources to maximize the current state of human service transportation programs and make recommendations for improvement.

Recommendation #40: *Include transportation as a critical component in developing and executing an Individual Education Plan (IEP), Individual Habilitation Plan (IHP), Essential Lifestyle Plan (ELP), or Individual Plan for Employment (IPE).*

Problem Statement: Individuals with ASD and their caregivers/case managers may not be aware of the variety of travel options available to them. Additionally, the services that are provided by New Jersey Transit, Access Link, and smaller regional service providers may have too limited services or scope of services (such as those that provide only non-medical trips). Private car and taxi services are prohibitively expensive to assist persons with ASD in their daily living and community integration.

As the New Jersey Council on Access and Mobility has conducted training sessions for DHS-DDD and DLWD-DVRS, it is recommended that the relevant case manager be responsible for the transportation aspects of each plan. The transportation plans should also encompass the wide range of transportation needs of the persons with ASD, such as employment, shopping, services and general community involvement.

Recommendation #41: *Establish a partnership between New Jersey AccessLink and regional providers to insure that students with ASD, who travel to schools outside their service area, receive appropriate training.*

Problem Statement: The quality and availability of travel training must be improved.

Recommendation #42: *Investigate creative solutions to vehicle liability issues in order to facilitate greater coordination among community transit systems and lessen the duplication of routes and resources.*

Problem Statement: Both real and perceived restrictive policies related to vehicle liability insurance as well as volunteer driver insurance serve as a major barrier to effective transportation coordination.

Recommendation #43: Adjust the New Jersey Casino Revenue Fund Advisory Commission's formula for para-transit aid to reflect the relevant county's population of seniors and persons with disabilities.

Problem Statement: The New Jersey Casino Revenue Fund Advisory Commission is responsible for allocating funds from the Casino Revenue Fund. Riders with disabilities are not considered in the distribution of casino tax revenues to counties to fund para-transit programs.

Aging

Recommendation #44: Train county-based offices on aging and other aging-related service providers regarding the needs of persons with ASD.

Problem Statement: During the public forums and through written testimony received by the Adults with Autism Task Force, a few families voiced the concern that it was not just they who were aging but so were their adult children with ASD. Many noted that the current systems serving older residents, such as nursing homes, were not trained or prepared to address the particular needs of older persons with ASD who are beginning to need these facilities.

Note: For the most part, the Adults with Autism Task Force focused its attention on the most current problems that are facing individuals with ASD and their families. These needs are primarily directed to those persons with ASD who are preparing to leave the school system or are now young adults.

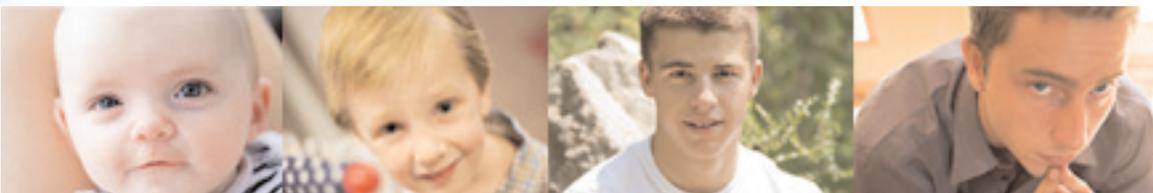
The children... who started receiving services 34 years ago have now grown into adults who need adult medical services. Most Hospitals, Nursing Homes, Rehab Facilities and Assisted Living facilities do not understand how to treat adults with Autism. These adults will require the same services that all aging parents and the general aging population will need, but they are not available.

Develop training programs to educate all the facilities that offer services to the aging population and to the community in general.

Develop a certified list of nursing homes and rehab professionals who are capable of treating the adult population with Autism.

Set up a Special nursing home unit within each facility to address the needs of this population.

- Parent of a forty year old man with ASD



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Principal Investigator: Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder: Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2002. MMWR Surveill Summ. 2007; 56(1)12-28.
2. Ganz, ML. The Lifetime Distribution of the Incremental Societal Costs of Autism. Arch Pediatr Adolesc Med, Apr 2007; 161: 343 - 349.

Appendix A

SUB-COMMITTEE MEMBERSHIP

Day Program

Mary Meyer, Chair
Dorothy Blakeslee
Linda Walder Fiddle, Esq.
Mary Laresh
Leslie Long

Education to Adult Services Transition

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Michael Gallo
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Employment

Ari Ne'eman, Chair
Karen Carroll
Brian Fitzgibbons
Anthony Langdon

Health

Leslie Long, Chair
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Housing

Dorothy Blakeslee, Chair
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Mary Meyer
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Legal Issues

Lawrence R. Jones, Esq., Chair
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Life Skills

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Linda Walder Fiddle, Esq.
Lawrence R. Jones, Esq.
Mary Laresh
Ari Ne'eman
Michelle Smigel

Private Sector Engagement

Linda Walder Fiddle, Esq., Chair.
Lawrence R. Jones, Esq.
Ari Ne'eman

Survey

Dorothy Blakeslee, Chair
Cecilia Feeley
Linda Walder Fiddle, Esq.
Mary Meyer

Transportation

Mary Meyer, Chair.
Dorothy Blakeslee
Cecilia Walder Fiddle, Esq.
Linda Walder Fiddle, Esq.
Ari Ne'eman

Appendix B

NEW JERSEY GOVERNOR'S TASK FORCE ON ADULTS WITH ASD LEGAL ISSUES SUB-COMMITTEE

I) Recommendations for Judicial Education on Autism Spectrum Disorder

Based on factors set forth below, and upon the increasing prevalence of Autism Spectrum Disorder (ASD) as a significant issue in New Jersey, the Adults with Autism Task Force recommends the following:

- A) As a matter of public policy, Superior Court judges should receive ongoing continuing education in ASD. Such education can greatly assist Superior Judges in cases involving individuals with ASD -- particularly in the Family Courts, Surrogate/Probate Courts, and Criminal Courts;
- B) The legislative and executive branches of New Jersey government should support this concept as a matter of official public policy, and take all reasonable steps necessary to ensure there is adequate funding for such education to take place;
- C) As a matter of public policy, the New Jersey Judiciary is encouraged to take affirmative steps to incorporate educational programs on ASD into its annual Judicial College and curriculum for ongoing education of Superior Court judges, and/or in other similar educational forums for judges;
- D) Judicial education programs on ASD should be initiated in conjunction with members of the Judiciary, members of the State Bar and/or other individuals with substantial knowledge of/experience with autism spectrum disorder, including but not limited to, professionals, ASD advocacy organizations and members of the autism community including self-advocates;
- E) The New Jersey State Bar Association -- through its Institute for Continuing Legal Education (ICLE) -- is encouraged to support a public policy of ASD awareness within the legal community by developing educational programs specifically to educate attorneys on autism spectrum disorder.

II) The Need for Ongoing Judicial Education on Autism Spectrum Disorder

- A) In the past decade, the number of New Jersey residents diagnosed with Autism Spectrum Disorder (ASD) has grown substantially.
- B) As a natural result of this development, it is predictable that Superior Court Judges will have an increased amount of cases involving persons with ASD. In many of these cases, ASD may be material to the legal issues requiring adjudication. Thus, it is desirable for Superior Court Judges to be familiar with the disorder.
- C) Particularly in Family Court matters, Surrogate Court matters and Criminal Court matters, the fact that a person has ASD may potentially be highly relevant to issues before the Court.
- D) Accordingly, it is in the public's best interest for New Jersey Superior Court judges to have opportunities for ongoing continuing judicial education on ASD.

- E) Accordingly, New Jersey public policy should support the establishment of continuing ASD education courses for Superior Court judges. Such education can ideally take place in conjunction with the Administrative Office of the Courts, through its annual Judicial College and other outlets for ongoing judicial education.

III) New Jersey Family Court: The Relevance of Autism Spectrum Disorder

- A) Statistics show there is a high percentage of marriages that end in divorce when the parties have a child with ASD. Some studies place the percentage as high as 80 percent. Thus, children with ASD are often the subject of court proceedings relating to custody, visitation schedules, support, and scheduling of programs to accommodate special needs relating to ASD.
- B) Pursuant to the concept of *parens patriae* jurisdiction, the court must act to protect the best interest of a child, so that the child may hopefully grow and transition into adulthood as an independently functioning member of society. In the case of a child with ASD, the need for appropriate guidance and assistance into adulthood is particularly compelling.
- C) Many children with ASD spectrum disorder are unable to function and support themselves independently following their 18th birthday. Accordingly, many children with ASD become adults with ASD who are still dependent on parents, guardians, or other family members. Such adults with ASD may remain under *parens patriae* jurisdiction of the Family Court beyond the age of 18. This happens with particular frequency when the parents of the over-18 autistic child are separating or divorcing, with disputed issues over custody, parenting time, child support, the decision-making process relative to the over-18 child with ASD.
- D) There are many adults with ASD spectrum disorder who marry, have children, and function successfully as parents. Accordingly, some adults with autism become litigants themselves in custody parenting disputes involving their own children. In such cases, the court must always consider the best interests of the child. However, the fact that a parent has ASD should not automatically give rise to any custody presumption against the autistic parent or in favor of the non-autistic parent. A parent must be judged on his/her specific parenting abilities, and not disqualified from custody solely on the basis of a diagnosis, stereotype or label relative to ASD.
Note: Accordingly, Family Court judges can benefit from continuing education on Autism Spectrum Disorder. Such education can help judges address the above concerns as well as other autism-related issues which may arise on a case-by-case basis.

IV) New Jersey Surrogate Court: The Relevance of Autism Spectrum Disorder

- A) Once an autistic child is over 18 years of age, he/she may possibly be the subject of a guardianship proceeding filed in Surrogate/Probate Court.
- B) A judge who adjudicates an application for guardianship over an individual with ASD must determine whether the individual with ASD can or cannot function independently without a guardian. In some cases, a court may find that while the individual with ASD needs assistance, a remedy other than guardianship may be appropriate (i.e, such as a limited guardianship or a conservatorship).

- C) In court, there should never be an automatic presumption in favor of guardianship or conservatorship solely on the basis of one's diagnosis with ASD. Many persons with ASD can function independently without a guardian or conservator. The term "autism" covers a vast spectrum of individuals with different levels of impairment. Some persons with autism may need a guardian or conservator, while others may in fact function independently.
- D) In cases where a guardianship or conservatorship is deemed necessary by the court, it must also determine who should be the guardian/conservator of the adult with ASD. Further, to protect the best interests of the autistic individual, the court must consider what if any additional responsibilities should be placed upon the guardian/conservator as an advocate for the autistic individual's rights.
- E) In some cases, a judge may deem it advisable or necessary to have the proposed guardian of an individual with ASD undergo ongoing education on ASD. A guardian who has limited or no knowledge of ASD, and who is unwilling or unable to obtain such knowledge, may potentially cause a disservice to the autistic adult by making decisions and choices that are contrary to the autistic adult's best interests.
- F) Issues that a guardian of an autistic person may encounter include, but are not limited to, issues of behavioral therapy; other related therapies; medical issues; housing issues; educational issues; employment issues; transportation issues; estate-planning issues; and, navigation through various state and federal agencies (designed to provide assistance to developmentally disabled individuals). **Note:** Accordingly, Surrogate/Probate Court judges can benefit from continuing education on Autism Spectrum Disorder. Such education can help judges address the above concerns as well as other autism-related issues which may arise on a case-by-case basis.

V) New Jersey Criminal Court: The Relevance of Autism Spectrum Disorder

- A) A person with autism may become involved in the criminal justice system as a victim, a witness or as a criminal defendant. Studies reflect that persons with disabilities are involved in one role or another in the criminal justice system, more frequently than non-disabled persons.
- B) There are a host of different legal issues that may arise when a person with ASD becomes involved in a criminal court proceeding. Such legal issues include, but are not limited to: competency of the person to testify as a witness; competency of the person to stand trial as a criminal defendant; the autistic person's state of mind at the time of committing an alleged offense; the autistic person's capacity to consent if he/she is the alleged victim of a sexual crime, and consent is raised as a defense; if the autistic person is a crime victim, then the issue of whether the ASD should be considered a possible aggravating factor for purposes of sentencing the criminal defendant; if the autistic person is a convicted defendant, then the issue of whether the person's ASD should be considered a possible mitigating factor for sentencing purposes; and, conditions of incarceration of a person with ASD relating to safety and health.
- C) Accordingly, Criminal Court judges can benefit from continuing education on ASD. Such education can help judges address the above concerns as well as other autism-related issues that may arise on a case-by-case basis.

Appendix C

Models of Community Services and Housing

(As discussed by the Adults with Autism Task Force and suggested through testimony at public forums)

During its deliberations, the Adults with Autism Task Force members discussed numerous models for community services, housing and other related programs, including family support services, which are intended to assist families or other uncompensated caregivers who are caring for individuals (typically children) who are eligible for DHS-DDD-funded services. DHS-DDD evaluates requests for Family Support sources based upon an individual's need, the services and supports already available and/or being used, and the availability of their resources.

Family Support services include:

- In-home and out-of-home respite
- Camp funding
- Assistive technology devices
- Home and vehicle modifications
- Tutoring
- Cash subsidies for use in purchasing necessary goods and/or services
- Family-facilitated networking opportunities

Other concepts often echoed by some of the individuals who provided testimony at the forums emphasize the need for innovative approaches to community housing. While the recommendations of the Adults with Autism Task Force focus on major legislative, policy and programmatic services, the members did not want the creative and innovative ideas for services to be excluded. The Adults with Autism Task Force also considered the policies and programs that have been undertaken by other states.

The expansion of appropriate, affordable and effective residential services for adults with Autism Spectrum Disorder (ASD) is of major concern to individuals and families affected by ASD. Currently, there are limited residential programs in New Jersey that offer placement for relatively few individuals, while the vast majority of adults remain on the DHS-DDD wait-list to obtain services.

Long-term residential service options should be expanded to encompass the range of needs of adults. Currently the range of options include:

- 1) **Supported Living:** Provides residential services for adults who are able to live in self-owned or leased homes in the community. Many individuals with Asperger Syndrome can benefit from this setting providing that programming and instruction are directed by the consumer and that communities of support are built around the consumer. Supported living fosters individual growth and community participation because it is designed to meet the needs of the individual consumer with their input.
- 2) **Supervised Living:** Provides residential services for adults who require greater oversight than those who would benefit from supported living. Usually this setting is a home or apartment with two to four consumers and there is monitoring and support provided by professional staff in terms of executive management and support. Notably crisis support should be available 24 hours/day. Individual input in terms of needs and preferences is inherent to supervised living.

- 3) **Group Homes:** Provides small, residential facilities (actual homes) located in the community that are typically staffed 24 hours/day by agency trained staff. Ownership of the home is usually by the provider agency, which also supervises staff; encompassed in this is the teaching family model where teaching “parents” live in their own “apartment” in the home, thus reducing influx of staff and turnover of staff. Usually six to eight consumers live in a group home, but the objective should be to include as much self-determination as possible for the consumers, including the potential for resident home ownership when appropriate.
- 4) **Farmstead Programs:** Provides a residential setting within the context of a working farm.
- 5) **Urban Housing:** There is a lack of housing for persons with developmental disabilities in urban areas. Placements are typically made in suburban areas which are far away from their natural supports.
- 6) **Campus Style:** This model creates a built-in community and could result in lower cost delivery of services. This type of housing is compelling for the ASD population as lack of social skills impedes the ability to develop a community.
- 7) **Parent-Purchased Housing:** Allows parents to plan for the transition by providing a tax deduction in the gifting of a house to a non-profit and allowing their children to live in the house. This will also decrease the cost of capital for the State and possibly decrease operating costs. Parents who have an ownership in the property will be required to maintain the property and develop a support system with other families involved in the house.
- 8) **Low and Moderate Income Housing:** Persons with developmental disabilities have found housing in low- and moderate-income housing complexes. Those housing projects with a built in service infrastructure for transportation, meals, medical assistance or supervision, and recreation are particularly suitable. Additional facilities that include the possibility of employment have the potential for a long-term symbiotic situation. In the case of a Low- and Moderate-Income facility where the population is predominately senior, particular attention must be given to the individual's civil rights and American with Disabilities Rights Act.

Appendix D

MINORITY REPORT

Deborah E. Cohen, Ph.D.
Chair, Adults with Autism Task Force

Dear Deborah:

Over the past half-year, the members of the NJ Adults with Autism Task Force have worked tirelessly to advance the interests of Autistic adults in the State of New Jersey. It has been our pleasure to serve on the Task Force and we look forward to seeing the successful implementation of the Task Force's recommendations around autism policy for the State of New Jersey.

We have chosen to exercise our rights as members of the NJ Adults with Autism Task Force to file a minority report to highlight particular attention to a crucial piece of civil rights legislation that promises to dramatically improve policy and service-provision for adults with developmental disabilities, including Autistic adults, in the State of New Jersey. We are referring to A3625/S2654, which provides a plan to rebalance state resources to provide community services and supports for persons with developmental disabilities. In the attached document, we support the Task Force's policy recommendations by highlighting the fact that swift passage of A3625/S2654 will serve to implement a portion of the Task Force's priorities around housing and long term services and supports. Furthermore, we identify particular priorities for implementation and funding of the legislation.

New Jersey's current over-reliance on institutional care has placed the state 49th in the nation on this crucial issue, placing us in violation of the *Olmstead v. L.C.* Supreme Court decision. This, combined with the tremendous problem of waiting lists for community services, calls out for a solution. It is our belief that A3625/S2654 is such a solution. Attached you will find our report.

Regards,

Ari Ne'eman
NJ Adults with Autism Task Force, Vice Chair
Autistic Self Advocacy Network, President

Leslie Long
Autism New Jersey, Director of Public Policy

Michelle Smigel
Autism Speaks

In 1999, the United States Supreme Court ruled in the landmark *Olmstead v. L.C.* decision that the Americans with Disabilities Act required states to provide services to individuals with developmental disabilities in the most integrated setting possible. According to Court, inappropriate institutionalization represents a violation of the Americans with Disabilities Act. To assist states in complying with their legal obligations in the *Olmstead v. L.C.* decision, the federal government created a “waiver” program that allows states to waive the Medicaid requirement that an individual reside in an institution, developmental center or nursing home in order to receive federal funding for their care. Instead, individuals can be served in the community, affording greater quality of life and consistency with the state’s legal obligations. To serve individuals in the community, New Jersey receives approximately half of the cost of community services from the federal Medicaid waiver program. However, although federal law requires that states receiving such funding provide services with “reasonable promptness” following a request for services from a qualifying individual, New Jersey has a waiting list of over 8,000 people who meet service-provision requirements but are being denied access to home and community-based services. This extensive and unconscionable waiting list is the direct result of New Jersey’s failure to invest in its community services infrastructure and end the state’s reliance on institutions.

Since 1969, over 140 closures of large public institutions have occurred across the country. Nine states and the District of Columbia no longer have any institutions within their borders. The overwhelming direction of the nation in respect to serving people with developmental disabilities, of which Autistic adults are a significant portion of said population, is to serve people in the community. According to the New Jersey Council on Developmental Disabilities, half the states in the country have less than 1,000 people in their institutions. Twenty four states – almost half – have two or fewer institutions within their borders. By contrast, New Jersey has seven large state-run institutions with, as of the end of Fiscal Year 2008, 2,970 people living within them. With 34.9 of every 100,000 people in a state institution (as compared to a national average of 12.9 per 100,000), New Jersey is ranked 49th of 50 in the nation in respect to utilization of developmental centers. Clearly, New Jersey faces a problem in this area that has been allowed to fester for far too long.

As such, we propose the use of A3625/S2654 as a mechanism for the correction of this problem. A3625/S2654 would establish a Community Services and Supports for Persons with Developmental Disabilities Bridge Fund. The money in the fund would be utilized to build capacity to end the community services waiting list and shift investment to address New Jersey’s over-reliance on developmental centers. According to the legislation, New Jersey would transfer to a system of two rather than seven developmental centers within five years, bringing at least 80 percent of the 81 percent of the population of the developmental centers that have been assessed as ready for community placement into the community. The legislation identifies a number of services that must be provided in implementing this legislation, including crisis intervention and stabilization systems, including, but not limited to, mobile response, in-home supports, and crisis respite beds, consistent with the recommendations of the department’s Dual Diagnosis Task Force Report; respite care; timely and flexible residential options that maximize choice; community medical, behavioral health, dental, and specialty care similar to that care provided to other members of the community, including training and regulatory or policy changes necessary to provide such care; flexible case management and support services; employment and skills training to meet the changing job market; education and training of staff to enhance skills; social, recreational, and meaningful daytime activities that include programs that are responsive to persons throughout their lifespan; peer and family supports and in-home and family preservation services; and assistive and adaptive technology, including vehicle and environmental modifications to promote independence. These services are consistent with the recommendations of the New Jersey Adults with Autism Task Force and should be implemented in a manner consistent with its recommendations.

We call for the swift passage of A3625/S2654 as a solution to the pressing civil rights problem caused by New Jersey’s over-reliance on state institutions and the growing community services waiting list. In addition, we call for implementation to include the following factors:

- 1) A3625/S2654 calls for a staff redeployment from the developmental centers into the community. In order to ensure that medical, behavioral health, dental and other specialty care continues uninterrupted and that crisis response systems are efficient and effective, we call for the redeployment of trained staff into community health centers and crisis response and intervention centers in locations throughout the community, as necessary and appropriate, to ensure a seamless level of services and supports during the transition of individuals from the developmental centers into the community.
- 2) The American Recovery and Reinvestment Act of 2009 increases the Medicaid Federal Medical Assistance Percentage (FMAP), bringing an estimated \$2.2 billion in new federal funds to the State of New Jersey over the next three years. The purpose behind these funds is to allow the state to avoid decreasing Medicaid eligibility as tax revenues drop and unemployment increases during the economic recession. By not only avoiding a decrease in Medicaid eligibility but by keeping our current level of state expenditures stable, re-allocating funds offset by the increased FMAP to the Community Services Bridge Fund, New Jersey can use the unique opportunity posed by the stimulus to fund a more seamless transition into the community for individuals with developmental disabilities, including Autistic Adults, in the State of New Jersey.
- 3) Autistic adults often have unique sensory, social, communication and other needs that require specialized training, support services and accommodations. Personnel deployed to serve Autistic adults must receive appropriate training in these unique needs, with particular focus given to those needs associated with communication. Furthermore, any housing provided must be consistent with the sensory needs of the individuals who will live in it. The recommendations of the NJ Adults with Autism Task Force will be helpful in the implementation of this recommendation.

Charts (Recommendations)

| Office of Autism Services (Recommendation #1) | | | | |
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| Short-term Recommendations | Action Needed | Long-term Recommendations | Action Needed | Agencies Involved |
| Office of Autism Services established in the DHS Division of Disability Services to coordinate services to adults with ASD | Governor Executive Order | Within 18 to 36 months, the Office of Autism becomes the Division on Autism staffed by persons trained in ASD | Legislation | DHS-DDS |
| Office of Autism Services will serve as New Jersey's designated autism agency | | | | |

| Establish Executive Oversight Board (Recommendation #2) | | | | |
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| Short-term Recommendations | Action Needed | Long-term Recommendations | Action Needed | Agencies Involved |
| Establish an Executive Oversight Board to monitor the implementation of recommendations | Governor Executive Order | Permanent advisory board established to develop and maintain minimum requirements for ASD protocols | Legislation | DHS (host agency), with participation by OAS, DOE, DHSS, DCA, DLWD, DOT, DHS-DDS, and Governor Appointees |

Transition to Adulthood (Recommendations #4 through #8)

| Short-term Recommendations | Needed Action | Long-term Recommendations | Needed Actions | Agencies Involved |
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| <p>Ensure funding available to support transition from school to adult services</p> <p>Develop Students Bill of Rights</p> | <p>Line item in the DHS-DDD budget</p> <p>To be developed</p> | <p>Mandatory Growth Legislation</p> | <p>Sponsor Legislation</p> | <p>OAS, DOE, DHS-DDD</p> <p>OAS</p> |
| <p>Develop user-friendly manual for parents and professions that provide uniform guidelines regarding the transition process</p> | <p>Compilation of a Best Practice Manual</p> | <p>Ongoing and updated</p> | <p>Researched and written</p> | <p>OAS, DOE</p> |
| <p>Establish best practices quality guidelines for transitional programs</p> | <p>Update Quality Indicator Guide</p> | <p>Ongoing</p> | <p>Compile Advisory Board and Update with additional expertise</p> | <p>OAS, DOL</p> |
| <p>Establish a pool of consultants with autism-specific expertise</p> <p>Implement existing programs to train teachers in best transitional practices for students with ASD</p> <p>Implement and monitor mandatory ASD-specific training and coordinators working with students with ASD</p> <p>Improve coordination between DOE, DHS-DDD, DLWD-DVRS other service providers</p> | <p>Curriculum written</p> <p>Ensure inclusion of ASD-specific transitional practices training included in annual convention of the New Jersey Education Association</p> <p>Ensure Training provided annually</p> | <p>Ongoing and updated throughout colleges</p> | <p>Curriculum written</p> | <p>OAS, DOE, Commission on Higher Education</p> <p>OAS, DOE</p> <p>OAS, DOE</p> <p>OAS, DOE, DHS-DDD, DLWD-DVRS</p> |

Day Programs (Recommendations #9, #10 and #11)

| Short-term Recommendations | Action Needed | Long-term Recommendations | Action Needed | Agencies Involved |
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| <p>Fully utilize Existing Staff Training Programs that include:</p> <ul style="list-style-type: none"> •Consumer involvement •Cultural competence •Self-direction •Self-determination •Autism appropriate interventions | Augment to include autism information, interventions | <p>Minimum Training Required for State Licensed Agencies</p> <p>Establish staff training quality criteria that includes field experience</p> | Encourage colleges to create training programs | OAS |
| <p>Program focused on skill building to include:</p> <ul style="list-style-type: none"> •Social skills •Pre-vocational •Job skills | Augment and update existing programs | Enriched programs with potential quality of life improvement such as exercise and nutritional counseling | | OAS |
| Day program tailored for individuals with Asperger's Syndrome and High Functioning Autism at appropriate level and intensity | Review existing programs | Program to provide services, exercise and nutritional counseling to individuals with ASD who would benefit from such programs | | OAS |

| Life Skills (Recommendations #12 & #13) | | | | |
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| Short-term Objectives | Needed Actions | Long-term Objectives | Needed Action | Agencies Involved |
| Develop person-centered program of supports and services for individuals with ASD | Develop criteria with team of parents, professionals, and individuals with ASD | Individualized support plans | Monitor and refine | OAS |
| Develop life skills module as part of transitional programs and continue into community settings | Review existing materials, augment as needed | Transition curriculum to include life skills | | DOE, OAS OAS |
| Develop therapeutic social skills training program with both formal and natural supports | Assess current programs, adapt as needed | Social skills training available for all individuals with ASDs | | |

| Employment (Recommendation #14 - #20) | | | | |
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| Short-term Objectives | Needed Actions | Long-term Objectives | Needed Action | Agencies Involved |
| Establish employer program to train about the benefits of hiring people with ASD (See Private Engagement Priorities) | | Expand job coach opportunities at work cooperatives | Review publications that currently exist to identify appropriate ones to be used or replicated. | OAS, DLWD |
| Establish autism-specific vocational services program | | Establish co-worker training program so colleagues understand social skills needs of persons with ASD | | OAS, DLWD |
| With school transitional plan, provide pre-graduation career exploration and experience | | | | OAS, DOE, DLWD |

Healthcare (Recommendations #21 through #27)

| Short-term Objectives | Needed Actions | Long-term Objectives | Needed Action | Agencies Involved |
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| Educate the health care industry to improve services to persons with ASD | Develop a training curriculum for primary care physicians and healthcare practitioners to better serve adults with ASD | Implement this training on an ongoing basis | Review publications that currently exist to identify appropriate ones to be used or replicated | OAS, DHSS |
| Establish a comprehensive database of providers of health care to persons with ASD | Review existing data bases and develop criteria to add appropriate providers to the list | Ongoing data that is accessible to individuals and families | | OAS, DHSS, DHS |
| Develop consumer friendly materials regarding eligibility and health services available through the Medicaid State Plan | Use existing material from Autism NJ for the Community Care Medicaid Waiver, use existing information from DDS on the Medicaid | Information is given to every consumer that applies to DHSS, DOE and/or DHS | | OAS, DHSS, DOE and DHS |
| Educate persons with ASD and families to understand the authorities and regulations which govern various health benefit plans | Expand information that may exist from DHSS and DHS | Adults with autism and their families will understand their health plans and the authorities that govern them so information is easily accessible | | OAS, DHSS, DOBI |
| Determine the commonalities between the aging population and persons with ASD with respect to long-term care issues | DHSS Commissioner convenes a think tank (that includes experts in the aging community) to strategize long-term care services and funding usage for adults with ASD | Long-term care services are transparent to New Jersey residents on the spectrum and their caregivers | | OAS, DHSS |
| Explore expanded partnerships with federal agencies to maximize and enhance federal resources to serve persons with ASD | Governor's Office to review increased FMAP opportunities and Stimulus money usage | | | OAS, DHS, federal agencies |

Housing (Recommendation #28 through #32)

| Short-term Objectives | Needed Actions | Long-term Objectives | Needed Actions | Agencies Involved |
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| Reorganize Medicaid Waiting List by County | Completed by DHS-DDD | Operationalize the county waiting list | Write and adopt regulations | DHS-DDD |
| Improve access to housing information | Inventory all housing alternatives | Include in NJ Housing Resource Center Project housing needs by time and geography | Negotiate concerns of governmental entities with the need for public information | DHS-DDD |
| Grant or Pilot Program to develop local housing Develop alternative housing plans prior to DHS-DDD placement Increase funding to DHS-DDD | Develop program to encourage local development of housing for persons with ASD Identify family support funds, savings plans, self-determination programs, family coop models based on donation of time and expertise | Identify successful housing models and duplicate Train families on what to do prior to DHS-DDD placement | Allocate DHS-DDD funds to support successful housing models | OAS, DHS-DDD OAS NJ Legislature |

Legal Issues (Recommendation #33)

| Short-term Recommendations | Needed Actions | Long-term Recommendations | Needed Action | Agencies Involved |
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| Establish Judicial Education Program regarding persons with ASD | | Training program available on an annual basis | | OAS, Office of Administrative Law |
| Amend the Law Against Discrimination to provide better protection for persons with ASD | Change current Legislation | | | OAS, NJ Legislature |
| Revise the Autism Registry to include persons older than 21 | Amend legislation or regulations to include registration of adults | | | OAS DHSS |
| Include tax-exempt savings plan to provide for care and services for adults with autism | | | | OAS, NJ Legislature |
| Establish a tax-exemption for donations of houses even if own child will not directly benefit | Legislation | | | OAS, NJ Legislature |

Private Sector Engagement (Recommendations #34 through #38)

| Short-term Recommendations | Needed Actions | Long-term Recommendations | Needed Action | Agencies Involved |
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| <p>In conjunction with the New Jersey Ad Council, Art Director's Club and Broadcaster's Association, develop a series of public service announcements focusing on the strengths, talents and diversity of adults with ASD</p> | <p>Existing protocols are established</p> | | | <p>OAS NJ Ad Club, Art Director's Club, Broadcaster's Association</p> |
| <p>Develop community roundtable events with the New Jersey Chamber of Commerce to give adults with ASD and community businesses and civic organizations the opportunities to interact. Foster participation in community life and to provide opportunities for adults with ASD to work as volunteers in community-based businesses</p> | <p>Enhance existing disability awareness program</p> | | | <p>OAS NJ Chamber of Commerce</p> |
| <p>Establish an adult peer-mentoring program, with students at NJ universities and colleges, to provide friendship and support to persons with ASD</p> | <p>Enhance existing peer mentoring programs for children; develop partnerships with New Jersey's universities and colleges</p> | | | <p>OAS, DOE</p> |
| <p>Sponsor symposium by NJ not-for-profit community to enhance participation of adults with ASD in issues that affect their lives</p> | <p>Augment current symposium offerings to include avenues for participation for adults with ASD</p> | | | <p>OAS, Center for Non-Profit Corporations, Council of NJ Grantmakers</p> |
| <p>Maximize existing community support systems to enhance support of adults with ASD</p> | <p>Work with existing entities that are already engaging these kinds of supports</p> | | | <p>OAS, Elizabeth M. Boggs Center on Developmental Disabilities, community organizations</p> |

Transportation (Recommendation #39 through #43)

| Short-term Objectives | Needed Actions | Long-term Objectives | Needed Action | Agencies Involved |
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| | | Fully implement recommendations of "Meeting the Employment Transportation Needs of People with Disabilities in NJ" | Articulate the needs of the entire ASD population to the New Jersey Council on Accessibility and Mobility (NJCAM) | OAS |
| Improved use of transit resources through increased coordination among community transit providers | Investigate barriers to shared use of resources | Transit system that creates greater flexibility and cost savings through the use of shared resources | Develop plan to address restrictive vehicle insurance policies | OAS, NJ CAM, NJ Dept. of Banking & Insurance |
| Drivers trained to improve interaction with adults with ASD | Amend NJ Transit, DOT training to include ASD | Change county-based regulations so that transportation systems cross county lines | Base DOT Training on First Responder model | NJ Transit DOT Office of Autism |
| Continue development of concierge/broker service programs | Continue building partnerships among community transit providers | Expand concierge service state-wide | Develop and maintain database Increase cooperation among community transit providers | OAS NJ Transit DOT |
| Include transportation training in IEPs, IHPs, ELPs for persons with ASD | Provide travel options available by area | NJ Transit partnership with community providers to provide travel training | Develop training module | OAS, DOE, DDD, Community Transit providers |
| Adjust the Casino Revenue Fund formula to be commiserate with county populations of seniors and persons with ASD | Determine if change is to a law or regulation Use Census Data | Legislative Action Rule Change | | NJ Legislature DOT |

Aging Issues (Recommendation #44)

| Short-term Objectives | Needed Actions | Long-term Objectives | Needed Action | Agencies Involved |
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| Begin planning for the aging of the population with ASD | | | | OAS, DHS-DDD, DHSS, DHS-DDS |
| Train county offices on Aging and community service providers about needs of persons with ASD | Identify and adapt materials to address aging issues | | | OAS, DHSS, County Offices on Aging |