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Department of Health and Human Services

*Maine People Living
Safe, Healthy and Productive Lives*

Autistic Spectrum Disorders Report

In response to legislative directive:
The Autism Act of 1984, 34-B M.R.S.A. §6001

Prepared by:

The Department of Health and Human Services

With input from:

**Persons with Autistic Spectrum Disorders,
Parents, Advocates and Other Governmental Agencies**

June 2007

Life in the Community

People with Autism Spectrum Disorder ("ASD") and their families want a voice in the community more than anything else. While services are essential links for a life, services are not a life. Being able to participate in the community, have a job or vocation, go to post-secondary education, shop, go to a movie, get appropriate medical care, have friends, live in their own home with supports if necessary, have protections under the law - these are some of their expressed needs and desires. These are the same needs that many of us have.

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Executive Summary

The Autism Act of 1984, 34-B M.R.S.A. §6001 states that it is the intent of the Legislature that “social and habilitative services directed at persons who have been diagnosed as being autistic or having other pervasive developmental disorders (“PDD”) be developed and planned for, to the extent that resources exist.” This report fulfills the Act’s requirement that a biennial report be filed with the Joint Standing Committee on Health and Human Services.

Many individuals, parents and advocates believe that those diagnosed with Autism Spectrum Disorder (ASD) and other Pervasive Developmental Disorders (PDD)¹ remain underserved or unserved. Multiple planning and reporting initiatives to address the needs of this population were underway this fiscal year. It became evident that many of these independent initiatives may not have been extensive enough or were uncoordinated. The outcome of the efforts that were combined into a single initiative is presented in this report.

State agency policymakers are concerned with the demand that the increased numbers of people with ASD is having, and will continue to have, on our service systems. This report documents an increasing identification of persons with ASD, some of whom will need ongoing support in order to live full lives. Also it is acknowledged that an adequate comprehensive, collaborative, interagency-wide system capable of responding to increasing needs for early identification, assessment and treatment, and long term support does not currently exist. The Department recommends that the State of Maine, within available resources:

- Develop a statewide First Signs program;
- Develop an approach to an ASD surveillance system;
- Explore and recommend standard assessment and treatment protocols for PDD/Autism;
- Refocus the adult service system within DHHS to:
 - a. respond to changing needs of youth exiting school;
 - b. include adults with Autism Spectrum Disorder, and;
 - c. leverage existing resources and systems.
- Develop and implement a point of accountability for overall system performance.

¹ From Maine CDC.

What is Autism Spectrum Disorder?

Autism and related conditions (ASDs) are lifelong neurological disorders that affect the functioning of the brain in the areas of reasoning, social interaction and communication (including non-verbal) skills. ASDs include Autistic Disorder, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS, including atypical autism), Rett's Disorder, Childhood Disintegrative Disorder and Asperger's Disorder. Many people with ASDs also have unusual ways of learning, paying attention, or perceiving information from different sensations. As with any chronic disability these problems not only affect an individual but also have a tremendous impact on parents and siblings.

Autism Spectrum Disorders are four times more likely to affect males. Without special instruction, many children are unable to learn from the natural environment as most children do. A child with ASD generally appears to show little interest in the outside world. Although some children with ASD develop normal and even advanced skills, most display behaviors which interfere with their ability to learn and to participate in the community without support. These behaviors can prevent them and their families from participating in many activities in which their typical peers can participate. ASD is normally a lifelong developmental disability that profoundly affects the way a person comprehends, communicates and relates to others.

Early diagnosis is important. Intensive early intervention treatment (i.e., during the preschool years) has been shown to lead to improved outcomes for most young children with ASD. However, diagnosis is often delayed until school age; only about half of children with ASD are diagnosed before kindergarten. The report on Autism Spectrum Disorders Surveillance in Maine concludes that recent prevalence rates are considerably higher than those reported in the 1970s and 1980s. The increase may be due to a true increase in the occurrence or due to other factors such as changes in diagnostic criteria, early detection, increased awareness, environmental factors or improved services.

Autism, once a rare disorder, is now more prevalent than spina bifida, diabetes and Downs syndrome (cited at www.nimh.nih.gov/publicat/autism.cfm). The sustained increase in the population of persons with Autism, compared to other developmental disabilities, is causing fundamental changes in systems of care in the state.

The MeCDC report, along with other formal epidemiological studies, confirms that there is an increase in prevalence of Autism in Maine and requires special attention.

Responses of Individuals With PDDs When Asked About What They Needed and Wanted

- "Give me a helper"
- "I want a special restaurant for special people"
- "Need my family supported"
- "People who know how to work with individuals with Autism"
- "Better Pay"
- "Want to work in a company and not a workshop"
- "Real work with real people"
- "Better education for teachers and community about Autism"
- "Wants state to know that each individual has feelings"
- "Wants to work"
- "I wish I wasn't autistic"
- "Want to have a home with friends"
- "Better healthcare, faster"
- "The right to use FC with trained facilitators"
- "Training for home staff"
- "Help with publishing things written by autistics"
- "Colleges to accept autistic students with trained staff"
- "Understanding kinds of media coverage"
- "A home for women"
- "Information to parents about available homes"
- "More aids for typing"
- "Faster diagnoses"
- "Less experiments with medications"
- "Wish everyone could have a good job"
- "Want real friends and teachers who understand"
- "Want real friends, not people who are paid to be with me"
- "I would like good home for friends"
- "College"
- "Job Opportunities"
- "Understanding Autism"
- "Want a big house with trails and woods"
- "A group home with lots of land and a 4 bedroom house"
- "I like outdoors"
- "I like work"
- "Companion who can live with me"
- "I like going for rides to go to work"

- "More library and cultural trips"
- "Walk"
- "Eat out with friends"
- "I like to ride in quiet vehicles like cars or vans"
- "Want movies for people with Autism"
- "College course videos"
- "I want people to know we're smart. I think they put me in with retarded people and they need different things"
- "Want state to know how hard life is without a voice"
- "The state needs to come see us at the workplace"
- "IQ isn't judged correctly for individuals who don't speak"
- "You can't judge a book by its cover"
- "Mom wants me to be safe"
- "People are afraid of us because we act strange"
- "Understand our behavior"
- "Medical checks/eye/dental/hearing"
- "I would like a place where people with High Functioning Autism or Asperger's Disorder could live where we are supported but can still be independent. Not a group or nursing home."
- "Better medical care for people with Asperger's Disorder and High Functioning Autism"
- "More programs to learn social skills and safety for individuals with High Functioning Autism"
- "There are too many programs that I can't access because I am not mentally ill"
- "Communication Support - teach me"
- "People in professional fields need to understand that I need questions to be clear and concrete."
- "Medical personnel need mandatory training in Autism"
- "Social and communication training"
- "Someone consistent who could help for general things. High Level Support"
- "People with High Functioning Autism and Asperger's Disorder will need support and help all their lives"
- "Just because I have a college degree doesn't mean that I can survive without support"
- "Legal protection from hate crimes"
- "I need the legal system to understand me and protect me"
- "Why don't we get the same protection as other groups? It would not be okay to yell racial slurs but anyone can call me a retard."
- "I am not ashamed that I have Autism"

The Emerging Challenge

The Emerging Challenge of Autism in Maine

This report will summarize the current status of services for individuals with Autism and highlight activities and initiatives currently underway to improve the services for citizens of Maine with Autism Spectrum Disorder.

How Many People are Affected?

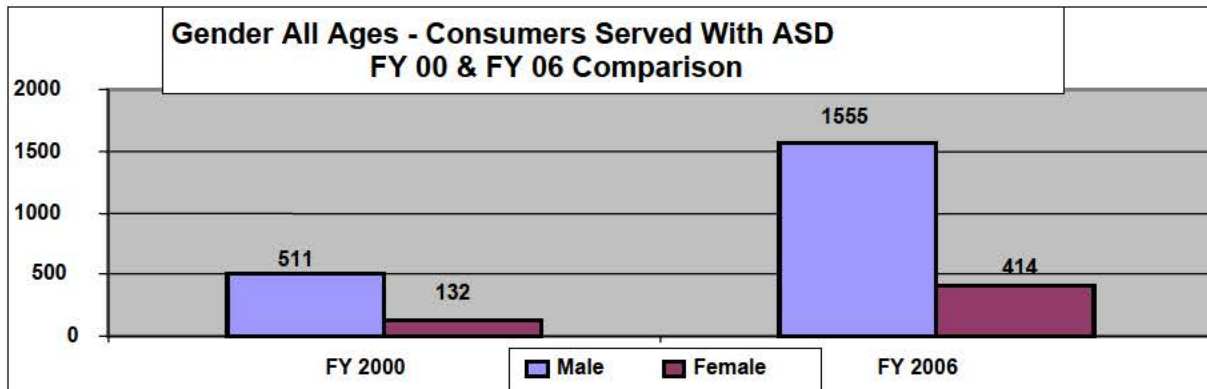


Figure 1

Autism is frequently a lifelong, neurological disorder. A male is almost 4 times more likely to be diagnosed with Autism than a female.

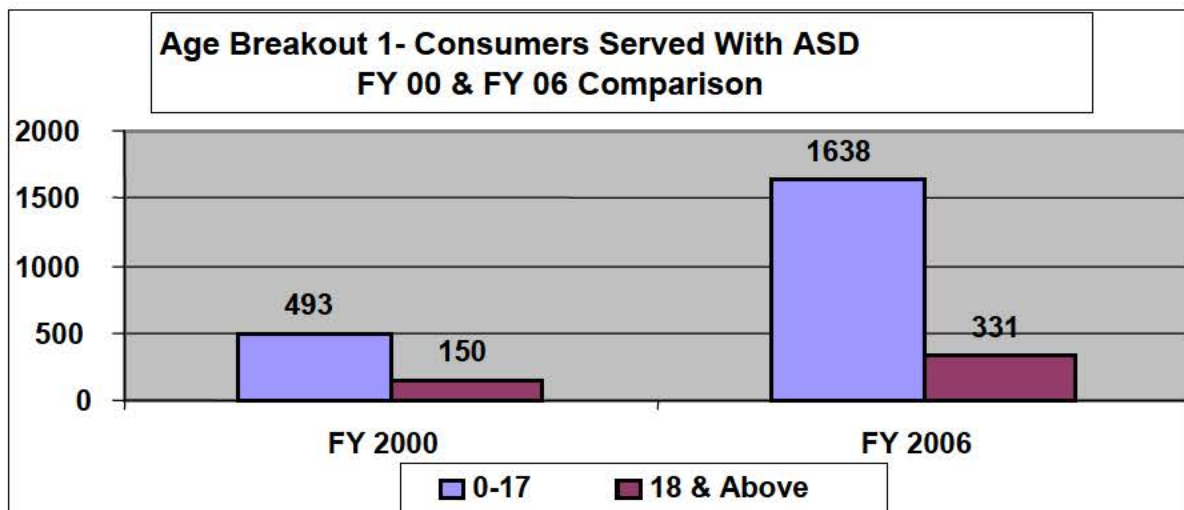


Figure 2

From FY 2000, the number of children with Autism served by DHHS increased three-fold and the number of adults with Autism served doubled.

Every County is Affected

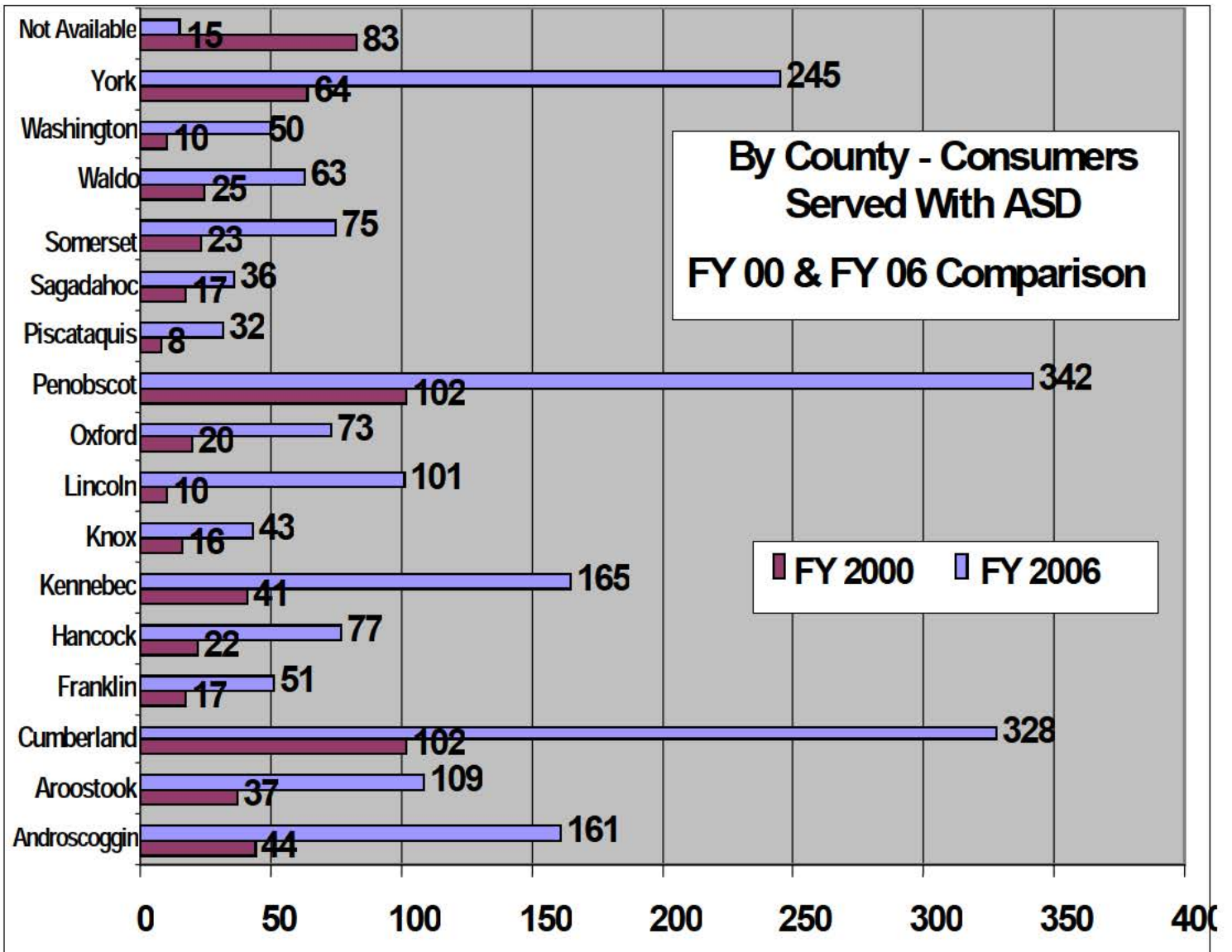


Figure 3

MaineCare Recipients with Autism have increased 300% from 643 in FY '00 to 1,969 in FY '06.

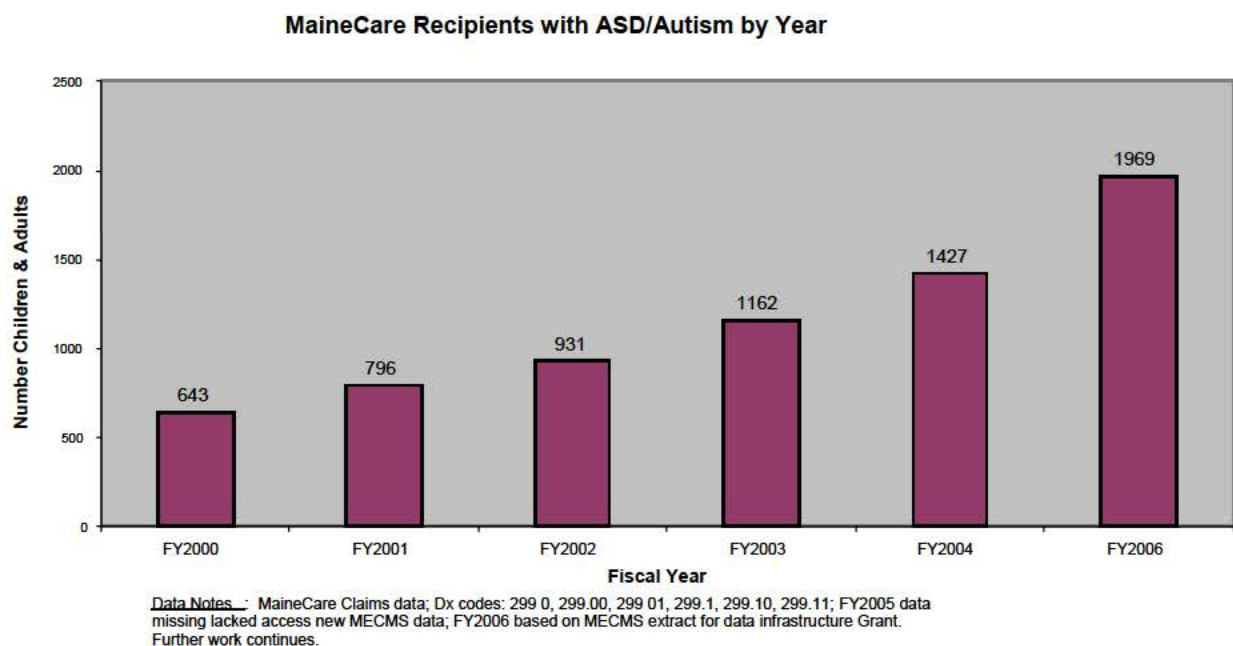


Figure 4:

The long-range implication of this sustained increase in the number of persons with ASD is profound and will have an enduring impact on public services, the state budget, and the overall health status of Maine citizens. Two age groups will drive an increase in the fiscal impact on the State's budget - very young children and young adults. As this report documents, there is an increasing number of children being diagnosed with ASD who must be served through special education services. As they exit school, these same young adults have an increased need for services. Intensive, early intervention is recommended for children as soon as the diagnosis is made, with the goal of diminishing future service costs and improving quality of life. Some individuals need intensive services beyond age 6 years.

Early Childhood

Research is showing that when early intensive Applied Behavior Analysis (ABA) intervention is provided to children with Autism Spectrum Disorders, there are very positive outcomes for 40% of those receiving treatment. This would imply that there will be an increased demand for earlier and more intensive social, behavioral and educational services. Increasing intensive services to very young children will result in an increased demand on state resources. A possible outcome may be diminished need for long term services.

Maine is on target in identifying Autism in children 3 years of age and up. Federal Centers for Disease Control estimates that Autism prevalence is one case in every 150 births or .67 percent. A system that is doing a good job with early detection should have an Autism ID (identification) rate in preschool that is essentially the same (or slightly higher) than in elementary school. Maine's Autism Identification Rate (ID) is almost the same in preschool and elementary school.

	% of Population Identified with Autism, 2004	
	US	ME
3 - 5 year olds	0.22%	0.67%
6 - 10year olds	0.41%	0.71%

Figure 5

Summary of Data:

1. Maine's elementary school rate is almost double that of the US overall.
2. Maine's Autism ID is **almost the same** in preschool and elementary school.
3. Maine Autism rate overall is a **close match** with US CDC's most recent estimate.
4. Maine public schools are doing a better job than the other states at identifying Autism.
5. Maine Child Development Services (Early Childhood) is doing a much better job than the national average at early identification of Autism.

The Subcommittee to Study Early Childhood Special Education reported January 22, 2007, while Maine does a "very good" job overall; Maine's identification rate for children with autism, birth to one, is below the national average.

School and Children's Services

School Age and Children's Behavioral Services

Maine school system and its programs for exceptional students has been the first system to feel the increase in the number of children with ASD. The school system has responded within the requirements of special education law.

Identification Change over Time - Maine Statewide Totals

Data source:

http://portalx.bisoex.state.me.us/pls/doe/eddev.efs05_user_reports.find_county?v_source=cexc

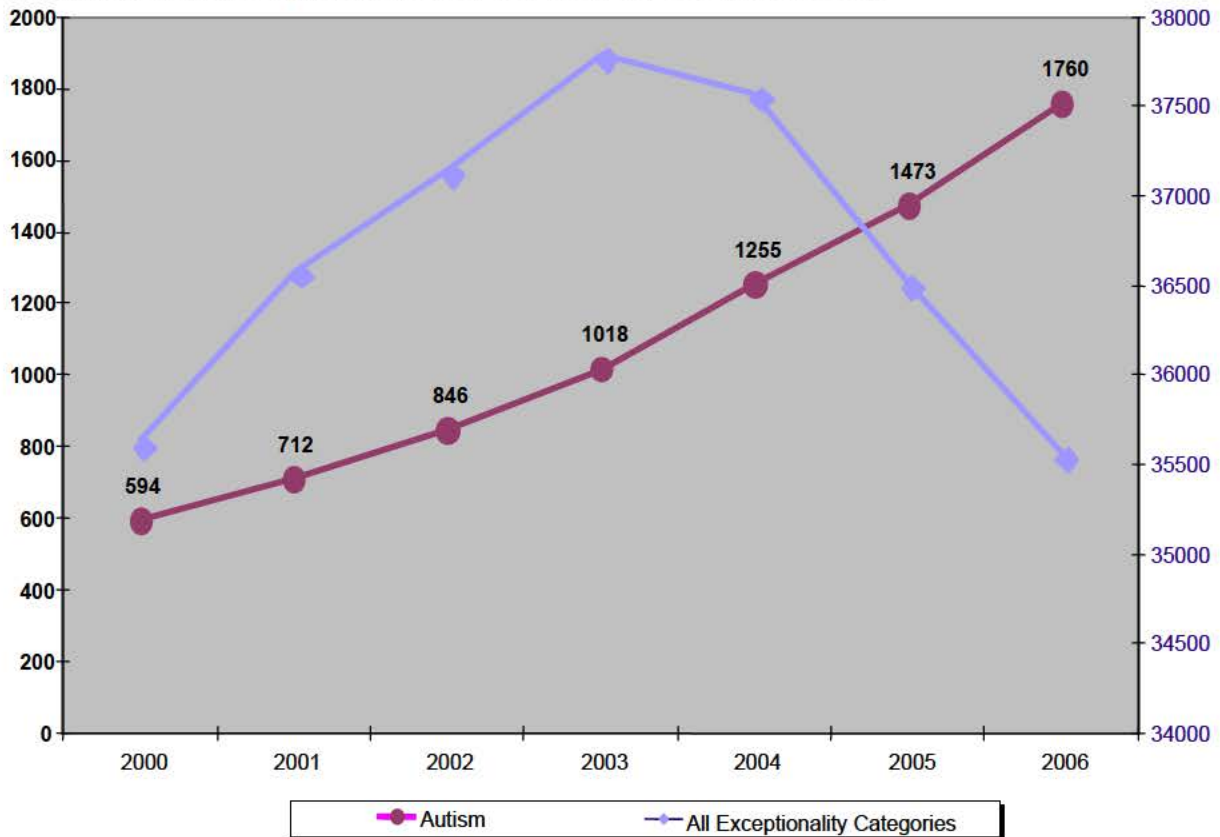
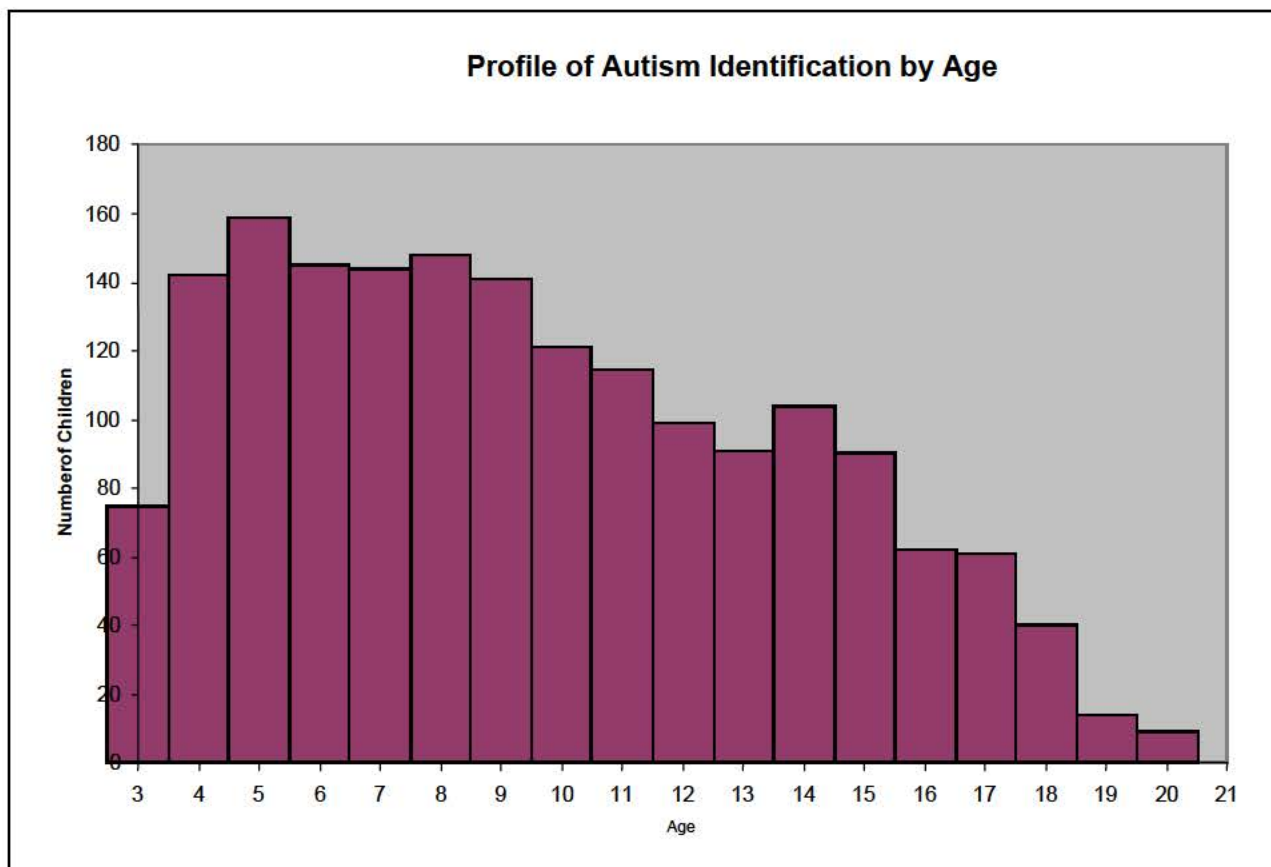


Figure 6

Department of Education data shows that while all "Exceptionality Categories" peaked in 2003, the number of "children with Autism" has risen steadily from 594 in 2000 to 1,760 in 2006, an average of 20 percent per year for an overall 300 percent increase. The implications of this steady increase point to severe pressures on our system to respond to the needs of an increasing number of young adults and then adults, as these children age. This data may also suggest a shift in diagnoses.

The average age of persons with Autism entering the system has shifted toward much younger children in recent years. Children with Autism comprise 5 percent of the children with exceptionalities. From ages 4 to 9 years old that percentage increases to a high of 11 percent.



The December 1, 2006 Child Count State Total Report by disability and age
Figure 7

Children are being identified at younger ages and in greater numbers. This increase in earlier detection means that entitlement services required by each individual with Autism could be sustained for a longer period of time.

Children's Behavioral Health Services

Children's Behavioral Health Services (CBHS) provides leadership in the development of a comprehensive system of care that ensures each child develops to their fullest capacity. Children's Behavioral Health Services offers an array of supports and treatment services to children from birth through age 20 with ASD. ASD diagnoses include Autistic Disorder, Asperger's Disorder, Pervasive Development Disorder-NOS, Rett's Syndrome, and Childhood Disintegrative Disorder. Funding sources include state and federal block grant funds, with the majority of funding coming from MaineCare.

The majority of services available to children and their families are provided through contracts with community-based agencies. Examples of services available include: case management, early intervention services, infant mental health services, outpatient treatment services, day habilitation services, in-home treatment services, medication management services, crisis services, residential services and respite care. CBHS collaborates with and provides funding for seven family / advocacy organizations including Maine Parent Federation, GEAR, Maine Autism Society, Helping Hands, Southern Maine Parent Awareness, Developmental Disability Council and NAMI.

Regional staff provide vital information and referral assistance, as well as oversee the flexible funds that assist families in various ways. A common request includes paying a registration fee, so that a parent can attend a training or conference in order to become better informed about their child's disability. Another example is funding environment modifications to assist families to keep their children safe (fences; window alarms).

Autism Spectrum Disorder Comparisons of Individuals Served FY 2000 & FY 2006

Charts & Graphs - DHHS Office of Quality Improvement

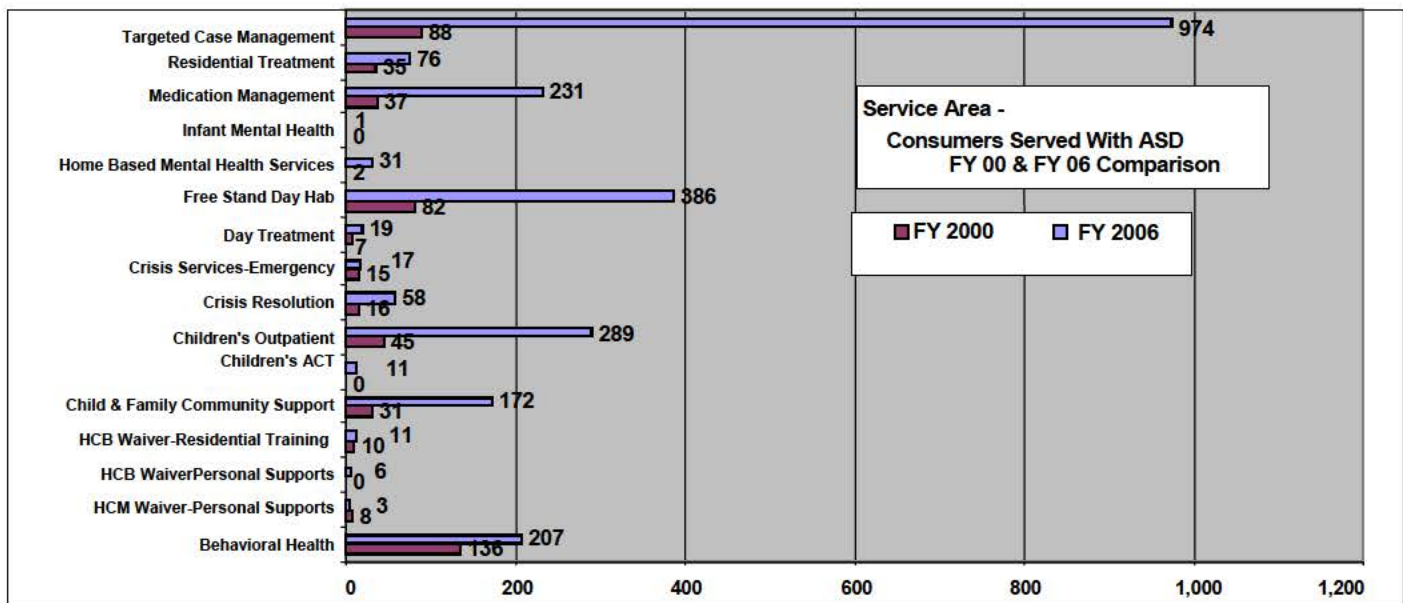


Figure 8

“The state cannot give my child a life, but systems can be developed to help him have a life.”

Parent

Already our educational and children’s service systems have significantly increased services for children with this disorder. Post-secondary education, employment training, employment, recreation and social activities are among the expectations of youth exiting school and their families. Maine’s adult service system faces significant challenges due to the diverse range of needs of individuals. Our adult service system is refocusing its services to meet the increased expectation of children transitioning from school. The refocusing of the adult service system needs to happen in a planned, phased way to also prepare for the increasing number of children now being identified with ASD. Parents are increasingly concerned about the future fate of their children when they are no longer alive to support and look out for them. Our adult service system needs to engage in a public discussion about how to develop strategies that serve the various levels of need across the spectrum.

The exploration of funding streams and development of transition plans need to involve resolving the philosophical dilemma of who is prepared to fund services for people with ASD. The current state system promotes collaboration among Department of Education (DOE), DHHS and Department of Labor (DOL) to the extent that there are clear diagnostic criteria. For those who do not meet DHHS/Mental Retardation guidelines or have an AXIS I DHHS/Mental Health diagnosis, this remains at odds no matter how much the individual and team can talk to each other. Access to adult case management and long-term support must be better identified for people with ASD.

The 123rd legislature is close to passing a bill clarifying the adults we serve fall within the category of Pervasive Developmental Disorders, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. It also permits the Department to adopt by rule levels of functioning impairment to determine eligibility of services. Currently, *eligible* adults with ASD can receive services from the various offices of the Department of Health and Human Services’ Office of Adults with Cognitive and Physical Disabilities (OACPD), Office of Adult Mental Health and perhaps in the future, the Office of Elder Services. Case management and day habilitation services may be accessed through the Office of Adults with Cognitive and Physical Disabilities (OACPD) depending on eligibility. Beyond that, there is a range of services available within the Home and Community based waiver program as well as ICF-MR and PNMI programs². Currently, only those individuals on the Autism Spectrum with adaptive skill ratings two deviations below the mean are eligible for services. The result is that people with “High Functioning Autism” and Asperger’s Disorder are not receiving services. (An example would be a young man who has an I.Q. greater than 100 wants to attend college but cannot complete the application process, and wants to work but cannot successfully interview because he lacks the needed social communication skills due to Asperger’s Syndrome. He is left, totally isolated in his home.) To compound matters the program funding these services (the Home and Community Based Waiver) is closed except to people who are in Adult Protective/Health and Safety situations resulting in people waiting for this service.

² At the present, there are approximately 2,800 people on the waiver program, 1,400 people in day habilitation separate from the waiver program, and 4,800 people receiving case management services. OACPD does **not** make a distinction for these services based on type of disability once eligibility for the service is determined. Therefore, it is not possible to isolate the number of people receiving these services who have ASD

Only persons with ASD who are eligible for mental health services may receive community support, vocational, peer residential, outpatient treatment, medication management, crisis, inpatient treatment and other mental health services. (For further detail, please see DHHS In Focus Briefing Book, December 2006 <http://www.maine.gov/dhhs/focusbook.pdf>)

Current Initiatives and Activities

In the fall of 2006, the Department of Health and Human Services and the Department of Education, in conjunction with the Autism Society of Maine, began a series of planning sessions to address the emerging challenges facing the ASD population and the potential impact on Maine's systems of care. Stakeholders from around the state including state agencies, service providers, education officials, and parents were assembled to assess the current state of services for the Autism population and identify service system improvements. The Pervasive Developmental Disability System of Care Group met for six days over a five-month period to identify strengths and gaps in the service system and make recommendations. This initiative resulted in 35 recommendations to improve the system of care for persons with ASD, listed beginning on page 20.

After reviewing these recommendations, the Department of Health and Human Services is proposing the following **State of Maine Strategic Interdepartmental Plan for a comprehensive, integrated system of care for persons with Autism Spectrum Disorders - July 2007 - June 2008.** Some of these tasks are already underway.

Maine Strategic Plan

State of Maine Strategic Interdepartmental Plan for a comprehensive, integrated system of care for persons with Autism Spectrum Disorders - July 2007 - June 2008.

- A. **Action:** Develop a statewide First Signs Program to identify children with ASD at the earliest possible time.
- Lead Responsibility:** Department of Health and Human Services/Department of Education
Time Frame: October 2007
- B. **Action:** Develop an ASD surveillance system.
- Lead Responsibility:** Department Of Health And Human Services/Department of Education/
Department of Administrative and Financial Services /Office of Information Technology
Time Frame: October 2007 - September 2009
- C. **Action:** Explore and recommend standard assessment and treatment protocols for ADD.
- Lead Responsibility:** Department Of Health And Human Services/Department of Education
Time Frame: June 2008
- D. **Action:** Refocus the Adult Service System to respond to the changing needs of children exiting school and leverage existing resources and systems to include adults with autism spectrum disorder.
- Tasks:**
1. Investigate future financing options including Medicaid financing options and altering funding mechanisms to provide more comprehensive access.
 2. Expand training for providers in supporting people with ADD, emphasizing the latest best practices. The DHHS training plan for 07-08 will include one statewide training session.
 3. Current efforts to integrate services, funding and system implications will be explored in order to expand DHHS services to people with Asperger's and high functioning Autism. This should include case management, employment support, supported living, and counseling.
- Lead Responsibility:** Department Of Health And Human Services
Time Frame: October 2007 - June 2008

- E. **Action:** Investigate post secondary and vocational opportunities for people with ASD and recommend a plan of action.

Lead Responsibility: Department of Health And Human Services/Department of Labor/ Department of Education

Time Frame: October 2007 - June 2008

- F. **Action:** Develop and implement a point of accountability for overall system performance.

Tasks:

1. Create an integrated system steering committee to oversee the work.
2. Develop quality improvement and outcome measures for system performance.
3. Commissioners' report biennially to the Legislature on the implementation of the Strategic Plan.

Lead Responsibility: Department of Health And Human Services

Time Frame: March 2009

This work plan will be continually updated throughout its implementation cycle.

Recommendations

Recommendations of the Pervasive Developmental Disability System of Care Group.

These recommendations were reviewed by the departmental workgroup and are the basis for the State of Maine Strategic Interdepartmental Plan for a comprehensive, integrated system of care for persons with autism spectrum disorder outlined on page 18.

Implementation

1. That implementation of these recommendations be overseen by a steering committee, include organizing and coordinating the activities of the multiple state agencies and creation and implementation of a work plan to improve the PDD system of care.

Early Intervention

2. Utilizing the Subcommittee To Study Early Childhood Education's recommendation to build a comprehensive early intervention service delivery system, incorporate *best practice early intervention treatment services* for children with PDD and ensure consensus and consistency about best practice treatment models within DOE and DHHS. These services should be consistent throughout the state.
3. That a statewide effort be developed and implemented to educate people in both medical and non-medical communities to recognize the first signs and symptoms of PDD.
4. That a process be created and communicated to individuals in both medical and non-medical communities that provides guidance about what to do when a child is suspected to have PDD.

Children's Treatment/Services

5. That DOE and DHHS jointly identify diagnostic evaluation tools for individuals with PDD and write policies to ensure consistency and quality of diagnostic practices throughout the state.
6. That DOE and DHHS jointly agree upon best practice treatment for individuals with PDD and write policies to ensure consistency and integration of treatment knowledge throughout the state.
7. That DOE and DHHS jointly determine and maintain state of the art services across systems and disciplines that span education, home, and community.

Adolescents' Treatment/Services

8. That DOE and DHHS jointly gain a clinical understanding of research-based methods and expertise of how to support adolescents with PDD, and make recommendations for services that would meet the needs of adolescents with PDD.

Adults Treatment/Services

9. That DHHS take the lead in developing a clinical understanding of effective research-based treatment systems for adults with PDD and that adults have ongoing access to these treatments as needed.
10. That DHHS take the lead in determining the supports needed by adults with high functioning PDD that would work to create a pilot.
11. That DHHS review and explore Adult Developmental Services programs and Mental Health programs to determine if integration of services could improve support for individuals with PDD.
12. That DHHS and DOE jointly work to gain a clinical understanding of how to support individuals with PDD in post secondary education, addressing both social and academic issues.
13. That DHHS take the lead in reviewing housing needs and living supports to determine levels of support that will meet the various needs of individuals with PDD.
14. That DHHS revise eligibility standards to reflect the current population of individuals with PDD and identify and define the organizational unit(s) responsible for supporting the individuals.
15. That DHHS take the lead in reviewing national models that outline successful support and treatment for people with PDD.
16. That DHHS take the lead in reviewing how the State is delivering services and how it could better meet the needs of individuals with PDD in an efficient and cost effective way.
17. That DOL take the lead in reviewing national models that outline successful employment for individuals of all functioning levels with PDD.
18. That the service responsibilities and boundaries within DHHS organizational units be defined, and in collaboration with DOL, MSHA, DOC, and DOT, develop a process to communicate with each other about common clients.
19. That Memorandums of Understanding (“MOU”s) be developed between/among state agencies that serve individuals with PDD, including DHHS, DOL, MSHA, DOT, and DOC. The MOUs should set forth how staff will work together to support individuals with PDD and define organizational and staff responsibilities.
20. That DOL and DHHS jointly take the lead in creating and implementing a statewide effort to educate and increase awareness to support employers, staff, and DHHS and DOL staff in understanding PDD and working with individuals with PDD.

All Individuals: Treatment/Services

21. That the in-home support system be revised to ensure consistent, quality services to individuals with PDD and to eliminate any duplicative practices
22. That client need be the driving force in determining services and methods of service delivery.
23. That DHHS take the lead in revising the current case management system across the appropriate state agencies and organizational units so there will be only one case manager assigned to an individual. That the case manager positions will help the individuals navigate the system throughout the individual's life.
24. That DHHS take the lead in determining how to ensure that individuals with PDD have quality access to medical and dental care.

Integrated Ongoing Individual Planning

25. That DOE, DOL and DHHS jointly develop policies and procedures to support a comprehensive integrated dynamic plan that can be used throughout an individual's life, and create standard practices for implementation of that plan, including updates of the plan and identification of unmet needs. (See recommendation 31)

Funding Streams

26. That performance indicators currently being used to satisfy the multiple funding streams be standardized so that one report will satisfy all reporting requirements.
27. That funding streams in DHHS, DOL, and DOE be reviewed for ways to optimize flexibility across these funding streams.
28. That the state and federal funding opportunities be reviewed to maximize resources for adults with PDD.

Data

29. That the Maine CDC conduct an incidence study of PDD in child and adult populations.
30. That the data systems of DOE, DHHS, DOL, and DOC be analyzed to determine what data about services and demographics can be extracted, integrated, and/or analyzed.
31. That a confidential HIPPA-compliant data system be created that can track individuals through multiple service delivery systems and that collects information about when and how the individuals access services. This data system should be utilized jointly between DOE, DHHS, DOL, and DOC, ensure that an individual has only one intake throughout his or her experience with the service systems, and ensure that each service delivery agency would have the same knowledge set. This data system should be accessible and able to provide pertinent information from a public health point of view. The system should routinely cross match infants/children/individuals in various DOE/DHHS/DOL services to ensure that individuals are receiving the services that they need and that data is not duplicative.

Transition

32. That DOE, DHHS, and DOL jointly develop transition plans beginning no later than age 14 including, but not limited to, individual education, behavioral health, housing, vocation, and physical health. The plans should have preparation for employment as a major focus and should include what is available and what needs to happen to achieve life goals. (See Recommendation #25)

Community Involvement

33. That the private sector be encouraged to consider ways to naturally include individuals and families with disabilities.
34. That a public awareness campaign about PDD be developed, focusing on positive stories.
35. That a workgroup identify institutional, familial, and other barriers to community involvement and recommend how they can be mitigated or removed.