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# Department of Health and Human Services

*Maine People Living  
Safe, Healthy and Productive Lives*

## **Autism 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 Autism Spectrum Disorders,  
Parents, Advocates and Other Governmental Agencies**

**March 2011**

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# Executive Summary

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In the last couple of decades, there has been a dramatic increase in the number of individuals diagnosed with autism and other pervasive developmental disorders (PDD) in Maine and across the country, with an associated increase in the need of services for children and adults. Service systems are being asked to meet different sets of needs than those for which they were originally designed and demand is growing rapidly. Maine has continued its coordinated PDD Systems Change Initiative to improve those systems and work toward meeting these challenges. In accordance with the Autism Act of 1984, 34-B M.R.S.A. §6001-6004, this biennial report describes the current status of services for persons with autism and other PDDs, and initiatives underway to improve and expand systems' quality, capacity, and efficiency.

PDDs are lifelong neurological developmental disabilities that profoundly affect the way a person comprehends, communicates and relates to others. Many organizations, such as the American Academy of Pediatrics, have made clear that early identification and intervention can greatly improve the long-term prognosis for people with PDDs.<sup>1,2</sup> As pointed out by the Autism Society of America, however, many adults with PDDs may need some level of support throughout their lifetimes.<sup>3</sup>

The rapid increase in the number of individuals with PDDs is escalating the need to expand Maine's ability to serve this population. In 2009 MaineCare claims data indicated that there were over 4,150 individuals who had a diagnosis of PDD and received Mainecare, a 23% increase from just two years earlier. The Department of Education's annual 2009 Child Find data also indicated a dramatic increase in students being served for special education under the category of autism with a 316% increase over the previous ten years.

In 2008 Maine created the PDD Systems Change Initiative to analyze the systems individuals with PDD and their families utilize and make these systems more effective and efficient in responding to the needs of persons with PDDs. The Initiative exemplifies public and private collaboration, bringing together state agency staff, service providers, educators, individuals with PDD, their families, and other interested parties. Over the last three years the PDD Initiative has examined issues and developed plans for improvement in the processes of early identification, intervention, and transition. It has also worked with physicians to improve healthcare for individuals with PDD. Through the Initiative significant gains have been made in implementing the early identification plan. For example, in the spring of 2009, the PDD Initiative provided the opportunity for medical practices to field test screening all children for autism at 18 month of age. Over 3,500 children were screened and the feedback from the physicians and other medical staff was positive.

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<sup>1</sup> Johnson, MD et. Al. (2007) Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics Vol. 120

<sup>2</sup> Myers, MD et. Al. (2007) Management of Children with Autism Spectrum Disorders [PDD], Pediatrics Vol. 120

<sup>3</sup> Autism Society of America (2010) Autism Through the Lifespan <http://www.autism-society.org/living-with-autism/lifespan/> Site accessed February 2, 2011

## Executive Summary (Continued)

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Over the past two years Maine's Evidence-Based Practice Subcommittee has continued its work to identify evidence-based therapeutic treatments. This subcommittee includes representatives from governmental agencies (Department of Health and Human Services, Department of Education, and Department of Corrections), parents, providers, individuals with a PDD, and those involved with training mental health professionals. The subcommittee examined the quality of available research and published a report that detailed the evidence on the effectiveness of the most commonly used treatments for children and youth with Autism Spectrum Disorders (ASD).

Maine was awarded a five-year Child Health Quality Improvement Grant totaling \$11,277,362 to improve health outcomes for children enrolled in MaineCare. One of the many tasks that the grant will fund is development and implementation of patient-centered medical home pilots to enhance practice-level capacity for child health quality improvement and to evaluate the impact on quality.

In 2010, Maine's demonstrated success in planning and coordinating activities led to the Department of Health and Human Services also receiving a three-year State Autism Implementation Grant (AIG) of approximately \$300,000 annually. The grant will allow PDD Initiative work to continue to improve health outcomes for individuals with autism and other PDDs through early identification and the provision of effective and coordinated treatment. In addition, the AIG will build upon the Child Health Quality Improvement Grant by providing additional support to two of the medical practice pilots so they can provide an enhanced level of care coordination within the medical home process.

Over the last two years the Legislature passed two key pieces of legislation directly related to individuals with autism and other PDDs. In order to ensure that all Maine children at risk of a PDD receive early identification and intervention, the 124<sup>th</sup> Legislature passed PL 2009, c. 635, which mandates insurance companies to provide coverage for the diagnosis and treatment of ASD for all children under the age of six. The law went into effect in January 2011. The 124<sup>th</sup> Legislature also enacted Resolve 2009, c. 100, that directed the Department of Education (DOE) to convene a workgroup to analyze the quality of educational services for students with Autism Spectrum Disorders (ASD) and training resources available for teachers and paraprofessional staff. The workgroup was directed to make recommendations to DOE that would ensure that students with ASD receive appropriate and effective educational services. The workgroup's report is summarized within this document.

## Definition of Autism

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The Diagnostic and Statistical Manual of Mental Disorders fourth edition, text revised (DSM-IV-TR) defines Pervasive Developmental Disorders as “severe and pervasive impairment in several areas of development” characterized by patterns of unusual social interaction, communication, and behaviors/interests. Five PDDs are included: Autistic Disorder (Autism), Asperger’s Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)<sup>4</sup>, which are grouped together as Autism Spectrum Disorders (ASD) and two additional lower incidence disorders that are typically not included as ASDs, Childhood Disintegrative Disorder and Rett’s Disorder. According to the Autism Society of America and Autism Speaks, PDDs are lifelong, neurological developmental disabilities that profoundly affect the way a person comprehends, communicates and relates to others<sup>5,6</sup>. The way individuals experience PDD can vary greatly in intensity and degree. Therefore, treatment and educational strategies must be highly individualized to meet each person’s unique needs.

Publication of the new edition of the Diagnostic and Statistical Manual of Mental Disorders is scheduled to be released in May 2013. The draft manual changes the definition of PDDs significantly by combining all PDDs into one disorder grouping, Autism Spectrum Disorder. The draft manual also removes the presently used multi-axis system. Maine’s rules and statutes will likely need to be updated to reflect those changes when the new edition is published.

Autism was once considered a rare disorder. Now, according to the U.S. Center for Disease Control, Autism Spectrum Disorders are at epidemic levels, affecting 1 in 110 children, and are four times more likely to affect males<sup>7</sup>.

## State of the State

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In 1984 there were fewer than 40 individuals identified as having autism in Maine. To provide services to them, the 111<sup>th</sup> Legislature passed the Autism Act of 1984. At the turn of the 21<sup>st</sup> century, our schools served 594 students under the category of autism. In 2000, Schools reported 2,471 students being served in that category. In 2009, MaineCare paid claims for more than 4,156 Maine citizens diagnosed with a PDD. Maine is not alone with this increase. In 2010, the U.S. Centers for Disease Control updated its estimated prevalence numbers to 1:110. In fact, the growing epidemic is worldwide. Studies in Asia, Europe and North America have identified individuals with an ASD with an approximate prevalence of 0.6% to over 1% of the population<sup>8</sup>

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<sup>4</sup> Autism, Asperger’s Disorder, and PDD-NOS are sometimes referred to as Autism Spectrum Disorders or ASD.

<sup>5</sup> [http://www.autismspeaks.org/whatisit/index.php?WT.svl=Top\\_Nav](http://www.autismspeaks.org/whatisit/index.php?WT.svl=Top_Nav) accessed 1/29/2009

<sup>6</sup> [http://www.autism-society.org/site/PageServer?pagename=about\\_what](http://www.autism-society.org/site/PageServer?pagename=about_what) accessed 1/29/2009

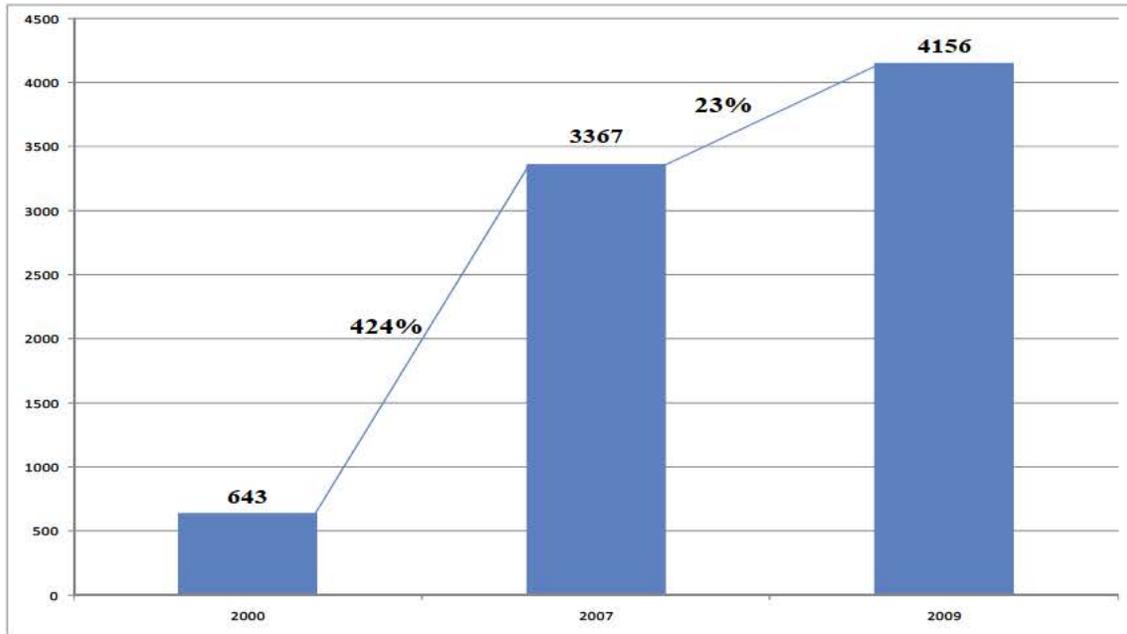
<sup>7</sup> [www.cdc.gov/ncbddd/autism/index.htm](http://www.cdc.gov/ncbddd/autism/index.htm) accessed 12/29/2008

<sup>8</sup> <http://www.cdc.gov/ncbddd/autism/data.html> Accessed 12/28/2010

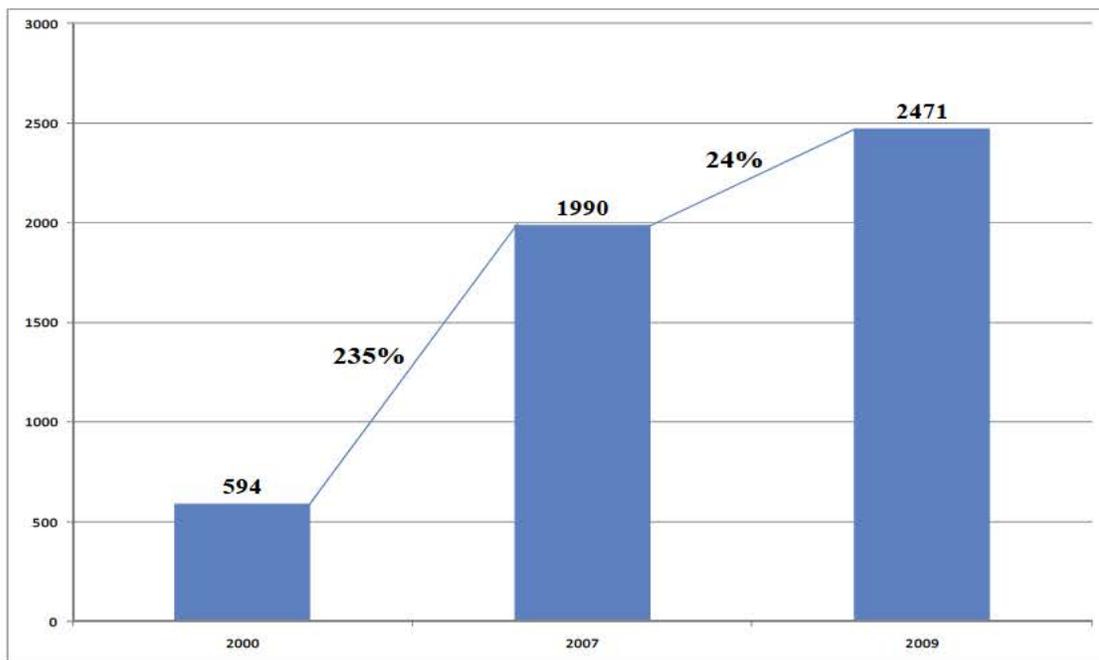
## State of the State (Continued)

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In 2007, MaineCare paid claims for 3,367 members with a PDD. In 2009, that number jumped to 4,156. **That is an increase of 23% within just the last two years. The increase is over 540% in the last nine years.**<sup>9</sup>



DOE data also indicates a dramatic increase in the number of students being served for special education under the category of autism, a **316% increase in just 10 years.**



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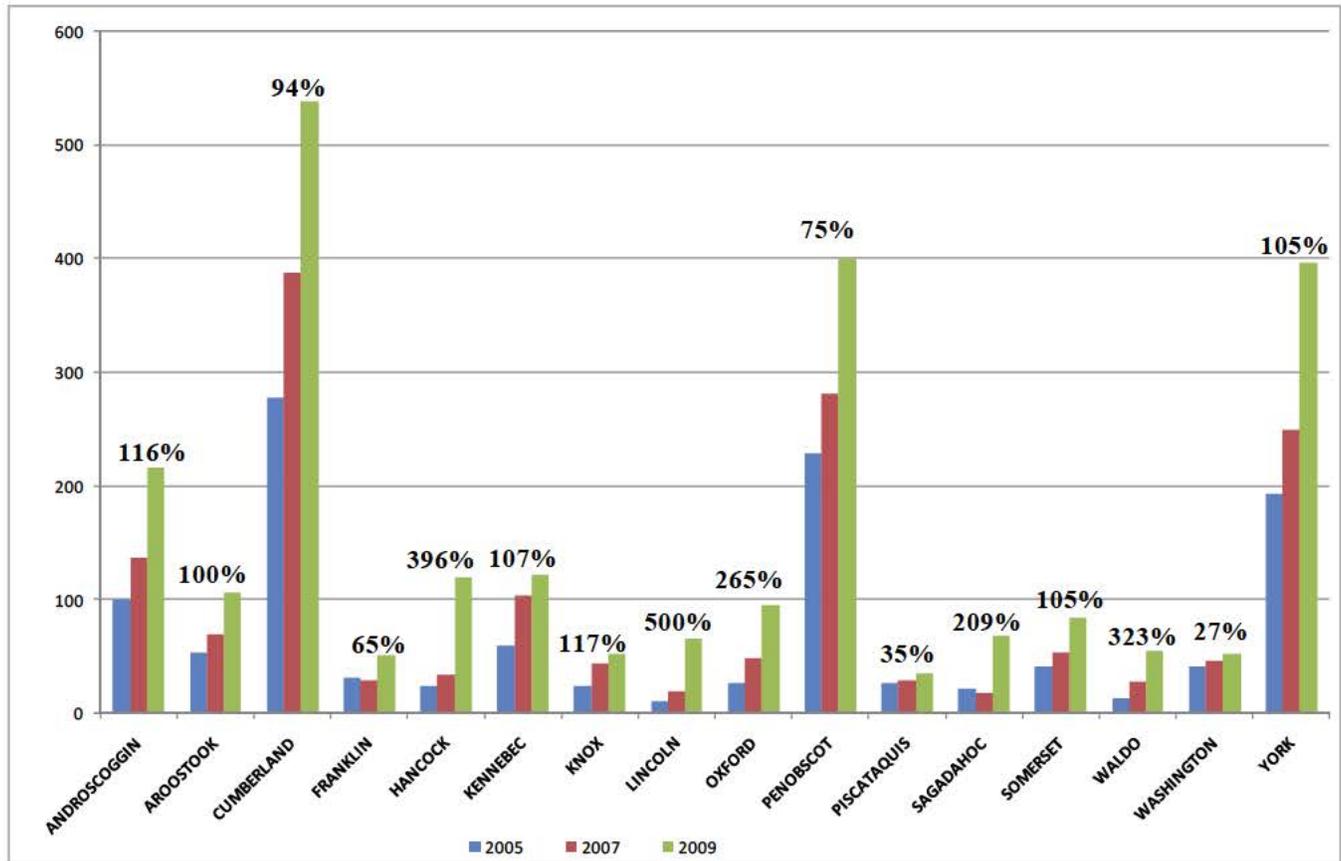
<sup>9</sup> MaineCare is an income-dependent service.

## State of the State (Continued)

According to MaineCare claims data, there has been an increase in the number of individuals with PDD in every age group. **Young adults aged 18 through 26 are the fastest growing groups. The largest number of individuals with PDD is the age group of those six through 12 years of age.**

Age	2007	2009	% Increase
0-2	91	102	12%
3-5	470	579	23%
6-12	1304	1659	27%
13-17	774	930	20%
18-20	239	315	32%
21-26	184	237	29%
27-64	296	323	9%
65+	9	11	22%
<b>Total</b>	<b>3367</b>	<b>4156</b>	<b>23%</b>

According to school Child Find data, since 2005 there has been an increase in the number of individuals served in the autism category in every county.



# Eligibility vs. Entitlement through the Lifespan

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Children and adults with PDDs need a variety of services. However, many services are dependent upon meeting eligibility standards which are different for children and adults. Once children meet eligibility criteria, they are entitled to an array of services. Adults who meet eligibility criteria are entitled to receive case management services, but there is no guarantee that they will receive any other services. Services for children and adults are paid for by a variety of different funding mechanisms.

## **Maine’s Bright Futures Campaign**

Maine’s DHHS has taken several steps to detect and diagnose, as early as possible, developmental delays and other disabilities. In order to screen all children in a timely and periodic manner, MaineCare has developed clinical forms, based on the nationally renowned Bright Future campaign, to be used during all recommended well-child visits. In 2010, DHHS added a screening for autism to the clinical forms. DHHS is actively encouraging medical practitioners to change their practice and screen for autism and other PDDs utilizing the recommended guidelines by the American Academy of Pediatrics. Medical practitioners who complete the forms and send them to the Office of MaineCare Services receive an enhanced rate.

## **School-Based Services**

A child is entitled to special education services if the child meets eligibility criteria. The federal Individuals with Disabilities Education Act (IDEA) specifies that every child who receives special education services is entitled to a Free Appropriate Public Education (FAPE) that is individually designed to meet the child’s educational needs.

## **Medical Services for Children**

The State is required to provide preventive screening and “medically necessary” treatment for all MaineCare eligible children pursuant to federal Early Periodic Screening Diagnosis and Treatment (EPSDT) requirements under Medicaid. Children covered by private insurance and/or rely on family resources, may have a more restricted ability to access to treatment and services.

# Eligibility vs. Entitlement (Continued)

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## **DHHS – Office of Child and Family Services, Division of Children’s Behavioral Health Services (CBHS)**

Children under six years-of-age with a documented ASD who receive MaineCare benefits are eligible for a wide-array of supports and services through CBHS<sup>10</sup>. Children and youth between the ages of six and twenty must score greater than two standard deviations below the mean using a functional assessment tool, such as the Vineland, or have a mental health diagnosis to be eligible for CBHS services. If resources are available, families whose children are not MaineCare eligible can receive Flex Fund services and Respite Services.

### **Insurance Mandate**

The 124<sup>th</sup> Legislature passed Chapter 635 (LD-1198), which mandates that insurance companies provide coverage for the diagnosis and treatment of ASD for all children under the age of six. The law went into effect in January 2011. There are no limits on the number of visits or cost, except that service policies may limit coverage for applied behavior analysis therapies to \$36,000 per year.

### **DHHS – Adult Developmental Services**

An adult is eligible for Adult Developmental Services if the adult has have a documented PDD and a score of greater than two standard deviations below the mean determined through a functional assessment. Eligible adults receive case management services and can apply for MaineCare waiver services. Some individuals receive services under the Home and Community Supports Waiver (MaineCare Section 21) while others receive services under the Community Supports Program (MaineCare Section 29), dependent upon individual needs and availability of funding<sup>11</sup>.

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<sup>10</sup> A list of available CBHS services can be found at <http://www.maine.gov/dhhs/ocfs/cbhs/programs.shtml> accessed 3/2/2011

<sup>11</sup> Both waiver programs currently have waitlists. As of January, 2011 there were 400 individuals with developmental disabilities on the Section 21 home and community supports waiver waiting list. Of that number, 189 individuals with developmental disabilities are in critical need of services; having been found to be at risk for their health and safety. As of January, 2011 there were 228 individuals with developmental disabilities on the waitlist for the Section 29 community supports waiver program.

## Autism Implementation Grant (AIG)

In 2010 DHHS' Children with Special Health Needs (CSHN) program applied for and was awarded a three-year State Autism Implementation Grant of approximately \$300,000 annually, funded under the federal Combating Autism Act Initiative. The grant is to improve health outcomes for individuals with autism and other PDDs through early identification, and provision of effective and coordinated treatment within a comprehensive medical home.

The grant will implement much of the early identification work designed by the PDD Early Identification Workgroup and other PDD System Change Initiative activities.

### PDD Systems Change Initiative

In 2007 DHHS submitted the "Autistic Spectrum Disorders Report" to the Joint Standing Committee on Health and Human Services. The report included the PDD Systems of Care Group's recommendations and a strategic plan incorporating those recommendations. The State of Maine Strategic Interdepartmental Plan for a comprehensive, integrated system of care for persons with Autism Spectrum Disorders focused on five tasks:

- Develop a statewide early identification and surveillance system to identify children with PDD at the earliest possible time.
- Explore and recommend standard assessment and treatment protocols for children with PDD.
- Refocus the Adult Service System to respond to the changing needs of children with PDD exiting school.
- Investigate post secondary and vocational opportunities for people with PDD and recommend a plan of action.
- Develop and implement a point of accountability for overall system performance.

The comprehensive review of services and systems addressing the needs of individuals of all ages with PDD identified targeted areas of concern and opportunities for improvements.

In 2008, the Departments of Health and Human Services, Education and Labor began implementing the strategic plan by launching the PDD Systems Change Initiative. The Maine Developmental Disabilities Council provides staff for the Initiative. The first three priority areas of the PDD Initiative, selected by the Steering committee<sup>12</sup>, were early autism identification and intervention systems, as well as the system to transition youth from school to adult systems. The PDD Initiative then convened multiple multi-stakeholder workgroups to analyze and develop plans to improve the systems. The Initiative has made significant gains implementing the early identification plan. To continue its work to improve early identification, intervention and other health concerns, the PDD Systems Change Initiative has been selected to assist CSHN with the management of the new State Autism Implementation Grant. This grant will support the continued work to implement the plans created by the Initiative's many workgroups.

<sup>12</sup> The PDD Steering Committee was made up by representation from the governor's office and the Commissioner's of DHHS, DOE, and DOL

# Early Identification and Intervention

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According to the Autistic Spectrum Disorders Report distributed by DHHS in 2007, “only about [one-] half of children with PDD in Maine are diagnosed before kindergarten.”<sup>13</sup> There is concern that children are not being diagnosed early enough to receive the full benefit of early intervention treatment.

The American Academy of Pediatrics [2007] has reported that studies indicate early intervention services for young children with ASD significantly improve the child’s prognosis and should begin as early as 18 months of age<sup>14</sup>. Research showed that almost all children with ASD benefit from early intervention therapies. The research further indicates that one-third of children receiving early intervention services improved so much that their need for ongoing support was dramatically reduced<sup>15</sup>.

Along with the benefits to the children, early intervention has been shown to save money. In 2007 the Harvard School of Public Health reported that many individuals with ASD require lifelong supports at a cost estimated at \$3.2 million per person. In addition, the U.S. Centers for Disease Control and Prevention has reported that individuals with ASD had median medical expenditures 8.4-9.5 times higher than those without ASD.<sup>16</sup> Several studies have shown that early intervention can reduce those costs by more than half over their life span.<sup>17,18,19.</sup>

## PDD Systems Change Initiative

In November 2008, a diverse team of medical professionals, including pediatricians, developmental specialists, and general practitioners, nurse practitioners, and professionals in the fields of social work and speech pathology met to address protocols for universal screening young children for ASD. This group made the following recommendations:<sup>20</sup>

- a) Screen all children using the Parents Evaluation Developmental Status (PEDS) at 9- and 18-month well-child visits;
- b) Screen all children using the Modified Checklist for Autism in Toddlers (M-CHAT) screening tool at their 18- and 24-month well-child visits; and
- c) Provide an automatic referral for services and further evaluation whenever a parent voices strong concern about his/her child’s development.

<sup>13</sup> DHHS (2007) Autistic Spectrum Report [http://www.maine.gov/dhhs/2007\\_autism\\_report.pdf](http://www.maine.gov/dhhs/2007_autism_report.pdf) Retrieved 12/30/2010

<sup>14</sup> Myers MD, Scott M (2007) Management of Children with Autism Spectrum Disorders. Pediatrics <http://www.aap.org/pressroom/AutismMgmt.pdf> accessed 1/13/2009

<sup>15</sup> Lord, Catherine (2001) Educating Children with Autism. National Academy Press ISBN: 0-309-07269-7

<sup>16</sup> CDC [www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html) accessed 12/30/2010

<sup>17</sup> Ganz PhD, Michael L (2007) The Lifetime Distribution of the Incremental Societal Costs of Autism, Pediatrics & Adolescent Medicine. Vol. 161 No. 4

<sup>18</sup> Jacobson, J. W., Mulick, J. A., & Green, G. (1998). Cost benefit estimates for early intensive behavioral intervention for young children with autism - general model and single state case. Behavioral Interventions, 13, 201-226.

<sup>19</sup> Chasson, G. S., Harris, G. E., & Neely, W. J. (2007). Cost comparison of early intensive behavioral intervention and special education for children with autism. Journal of Child and Family Studies, 16, 401-413.

<sup>20</sup> DHHS Autism Spectrum Report to the Legislature, February 2009 [http://www.maine.gov/dhhs/reports/autism\\_act\\_report.pdf](http://www.maine.gov/dhhs/reports/autism_act_report.pdf) accessed 12/30/2010

## Early Identification and Intervention (Continued)

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### **PDD Systems Change Initiative (Continued)**

In the spring of 2009, the PEDS and M-CHAT were field-tested in six medical practices, with over 3,500 children being screened. All of the medical practitioners successfully incorporated the tools into their practices and expressed mostly positive feedback about the screening tools. This feedback further supported the plan to adopt these as universal screening tools in Maine.

In addition, the PDD Steering Committee convened the PDD Early Intervention Workgroup to spend four intensive full days focusing on the process for planning and providing comprehensive early intervention services to young children identified with a PDD, and to find ways to improve those processes. By the completion of the work, multiple State agencies, provider agencies, and parents had documented and described the services and supports that exist for early intervention. The group concluded that in order “to receive comprehensive early intervention services for a child, the family often must work with multiple agencies, have multiple evaluations, and provide the same information to different case managers, many times, in order to have multiple plans.”<sup>21</sup> They determined that this fragmentation of services considerably delayed and complicated the delivery of an effective, efficient early intervention service system.

### **Improving Health Outcomes for Children in Maine and Vermont (IHOC)**

On February 4, 2009, the President signed into law the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) (P.L. 111-3). In addition to providing ongoing federal funding for public health insurance programs targeting children in low-income families, the CHIPRA law seeks to improve a child's access to quality health care. In particular, Title IV of CHIPRA creates a broad quality mandate for children's health care that authorizes health care quality initiatives for both the Children's Health Insurance Program (CHIP) and Medicaid programs. Section 401(d) of CHIPRA provided for competitive grant awards to no more than 10 projects to “evaluate promising ideas for improving the quality of children's health care.”

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<sup>21</sup> PDD Early Intervention Workgroup (2009) [Early Intervention Service System for Young Children with PDD](http://www.maineddc.org/documents/Early-Intervention-Report-Final.pdf)  
<http://www.maineddc.org/documents/Early-Intervention-Report-Final.pdf> Accessed 1/3/2011

# Early Identification and Intervention (Continued)

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## IHOC (Continued)

In February 2010, Maine, in partnership with the State of Vermont, was awarded a five-year child health quality improvement grant which will total \$11,277,362. The Maine/Vermont program intends to promote the use of quality measures and information technology to improve health outcomes for Medicaid eligible children (IHOC), thereby improving their timely access to quality care. Specifically, the State of Maine plans to:

- Collect and evaluate the CHIPRA core measures, a set of pediatric quality measures identified by a federal panel of experts, and additional pediatric quality measures identified by Maine stakeholders.
- Report pediatric quality measures to payers, providers, consumers and the Centers for Medicare and Medicaid Services, and identify barriers and solutions to implementation.
- Refine MaineCare's pay-for-performance program under its new managed care system to provide greater incentive for child health quality improvement.
- Align pediatric quality measures selected by the demonstration program with quality measurement activities of other payers, health care organizations, professional organizations, and with MaineCare payment incentives.
- Design, develop and implement health information technology linkages and systems within Maine's DHHS Services and with medical practices and health systems in order to collect and report EPSDT/Bright Futures preventive measures and other clinical data from the clinical record.
- Design, implement and evaluate an electronic health assessment for children in Maine's child welfare foster care system. Children in foster care have three times the medical problems and utilize up to eight times the behavioral health services in comparison to other children who receive Medicaid insurance coverage. Identifying their needs on entry to the child welfare system and managing their care could lead to a decrease in expensive crisis services and ultimately improved outcomes for the children.
- Implement the Bright Futures Resource Toolkit with Maine child health providers and assess the impact on the provision of EPSDT services in Maine.
- Develop and implement "Learning Community" activities with the Patient-Centered Medical Home Pilot and other medical practices to enhance practice-level capacity for child health quality improvement and to evaluate the impact on quality.
- Build a child health quality improvement partnership in Maine that will be sustained after the grant ends. This concept leads providers and their practices to continually improve care as new information is obtained.

# Early Identification and Intervention (Continued)

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## **Autism Implementation Grant (AIG)**

One of the primary goals of the AIG is to improve public health's capacity to recognize and provide early intervention services to children at risk of or diagnosed with PDD. The following discusses the specific actions Maine will be taking to reach this goal as part of the AIG grant.

### **Recognizing Autism Early**

The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) provides a valuable opportunity as it makes contact with thousands of young children and their families. Over the next year the AIG will fund the Autism Society of Maine to provide information to Maine's sixteen WIC offices about the first signs of autism so they can assist families of children who are displaying warning signs of autism to get the necessary screening and evaluations.

### **Implementing new Screening and Referral Procedures**

Many young children and their families are served by Maine's Head Start, Home Visiting, and Public Health Nursing Programs. Over the next three years, each of these programs will receive training on using the M-CHAT to screen young children for ASD. In addition, program staff will receive training on formal protocols to support and discuss with families screening results and to communicate the screening results to the child's Primary Care Physician (PCP).

### **Encouraging Maine's Physicians to Adopt Screening Recommendations**

Another step towards an effective early identification system is to encourage Maine's physicians to adopt the American Academy of Pediatrics' screening recommendations for young children. Over the next three years, the Maine Centers for Disease Control (CDC) will work with the PDD Systems Change Initiative to design and distribute guidance for quick, easy, and efficient PCP referrals to diagnosticians and early intervention professionals. They will also provide fourteen trainings in the form of "grand rounds" in hospitals across the State. Trainings will provide information to medical professionals about;

- The population of individuals with ASD in Maine,
- Why screening and referral is important, and
- Results of the screening pilots and options for incorporating the new processes into their busy offices.

## Early Identification and Intervention (Continued)

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### **Increasing the Effectiveness & Efficiencies of Diagnosis and Service Planning**

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During the PDD Early Intervention Workgroup, families and professionals reported that multiple, duplicative evaluations are sometimes conducted with little communication between medical specialists and early intervention professionals. They also discussed the multiple, uncoordinated service plans developed for children. To address this problem the AIG will support two pilot studies of methods to improve early identification and intervention. Over the next three years, the Department of Education's Child Development Services and medical professionals will work to improve coordination and communication between the two systems. They will work together to develop and pilot new procedures that improve communication and coordination between their two systems, from initial referral, through evaluation and development of an initial service plan for each child.

### **Facilitating Autism Screening and Treatment (FAST) Data System**

Maine will integrate and support the improved communication and coordination of the pilots by developing a comprehensive data system to facilitate prompt screening, diagnosis, evaluation and treatment for children with PDD. The FAST system will provide a portal for Head Start Staff, Home Visitors and Public Health Nurses to communicate quickly to primary care physicians about screenings. In addition, primary care physicians will be able to utilize FAST to refer children for evaluation and services. While the primary goal of FAST is to improve the early identification and intervention system, an added benefit will be the aggregate data it can provide for policymakers.

# Early Identification and Intervention (Continued)

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## DHHS – Division of Early Childhood

The Early Childhood Division’s mission is to ensure the seamless integration of early intervention and prevention programs into the family-centered practices of the Office of Child and Family Services. To support this mission, the Division has three major initiatives for inclusionary practices:

*Quality for ME, Maine’s Early Care and Education Rating System* - This is a four-step system that rates a licensed provider’s quality across eight standards of care. This system: provides individuals a simple tool to help recognize and choose quality child care, provides Maine child care programs help in improving their quality, provides a tool to measure the quality of child care programs, and allows Maine to join other states across the nation in measuring and supporting quality child care for all families.

*Child Care Plus ME (CC+ME)* - This project works to ensure that all infants, preschoolers, and young children, including those with and without disabilities, have an opportunity to be cared for and educated in high quality, inclusive schools and community child care settings. The project staff provides on-site inclusion consultation and time-limited supports based on individual child and program assessment.

*Maine’s Expanding Inclusive Opportunities (MEIO)* - This project is a federally-funded initiative designed to build on existing State efforts to improve inclusive opportunities for young children with disabilities and their families. It represents a collaborative commitment by the MEIO cross-agency state leadership team: the Maine DOE - CDS, the DHHS, and the Center for Community Inclusion & Disability Studies. The goal of the project is to support early childhood programs in providing high quality inclusive settings for young children and their families.

## Center for Community Inclusion and Disability Studies (CCIDS)

CCIDS, at the University of Maine, is part of a national consortium led by The Arc of the United States. The Arc was recently awarded a grant to develop and implement a national resource center on autism and other developmental disabilities. This four-year project began in October 2010. CCIDS will provide expertise and resources to this national initiative on a wide range of topics relevant to individuals with ASD and other developmental disabilities and their families. This work will complement and enable expansion of the Maine Autism Spectrum Disorders Resource Center launched by CCIDS in June 2010, with support from the Maine Department of Education.

CCIDS faculty and staff provide a wide range of technical assistance regarding services and inclusive practices to meet the needs of persons with ASD and related developmental disabilities throughout Maine and at the national level. For example, CCIDS faculty and staff provide autism-specific technical assistance to early childhood programs, schools, institutions of higher education, employers, and State and community agencies.

# Healthcare

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## IHOC Medical Home Project

Over the next few years the IHOC will work to develop and implement “Learning Community” activities with the Patient Centered Medical Home (PCMH) Pilot and other medical practices to enhance practice-level capacity for child health quality improvement and to evaluate the impact on quality. Maine currently has four pediatric practices included in the PCMH Pilot. The Medical Home concept began in pediatrics as a practice that would provide:

- Coordinated primary care with care of specialists,
- Availability 24 hours a day, seven days a week,
- Integration of **all** medical and behavioral health records for each patient, and
- Assure culturally sensitivity and patient and family centeredness.

### **Expanding the Capacity of Doctors to Provide Quality Healthcare**

In 2009, the Maine Developmental Disabilities Council provided funding for the development and delivery of training and technical assistance for general practitioners regarding strategies they can adopt to improve routine care for children with ASD. Pre-training survey results identified that medical practitioners were much less comfortable providing on-going care for children with ASD than for other disorders. Specifically only thirty percent of the physicians who attended the trainings rated themselves as comfortable or very comfortable providing ongoing care for children with ASDs.

Over the next three years, AIG funds will be utilized to expand the training to reach additional primary care physicians so that more primary care medical practitioners will have the knowledge and tools to provide quality healthcare for children and youth with ASD. In addition, AIG funds will be used to develop an online training program for other medical office staff to enhance their ability to support successful medical appointments for children with ASDs.

## Healthcare (Continued)

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### **Comprehensive Medical Home for children and youth with ASD**

A medical home is a model for providing primary care that includes medical care, preventive care, knowledge of educational services, community services, coordination of all needed services and resources to meet the needs of children and their families<sup>22</sup>. In 1999, the American Academy of Pediatrics published a study that emphasized the importance of care coordination to reduce the barriers to appropriate care because there is often no single entry point to multiple systems of care<sup>23</sup>. The PDD Early Intervention Workgroup mapped similar complexities and barriers in Maine's system of care. To reduce barriers that currently exist for families accessing care for their children with ASDs, DHHS has aligned the medical home portion of the IHOC grant with the AIG grant. Two of four pediatric offices involved in the PCMH pilots will enhance the existing medical home model<sup>24</sup> to also provide comprehensive coordination of the services individuals with ASD may utilize.

### **Expand the capacity of families to actively participate in medical homes**

Encouraging physicians to provide medical home services for individuals with ASD is only half of the equation. The other half is educating and supporting families to engage in the model. Over the next three years, the AIG will support Maine Parent Federation to develop and present a curriculum that provides information to families about medical homes. In addition, support will be provided to the Autism Society of Maine to enhance its website and serve as a resource to families regarding medical homes and how to maximize use of this model for the best interests of their children.

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<sup>22</sup> National Center of Medical Home Initiatives <http://www.medicalhomeinfo.org> accessed 1/5/2011

<sup>23</sup> American Academy of Pediatrics, (1999) Committee on Children with Disabilities, care Coordination: Integrating Health and Related Systems of Care for Children With Special Health Care Needs, Pediatrics, 104:978-981

<sup>24</sup> Waisman Center, National Medical Home Initiative <http://www.waisman.wisc.edu/nmhai/> accessed 1/5/2011

# Current Education Services for students with ASD (PL 100)

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The 124th Legislature enacted Resolve, To Provide a Program Model for Children with Autism Spectrum Disorder (Chapter 100) in 2009. The Resolve directed the Department of Education (DOE) to convene an ASD Workgroup to analyze six topics that focused on the current educational services for students with Autism Spectrum Disorders (ASD). The ASD Workgroup was directed to make recommendations to DOE that would ensure that students with ASD receive appropriate and effective educational services. This report summarizes, by topic, the ASD Workgroup's research, discussion, and recommendations.

## **Topic One: Barriers to Full Inclusion for Students with ASD**

Some of the issues that were repeatedly brought up included:

1. Lack of knowledge among teachers and paraprofessionals about ASD;
2. Challenges due to the variety of functioning levels and symptoms that individuals with ASD may have;
3. Funding issues;
4. Problems with coordination of therapeutic plans; and
5. Separate teacher training programs for regular and special education at the University level which fuel a continued sense of separation among professionals in schools.

Recommendations to address this topic included that DOE should:

1. Increase monitoring efforts;
2. Seek and encourage others to apply for funding from sources other than the State;
3. Create incentive programs to support schools; and
4. Work with the University systems to combine regular education and special education departments and course offerings.

## Education Services (Continued)

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### **Topic Two: Ensuring that Students with ASD Receive Appropriate Services in the Least Restrictive Environment (LRE) and that Parents are Included in the Planning Process**

There was acknowledgement that, for many reasons, there is often tension between professionals and parents. Another complication is that students may receive similar services in school and at home, but the plans are not coordinated and there is little to no communication between staff in the separate service systems. When there are multiple plans that have similar goals, but with different teaching methodologies, the student's ability to understand or master the skills may be significantly impacted. Lastly, the ASD Workgroup noted that, while schools may collect LRE data, there is no standardized requirement to share information, unless the data is directly related to federal indicators. Because the data that DOE receives is so limited, it is very difficult to identify specific issues and address them through public policy.

The ASD Workgroup presented a series of recommendation including:

1. A new workgroup be convened to:
  - a. Identify methods to reduce adverse relationships between parents and teachers, and
  - b. Review models for schools to self assess LRE and other quality indicators.
2. The DOE fund Regional Technical Assistance Mobile Centers to provide itinerant consulting services and assistance to school districts. The goal of these mobile centers would be to bring experts into schools to improve the achievement of children and youth with disabilities and children at risk for developmental delays. They would accomplish this by assisting educators and families in:
  - a. Development and delivery of specially designed instruction aligned with Maine's academic content standards,
  - b. Measuring student progress through, data collection and analysis for individual students, and
  - c. Working with specific issues that a child may have.

# Education Services (Continued)

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## **Topic Three: Improving Transition for Students from One Grade Level to the Next Level**

The ASD Workgroup acknowledged that individual teaching styles can make a difference and noted that students with ASD should be thoughtfully matched with teachers, whenever possible. The ASD Workgroup was concerned about the lack of a standardized method for carrying over long-term goals and communicating a student's effective learning styles to his or her teacher for the next year. The ASD Workgroup affirmed that students with ASD do best with a predictable routine and were concerned that there was no formal practice to prepare students for upcoming annual changes.

The ASD Workgroup recommended that the DOE should:

1. Amend the Individual Education Program (IEP) forms to include an annual plan of transition, and
2. Issue guidance on identifying the pathways to each student's desired long term outcomes.

## **Topic Four: Resources re ASD Available to Professionals and Paraprofessionals**

When the ASD Workgroup members reviewed the resources available to professionals and paraprofessionals, they were surprised to find how few are available. The resources that professionals identified that they access included the Autism Society of Maine, colleagues, paid consultants, and occasional trainings. Another existing resource identified in Maine was training available through the two paraprofessional programs in the State. The ASD Workgroup reviewed a software program, Autism Pro, that offers an online, searchable database of evidence-based resources including activity plans, teaching strategies and supports for students with ASD. The ASD Workgroup recommended further investigation of the feasibility of purchasing this software for educators in Maine to be able to make use of this resource, and whether strategies learned would be transferable.

Use of the internet as a means to locate resources was discussed at length. The ASD Workgroup decided that use of the internet to locate information was too time-consuming, because professionals would have to filter through information to verify that recommended practices are evidence-based. **The group urged instead that the DOE maintain an up-to-date website that includes evidence-based practices and promising practices about teaching students with ASD.**

The ASD Workgroup also noted that the limited availability of resources reinforced the need for regional technical assistance centers, as described above, to be available for educational professionals and paraprofessionals.

# Education Services (Continued)

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## **Topic Five: Gaps in Information about ASDs**

The ASD Workgroup discussed the wide range of gaps in information about ASD and ultimately decided that many of their concerns could be addressed by implementing the Universal Design for Learning teaching model for all children. This would not only assist students with ASD, but also other students. It would provide multiple opportunities and methods to obtain learning materials, express comments or questions, and determine appropriate accommodations to address each student's uniqueness and individual learning needs.

The ASD Workgroup also reviewed studies regarding training and supervision of teachers and paraprofessionals. The group was particularly concerned by the findings of William Breton, a professor at the University of Maine at Presque Isle, who recently completed a study about the current practices and adequacy of paraprofessional preparation in Maine. Breton's<sup>25</sup> review of literature and survey of over 750 Maine paraprofessionals showed that Maine's special education paraprofessionals not only administer the most content to students with ASD, but also frequently have the primary teaching responsibility. These paraprofessionals often lack academic qualifications and competencies and receive little or no training. In addition Breton pointed out that teachers receive little to no supervisory training, and often feel ill-equipped to oversee the work of paraprofessionals.

The ASD Workgroup also found that neither educational professionals nor paraprofessionals in Maine are required to have specific knowledge or expertise regarding students with ASD. The ASD Workgroup reviewed certification requirements and compared Maine to other states in the nation. They found that:

- Twenty states require formal endorsement, standards, and/or certification for providing instruction and related services to students with severe disabilities or students with ASD.
- Eight states do not require formal endorsement, standards, or certification, but have comprehensive training and/or technical assistance programs available for educational professionals.
- Twenty-two states do not currently require any training or certification. Maine is one of these states.

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<sup>25</sup> Breton, William (2010) Special Education Paraprofessionals: Perceptions of Preservice Preparation, Supervision, and Ongoing Developmental Training International Journal of Special Education Vol 25

## Education Services (Continued)

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The ASD Workgroup recommends that Maine take necessary steps to assure professionals and paraprofessionals have the necessary expertise to meet the needs of students with ASD. Specifically, the Workgroup recommended that one or more new workgroup(s) be convened to:

1. Establish the minimum level of competencies for all regular and special educators in order to provide educational services to students with ASD;
2. Examine available curricula and recommend a specific one that regular and special education teachers must complete for certification in order to be considered “highly qualified” teachers for students with ASD in this state;
3. Investigate the feasibility of adopting a loan forgiveness program and other incentives for existing teachers to take specific courses about ASD; and
4. Investigate the benefit and feasibility of adjusting certification for paraprofessionals to include concentrated specialties on ASD.

The ASD Workgroup also recommended that DOE:

1. Work with community colleges and universities to develop core certification programs for teachers and paraprofessionals that work with individuals with ASD,
2. Issue guidance on expected outcomes of paraprofessional supervision.

# Office of Child and Family Services – Division of Children’s Behavioral Health Services (CBHS)

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## CBHS Early Intervention Services

Early Intervention services focus on early identification of needs and preventive treatment for preschool-age children. Services include screening, diagnosis and evaluation, case consultation, developmental therapies and specific treatment directed to address the child’s needs. CBHS provides funding for the following programs;

Autism Consultation Services - In Washington County, CBHS funds specific Autism Consultation Services contracted through the Child and Youth Board of Washington County.

Project Relate - Located in southern, western, and central Maine and Mid-Coast Maine, Project Relate collaborates with preschool child care providers and contracted clinical professionals for the purpose of identifying children at risk of expulsion from day care due to disruptive behavioral issues. The service provides consultation services to provider staff as well as parents and caregivers of these children.

Family / Parent Support Services – CBHS provides funding to several family organizations to provide regional family support groups, information, referrals, and training opportunities.

## Targeted Case Management Services:

Children’s Targeted Case Management programs (TCM) utilize the Wraparound Process to develop and coordinate individual support plans and monitor services provided to children and their families and/or guardians. **According to MaineCare claims data, over 2,690 children and youth diagnosed with PDD received targeted case management services in 2009.**

## Residential Treatment

At times children are in need of short-term out-of-home residential services to stabilize behaviors and learn coping skills in order to return to their homes and communities and be safe and successful. Residential programs are available that specialize in the care of children and youth with cognitive disabilities and/or ASD.

## Respite Care

Families of children with autism and other PDDs are eligible for respite care services. Respite is planned, temporary care of a child with developmental or emotional/behavioral needs for the purpose of giving relief to the caregiver. Respite workers may be trained and certified individuals or they may be selected by the family seeking services.

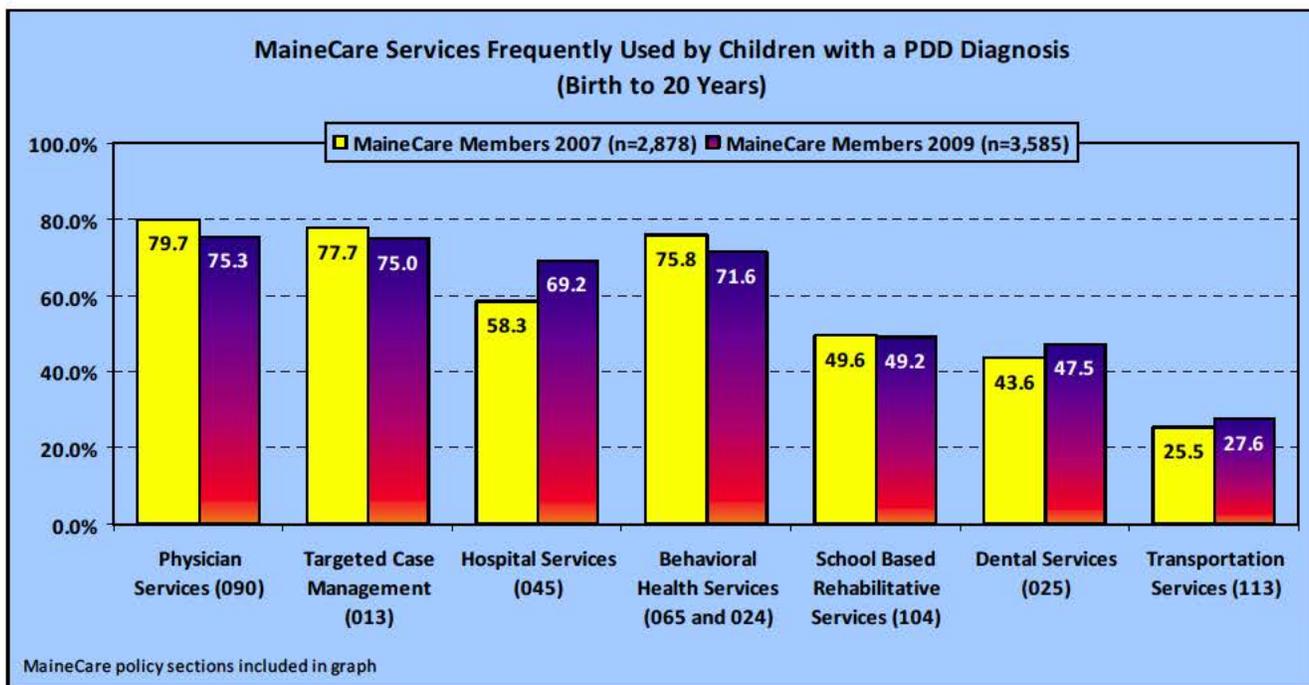
# CBHS (Continued)

## Home Based Services:

Rehabilitative Community Services (funded by MaineCare Section 28) for eligible children and youth with developmental disabilities or PDD, offer skill building in areas of daily living, communication and behavioral management to support the children’s functioning in their homes and communities. This service includes an evidenced-based model utilizing Applied Behavior Analysis practices to help maintain or improve the functional abilities of children in service. Section 28 services became available July 1, 2010, replacing “habilitative community services” previously offered under MaineCare Section 24, which was repealed. **According to MaineCare claims data, over 1,050 children and youth diagnosed with a PDD received habilitation services in 2009.**

Mental health treatment programs (HCT) (MaineCare Section 65) for children and youth with serious emotional disturbance work with the children and families in their homes and in their communities. The programs work to engage the children and families in family counseling and explore strategies to help the children and families manage mental health symptoms and improve overall functioning in the home, school and community. **According to MaineCare claims data, over 1,511 children and youth diagnosed with PDD received Section 65 mental health treatment services in 2009.**

**In 2009, over 70% of children and youth with a PDD diagnoses received home based services and targeted case management through the MaineCare Program.**



## CBHS (Continued)

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### **Flexible Funds**

Flexible funds provide short-term, individualized services for children and families, such as safety devices, assessments, transportation, emergency needs, adaptive equipment, therapeutic recreation and family support (including emergency and additional respite services).

### **Home and Community-Based Waiver (Draft MaineCare Section 32)**

DHHS was successful in its recent application to the Centers for Medicare and Medicaid Services (CMS) for authorization to develop a comprehensive waiver program that will provide a variety of services and supports for children and youth with cognitive disabilities and/or ASD. During the first year of the program, Maine is authorized to serve up to 40 children. Work is beginning to develop a network of providers and a system that will prioritize and perform clinical reviews of the children referred for this program, and oversee the collection of federally required quality measures.

## ASD Treatment Initiatives

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### **Evidence-Based Practices for children with PDD Subcommittee**

In the summer of 2008 CBHS coordinated a broad group of stakeholders who were involved either personally or professionally with PDD. This Subcommittee included representatives from child-serving governmental agencies (Department of Health and Human Services, Department of Education, and Department of Corrections), parents, providers, individuals with a PDD, and those involved with training mental health professionals. The Committee published its report in October of 2009; it is available online at <http://www.maine.gov/dhhs/ocfs/cbhs/ebpac/asd-report2009.pdf>. The report details the level of evidence supporting the effectiveness of all the most commonly used treatments (psychosocial and medication) for children and youth with ASD.

# ASD Treatment Initiatives (Continued)

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## **Applied Behavioral Analysis (ABA)**

As of September, 2010, CBHS is now authorizing a higher reimbursement rate for Rehabilitative and Community Services (MaineCare Section 28) for providers utilizing treatments supported by the highest levels of evidence. There are a growing number of agencies providing ABA, an evidenced-based practice that has strong and proven outcomes especially for very young children with ASD. CBHS has developed an application process whereby community agencies can submit requests for consideration for the enhanced MaineCare rate.

In addition, the University of Southern Maine has developed a graduate course for certification as a Board Certified Behavioral Analyst (BCBA). There are now over 40 BCBA's practicing in Maine who are considered by MaineCare as eligible providers in the development, provision and oversight of individual ABA treatment plans.

## **CCIDS Developmental, Individual-Difference, Relationship-Based Model**

For the past three summers, a team of CCIDS faculty and staff led by Dr. Sandra Doctoroff has coordinated and offered a summer institute for early intervention providers in the use of the Developmental, Individual-Difference, Relationship-Based Model (DIR), developed by Dr. Stanley Greenspan, for young children with autism spectrum disorders. In addition to this three-day intensive institute, led by nationally recognized experts in DIR, participants engage in a year-long follow-up of consultation and practice. In the Fall of 2010, CCIDS also sponsored a half-day seminar for families and community members on this evidence-based autism intervention model. CCIDS is currently exploring foundation funding to support and expand this initiative.

# Transition

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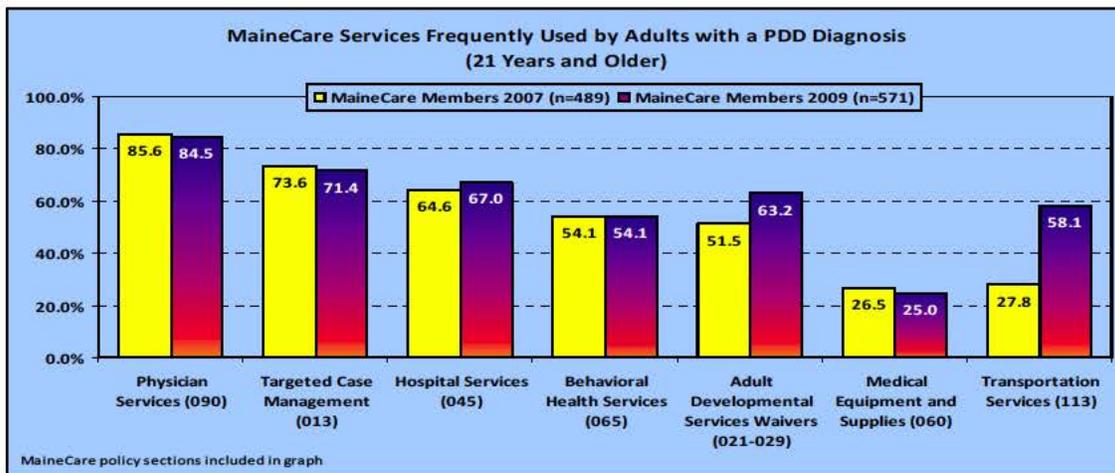
## **Family-Centered Transition Planning Project for Students with ASD**

CCIDS is involved in a two-year research project in collaboration with the Institute on Disability at the University of New Hampshire examining the effectiveness of a family-centered support program for students with ASD, ages 16 through 18 years. Participating families learn about practical strategies for person-centered planning, networking, and for utilizing a variety of adult service options and resources. In addition, project staff facilitates individual planning meetings and provides support for students to investigate career options. Because this is a research project, the program is currently closed to new participants. CCIDS hopes to be able to expand the project to a broader range of participants in coming years. The project has also developed a transition resource guide that will be available to all on their website.

# DHHS - Office of Adults with Cognitive and Physical Disabilities Services (OACPDS)

## Targeted Case Management Services:

Each person eligible for Developmental Services is entitled to receive case management services. The case manager assists the person with the development of a person-centered plan, coordinates the identified services, and assures the quality of services being provided. **According to MaineCare claims data, over 400 adults with PDD received targeted case management services in 2009.**



## The Home and Community Supports Waiver (MaineCare Section 21)

This is a comprehensive waiver that provides a variety of supports including residential, employment, community supports, counseling, therapies, transportation, and crisis. This waiver program has been closed and there is a waitlist for this service. As of January, 2011, there were 400 individuals with developmental disabilities on the waitlist. Of that number, 189 individuals with developmental disabilities were in critical need of services; having been found to be at risk for their health and safety.

**Over 350 adults with PDD received services through either the supports waiver or the home and community supports waiver in 2009.**

# OACPD (Continued)

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## The Supports Waiver (MaineCare Section 29)

The Supports Waiver provides employment and community supports to people living at home with their families, with a capped dollar amount. This waiver, implemented in 2008, has also been closed and there is a waitlist for this service. As of January, 2011, there were 228 individuals with developmental disabilities on the waitlist, with up to 100 individuals expected to be added as the end of the school year approaches.

### Other Services:

OACPDS has limited dollars to support people for professional services that are not covered by MaineCare. In addition to the services listed above, OACPDS provides crisis services, advocacy services, and adult protective services.

**According to MaineCare claims data, transportation services increased by more than one-third between 2007 and 2009**

## OACPDS Continuing Education

OACPDS is committed to providing continuing education to case managers and other service providers who work with adults with PDD.

- Developmental Services recently transitioned to training Direct Support Professionals through the College of Direct Support. The training includes a module specifically on working with people who have autism and other PDDs.
- Crises teams continue their clinical consultation in 09-10 with Dr. Richard Guare with an emphasis on PDD.

# OACPDS (Continued)

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## **The Emerging Challenge:**

OACPDS faces several challenges in supporting people with PDD. The number of people who are being referred is increasing and national statistics and State education data indicate that this will continue. However, funding for OACPDS programs has been reduced in each of the last several years. Both the Home-and-Community-Based-Waiver Program and the Supports Waiver have long waiting lists. OACPDS will need to work now and in the future with people with developmental disabilities and their families to develop new programs that provide the flexibility, training, and level of support to assist the persons with PDD to live and work in their communities, while at the same time doing so in the most cost effective means possible. This will require new approaches and new models of support.

## **Employment**

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### **Quality Employment Practices for Supporting Individuals with ASD**

The Center for Community Inclusion and Disability Studies at the University of Maine provides a two-day advanced training for individuals who provide employment supports to individuals with ASD. The training is based on a curriculum developed by Alan Kurtz and Janine Collins entitled *Quality Employment Practices for Supporting Individuals with Autism Spectrum Disorders*. The trainers recognize the incredible diversity among people on the autism spectrum and have designed a highly interactive training that includes frequent opportunities for participants to discuss the unique issues they may face when supporting individuals with this diagnosis.

## **Conclusion**

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Clearly, Maine continues to make great strides to improve its systems for children and youth with PDD. However, Maine shares with the nation the continuing struggle to adjust systems to meet the needs of the growing population of individuals diagnosed with a PDD. Most of Maine's systems and processes were designed to meet the needs of individuals with other disabilities and these services and supports may or may not be adequate for individuals with PDD. The work outlined in this report illustrates that gaps remain in our system of care. One severe challenge is the number of youth with PDD who are reaching adulthood. State agencies and other concerned parties will need to work now and in the future to develop new programs that provide the flexibility, training, and level of support to assist persons with PDD to live and work in their communities, using the most cost effective means possible. This will require innovative approaches and models of support. That said, all parties are encouraged by the continuing effort and commitment State agency staff, advocates, university staff, educators, service providers, family members, and individuals with PDD have made towards working together to find solutions in a collaborative, coordinated manner.

# Acronym Glossary

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Acronym	Definition
ABA	Applied Behavioral Analysis
AIG	Autism Implementation Grant
ASD	Autism Spectrum Disorder
CBHS	DHHS – Children’s Behavioral Health Services
CC+ME	Child Care Plus Me
CCIDS	Centers for Community Inclusion and Disability Studies
CDC	Centers for Disease Control and Prevention
CHIPRA	Children’s Health Insurance Program Reauthorization Act of 2009
CMS	Centers for Medicaid and MaineCare Services
CSHN	DHHS – Children with Special Health Needs
DHHS	Department of Health and Human Services
DOE	Department of Education
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders fourth edition, text revised
EPSDT	Early Periodic Screening Diagnosis and Treatment
FAPE	Free Appropriate Public Education
FAST	Facilitating Autism Screening and Treatment data system
HCT	Mental Health Treatment Programs
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Program
IHOC	Improving Health Outcomes for Children in Maine and Vermont
LD	Legislative Document
LRE	Least Restrictive Environment
M-CHAT	Modified Checklist for Autism in Toddlers
MEIO	Maine’s Expanding Inclusive Opportunities
OACPDS	Office of Adults with Cognitive and Physical Disabilities Services
PCMH	Patient Centered Medical Home
PCP	Primary Care Physician
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
PEDS	Parents Evaluation Developmental Status (screening tool)
PL	Public Law
RCS	Rehabilitative Community Services
TCM	Targeted Case Management
WIC	Special Supplemental Nutrition Program for Women, Infants and Children