

# MAINE STATE LEGISLATURE

The following document is provided by the  
**LAW AND LEGISLATIVE DIGITAL LIBRARY**  
at the Maine State Law and Legislative Reference Library  
<http://legislature.maine.gov/lawlib>



Reproduced from electronic originals  
(may include minor formatting differences from printed original)



# 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

February 2009

# Table of Contents

---

Executive Summary .....	3
Definition of Autism.....	4
State of the State .....	5
Eligibility vs. Entitlement through the Lifespan.....	7
PDD Systems Change Initiative .....	8
Early Identification and Intervention.....	9
Children Services provided by DHHS - Office of Child and Family Services – Division of Children’s Behavioral Health Services (CBHS) .....	14
Transition .....	15
DHHS - Office of Cognitive and Physical Disability Services (OACPDS).....	18
Activities and projects planned .....	19

# Executive Summary

---

In the last couple of decades, there has been a dramatic increase in the number of individuals with Autism and other Pervasive Developmental Disorders (PDDs) in Maine and across the country, with an associated increase in need for 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 embarked on a coordinated initiative to improve those systems and work towards 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' capacity.

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. MaineCare claims data indicate a 380% increase in individuals with PDD in the last eight years. This increase is reflected in a comparable 374% eight-year increase of the numbers of children receiving special education services in the Autism category. Both sets of statistics reflect an average growth of 17% annually.

The Governor and the Commissioners of the Departments of Health and Human Services, Education, and Labor have recognized the need to ensure that our service delivery systems adjust to meet the needs of people with PDD. In order to assure the most cost effective and efficient utilization of resources, the Commissioners are serving as the Steering Committee for a new PDD Systems Change Initiative. Through this collaborative endeavor, the state agencies will collaborate with other public and private entities to analyze current systems and implement changes that will make these systems more effective in responding to the needs of persons with PDDs.

---

<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> Sullivan, R. (2001) "Position Paper on the National Crisis on Adult Services for Individuals with Autism: A Call to Action." San Diego, CA: Autism Society of America [http://www.autism-society.org/site/DocServer/Adult\\_Services\\_vMay2007.pdf?docID=2601](http://www.autism-society.org/site/DocServer/Adult_Services_vMay2007.pdf?docID=2601) Site accessed January 29, 2009

## Executive Summary (Continued)

---

The initial areas of focus for the PDD Systems Change Initiative, begun in 2008, are Early Identification of PDDs in young children and the Transition Process from school to adult life. To date workgroups have evaluated current services and developed improvement plans. Some components of those plans are in the implementation phase. For example, screening tools and a schedule for use of those tools have been selected and pilot projects to field test universal screening for PDDs in young children are planned to begin in early Spring 2009. The goal is to implement universal screening on a statewide basis before the end of the year.

Future areas of focus for the Initiative include: early intervention services, health care, and services for youth and adults, including employment and community supports.

## Definition of Autism

---

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>, and two lower incidence disorders, 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 the person’s unique needs.

Autism was once considered a rare disorder. Now, according to the Center for Disease Control, Autism Spectrum Disorders are at epidemic levels affecting 1 in 150 children and are four times more likely to affect males<sup>7</sup>.

---

<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

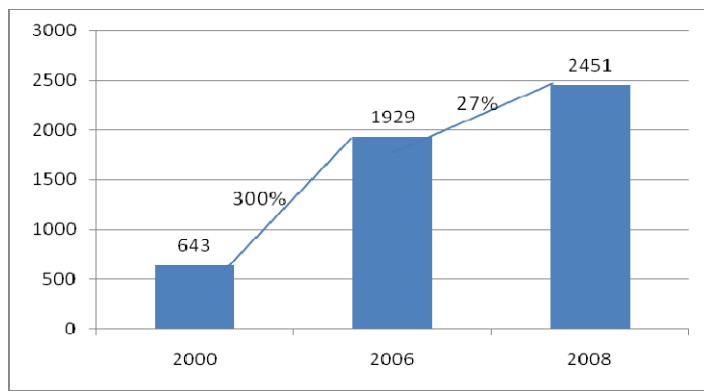
# State of the State

---

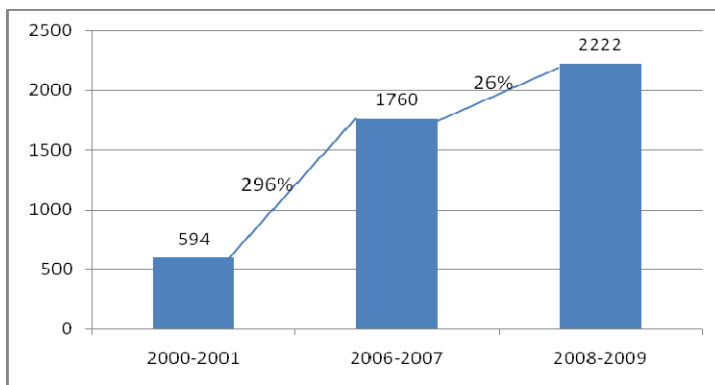
In 1984 there were fewer than 40 individuals identified as having autism in Maine. To provide services to them, the 111th Legislature passed the Autism Act of 1984. Today, in 2009, our schools serve 2,222 students identified with autism. According to the U.S. Centers for Disease Control, MaineCare has reported that 1:150 eight year olds are diagnosed with autism<sup>8</sup>. The Autism Society of America has stated that the numbers of individuals diagnosed with an Autism Spectrum Disorder increases between 10% and 17% annually<sup>9</sup>.

**According to MaineCare claims and School Special Education data, the numbers of individuals with PDD in Maine have increased approximately 26% since 2006.**

MaineCare payment data indicates that the number of individuals with PDD receiving MaineCare funded services has increased by 27% within just the last two years and 380% over the last eight years.<sup>10</sup>



Preliminary IDEA<sup>11</sup> data, collected on December 1, 2008 by the Maine Department of Education, suggests that the numbers of children age 3-20 receiving special education services under the category of autism has increased 26% within the last two years.



---

<sup>8</sup> <http://www.cdc.gov/Features/CountingAutism/> Accessed January 29, 2009

<sup>9</sup> [http://www.autism-society.org/site/PageServer?pagename=about\\_what\\_is\\_factsstats](http://www.autism-society.org/site/PageServer?pagename=about_what_is_factsstats) Accessed January 29, 2009

<sup>10</sup> MaineCare is an income dependent service.

<sup>11</sup> Individuals with Disabilities Education Act (IDEA)

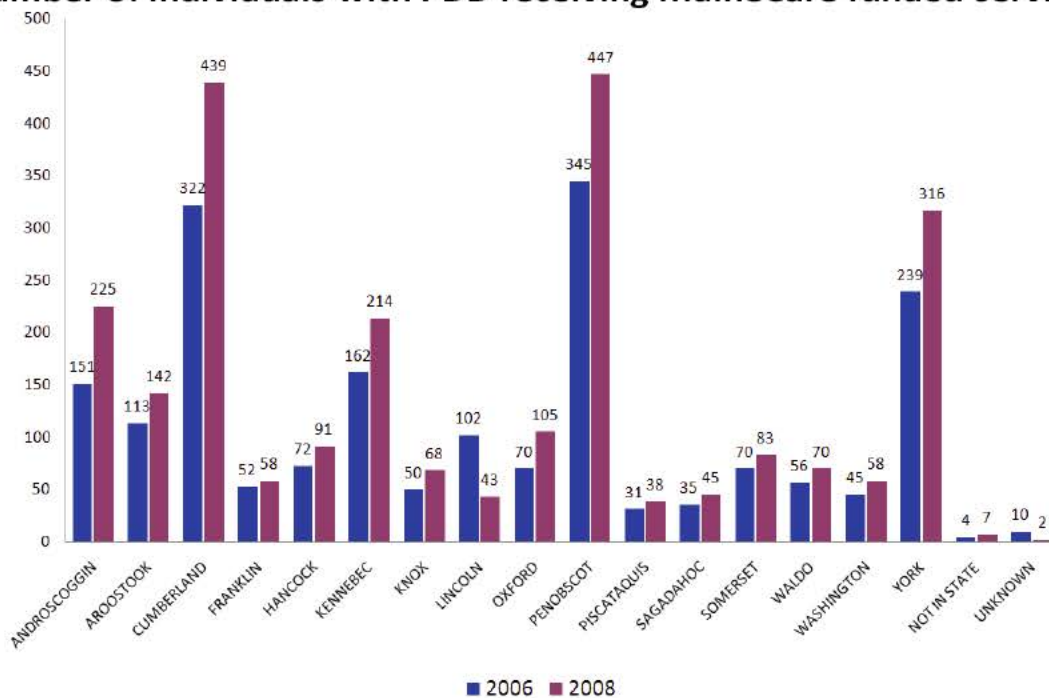
## State of the State (Continued)

According to MaineCare claims data, there has been an increase in the number of individuals with PDDs in almost every age group.

<i>Age</i>	<i>2006</i>	<i>2008</i>	<i>% Increase</i>
<i>0-3</i>	<i>173</i>	<i>225</i>	<i>30%</i>
<i>4-5</i>	<i>252</i>	<i>302</i>	<i>20%</i>
<i>6-11</i>	<i>685</i>	<i>910</i>	<i>33%</i>
<i>12-17</i>	<i>489</i>	<i>607</i>	<i>24%</i>
<i>18-20</i>	<i>103</i>	<i>131</i>	<i>27%</i>
<i>21-34</i>	<i>128</i>	<i>161</i>	<i>26%</i>
<i>35-54</i>	<i>78</i>	<i>94</i>	<i>21%</i>
<i>55-64</i>	<i>17</i>	<i>16</i>	<i>-6%</i>
<i>65+</i>	<i>4</i>	<i>5</i>	<i>25%</i>
<i>Total</i>	<i>1929</i>	<i>2451</i>	<i>27%</i>

There has been an increase in the number of individuals with PDD in almost every county.

**2006/2008 Comparison by County**  
**Number of individuals with PDD receiving MaineCare funded services**



Data Source: Office of Quality Assurance Services – Medicaid Data

# Eligibility vs. Entitlement through the Lifespan

---

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 service, 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 Future Campaign**

Maine's DHHS has taken several steps detect and diagnose 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. Providers who complete the forms and send them into the Office of MaineCare Services receive an enhanced rate.

## **School Based Services**

A child is entitled to special education services if he/she meets eligibility criteria. The federal Individuals with Disabilities Education Act (IDEA) assures 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**

Children who are eligible for MaineCare should receive preventive screening and "medically necessary" treatment pursuant to Federal Early Periodic Screening Diagnosis and Treatment (EPSDT) requirements under Medicaid. Children who are covered by private insurance may have more restricted access to treatment and services.

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

Children under six years-of-age with a documented PDD who receive MaineCare benefits are eligible for a wide-array of supports and services through CBHS. Children and youth between the ages of six and twenty must score greater than two standard deviations on a functional assessment or have an 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.

## **DHHS – Adult Developmental Services**

An adult is eligible for Adult Developmental Services if they have a documented PDD and a score greater than two standard deviations below the mean determined through a functional assessment. Eligible adults receive case management services and can apply for waiver services. Some individuals receive services under the Home and Community Supports Waiver while others receive services funded by the Supports Waiver.



# PDD Systems Change Initiative

---

In 2006 DHHS convened a stakeholder group with broad public and private representation to assess the current state of services for individuals with Autism and other Pervasive Developmental Disorders (PDD). A key component of the PDD System of Care Group’s discussion was the need to address the range and variety of needs that individuals with PDD may have, given the characteristics and variability of this spectrum disorder.

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, after reviewing the recommendations, DHHS developed a strategic plan. 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.

Their 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. Utilizing federal funds, a contract between the Maine Department of Education (DOE) and the Maine Developmental Disabilities Council (MDDC) provides staff support and coordination for the Initiative.

The Initiative exemplifies public and private collaboration. The Commissioners of the three State agencies and a representative of the Governor’s Office make up the Steering Committee. Lead staff in each agency coordinate and ensure the availability of staff and other resources necessary to accomplish project tasks. The PDD Initiative Coordinator, housed at the MDDC, organizes and facilitates all work to address the areas of focus. An Advisory Committee provides input on the work and recommendations to ensure the work is relevant and likely to achieve desired outcomes.

The Advisory Committee includes representatives of:

- Autism Society of Maine (ASM)
- Center for Community Inclusion and Disabilities Studies (CCIDS)
- Disability Rights Center (DRC)
- Parents of children with PDDs

- Provider
- Maine Parent Federation (MPF)
- Maine Administrators of Services for Children with Disabilities (MADSEC)
- Maine Transition Network (MTN)

## PDD Systems Change Initiative (Continued)

---

In addition to incorporating recommendations from the Advisory Committee, the Initiative has formalized the opportunity for individual input. During 2008 more than 100 adults with PDD, family members, physicians and other interested parties provided ongoing input to the Initiative’s work and products. Their comments are documented and incorporated in all work products of the Initiative. The number of interested parties continues to grow as the Initiative proceeds and expands areas of work.

The Initiative Steering Committee chose Maine’s early identification system and the system to transition youth from school to adult systems as the first priority areas. With major work having been completed on early identification by late 2008, the Steering Committee directed that new priorities be added. Early intervention and access to appropriate health care were chosen as the next priority areas. Future work will address other systems and services that support successful community living for persons with PDD, in environments ranging from home to school, employment, and other community settings.

## Early Identification and Intervention

---

### PDD Early Identification

According to the Autistic Spectrum Disorders Report distributed by DHHS in 2007, “only about half of children with PDD in Maine are diagnosed before kindergarten.”<sup>12</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 PDD significantly improve the child’s prognosis and can begin as early as 18 months of age<sup>13</sup>. Research showed that almost all children with PDD directly benefited from early intervention therapies. The research further indicates that one-third of the children receiving early intervention services improved so much that their need for ongoing support was dramatically reduced<sup>14</sup>.

Along with the benefits to the children, early intervention has been shown to save money. In 2007 Harvard School of Public Health reported that many individuals with PDD require lifelong supports at a

---

<sup>12</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 1/13/2009

<sup>13</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>14</sup> Lord, Catherine (2001) Educating Children with Autism. National Academy Press ISBN: 0-309-07269-7

cost estimated at \$3.2 million per person. Several studies have shown that early intervention can reduce those costs by more than half over their life span<sup>15,16,17</sup>.

## Early Identification and Intervention (Continued)

---

### PDD Systems Change Initiative Activities – Early Identification

Recognizing the urgency of identifying children early, the Steering Committee of the PDD Systems Change Initiative chose to make early identification one of its first priorities. In May 2008 the DHHS Office of LEAN Management hosted four full-day meetings to focus on the process of identifying children with Autism and other PDDs and find ways to improve that process.

Families met the first day to share their stories and provide recommendations for improvement in the identification process. They described their experiences which included long wait times, multiple steps, inconclusive answers or no answers at all. The family stories documented that obtaining a diagnosis took an average of 31 months.

The PDD Early Identification Workgroup convened for three full-day meetings to: examine the current system; design an improved system; and create an implementation plan to accomplish needed changes and additions. This Workgroup included broad representation from physicians, psychologists, developmental clinicians, families, and advocates. The Workgroup also included representatives from Head Start, Child Developmental Services, and staff from various divisions of DHHS including Child Behavioral Health Services (CBHS) and Children with Special Health Needs (CSHN)

The Workgroups recommendations included that Maine State agencies:

- Sponsor a public awareness/education campaign,
- Ensure the use of standardized tools for universal screening,
- Design and implement an efficient referral for diagnostic evaluation by a qualified medical provider, and
- Ensure prompt referral to early intervention services.

In July the Steering Committee reviewed the work plan and approved the next phase of work to develop recommendations and determine cost and resource implications for:

- Tools for universal screening,

---

<sup>15</sup> Ganz PhD, Michael L (2007) The Lifetime Distribution of the Incremental Societal Costs of Autism, Pediatrics & Adolescent Medicine. Vol. 161 No. 4

<sup>16</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>17</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.

- Process for referral to a diagnostician,
- Diagnostic evaluation components, and
- Required credentials for qualified diagnosticians.

# Early Identification and Intervention (Continued)

---

## **PDD Systems Change Initiative Activities – Early Identification (Continued)**

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. This group made the following recommendations:

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

The Workgroup also recommended a minimum of four concurrent pilot projects lasting approximately six months should be established to test how best to implement these requirements on a statewide basis. This will provide the basis for continuing support for medical offices to integrate the screening tools and schedule into their practices on a statewide basis.

The PDD Initiative Steering Committee has approved the pilot projects to field test use of the two screening tools. The pilots are scheduled to begin in early Spring, 2009.

## **CBHS Early Intervention Services**

Early Intervention services focus on early identification of needs and preventive treatment for pre-school children. Services include screening, diagnosis and evaluation, case consultation, developmental therapies and specific treatment directed to the child's needs. In FY08, eleven agencies provided services to 1,681 children and their families. Furthermore, 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 Central Maine and Mid-Coast Maine, Project Relate collaborates with pre-school 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/ caregivers of these children.

# Early Identification and Intervention (Continued)

---

## Public Health Initiative re Autism

The Maine Center for Disease Control will sponsor and host a Medical Conference on Autism at the Augusta Civic Center on May 12th, 2009. The Conference's purpose is to educate physicians and other health care providers about the newest research on causes of and treatments for Autism, and to promote the new screening tools. Co-sponsors include the Maine Medical Association, the Maine Chapter of the American Academy of Pediatrics, the Maine Osteopathic Association, and the Autism Society of Maine. Parents as well as physicians serve on the conference planning committee, in part to help bridge the divide between parents and physicians in addressing emerging treatments for Autism. Dora Anne Mills M.D., Director of the Maine CDC, is chairing the Planning Committee and the Conference.

## PDD Early Intervention

Identification of PDD in infants, toddlers, and young children helps assure that appropriate early intervention services designed to address developmental issues are provided in a timely manner. Early intervention services, designed to meet the child's unique needs, may include a wide menu of services, such as:

- Therapies including speech, occupational, developmental, and physical therapy
- Family support such as case management and counseling
- Medical care for co-morbid disorders
- Early education
- Social Development

## PDD Systems Change Initiative Activities - Early Intervention

The PDD Systems Change Initiative Steering Committee has chosen early intervention as their next focus area. They requested that the Maine Developmental Disabilities Council work with the DHHS Office of LEAN Management to facilitate a full-day meeting with families to capture their experiences with early intervention service systems. This will be followed by three full-day meetings with families, State agency staff, early intervention professionals, and other stakeholders to analyze the current system and provide recommendations to improve the system.

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

---

## Targeted Case Management Services:

Children’s Targeted Case Managers (TCM) utilize the Wraparound Process to develop and coordinate individual support plans and monitor services provided to children and their families or guardians.

**According to MaineCare claims data, over 800 children and youth diagnosed with PDD received targeted case management services in 2008.**

## Home Based Services

Habilitative programs (MaineCare Section 24) for children/youth with developmental disabilities or PDD, work on skill building in areas of daily living, communication and behavioral management to support the children’s functioning in their homes and communities. **According to MaineCare claims data, over 420 children and youth diagnosed with PDD received habilitation services in 2008.**

Mental health treatment programs (MaineCare Section 65) for children/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 100 children and youth diagnosed with PDD received mental health treatment services in 2008.**

## 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 such as emergency/additional respite services. While CBHS has not typically kept data on the specific diagnosis of children served with flexible funds in the past, they are scheduled to begin capturing the data. In general, 4,558 children and families received flexible funded services in 2008.

## Respite Care

Families of children with PDD/Autism 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.

## Services provided by CBHS (Continued)

---

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

In the summer of 2008 CBHS coordinated a broad group of stakeholders either involved personally or professionally with PDD. This Subcommittee includes 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. This Subcommittee is currently reviewing medical and psychotherapeutic treatments that are used to treat individuals with PDD's. The goal is to complete this review and disseminate the findings on the CBHS web site in 2009. The results of these reviews will then be forwarded to CBHS management with recommendations on use and selection of specific treatments.

The PDD Evidence Based Practice Subcommittee is reviewing medical and psychotherapeutic treatments that are used to treat individuals with PDD's. This task has required the development of a special review process to incorporate the review of single case design studies. The results of these reviews will be forwarded to CBHS management with recommendations on use and selection of specific treatments.

## Transition

---

According to the 2007 Autistic Spectrum Disorders Report distributed by DHHS, data indicated that Maine youth with PDD often exit the secondary education system and the children's service system without a plan for housing, community supports, employment, post-secondary educational supports, and/or needed adult support services.<sup>18</sup>

In Mary Corpi's book Guiding Your Teenager with Special Needs through the Transition from School to Adult Life(2008), the author notes that the two most critical times in a child's life are during the early intervention period and when the child is preparing to transition from school to adult life. This is equally true for youth with PDD. Corpi points out that most children learn about life through observation and participation. Dr. Brian Siegel has noted that lack of observation skills may be one of the greatest challenges a child with autism has for learning because that lack of skill inhibits the individual's ability to assimilate information<sup>19</sup>.

---

<sup>18</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 1/13/2009

<sup>19</sup> Siegel, Brian (2009) Helping Children Learn – Imitation as the Gateway to Learning  
[http://www.togetherforautism.org/articles/autism\\_children\\_learn.php](http://www.togetherforautism.org/articles/autism_children_learn.php) Retrieved 2/3/2009



## Transition (Continued)

---

When a youth with PDD turns fourteen, Maine State law<sup>20</sup> requires that activities begin that will prepare the youth to transition into adult life. According to the Federal IDEA, transition is required to be based on the youth's strengths, preferences and interests to be outcome-oriented and to include interagency linkages. Transition services are intended to promote a youth's movement into adult life, independent living, and community integration, with services that may include post-secondary education, vocational training, employment and/or adult services<sup>21</sup>.

### **PDD Systems Change Initiative Activities - Transition**

To address this need and the increasing number of children reaching transition age, the Steering Committee of the PDD Systems Change Initiative chose transition as the other high priority focus. In June of 2008 the DHHS Office of LEAN Management hosted four full-day meetings to review the process of transition for youth with Autism and other PDDs and find ways to improve that process.

Families met the first day to share their stories and provide recommendations for improvement in the transition process. The process they shared had no discernable pattern, was full of distress and uncertainty, and ended with questions about their child's future.

One mother's comments reflected many other families concerns. She said:

*"...Transition is one thing, but if there is little of quality or even adequate to transition to, the point of transitioning is completely lost. My experience and observations are that a sufficient and qualified pool of support people doesn't exist, aren't paid or supported well enough, etc.*

*"Right now my husband and I feel like the most realistic plan for our daughter's future is that we must never become ill and must never die OR we should clone ourselves. I know that seems absurd, but it is not said necessarily in jest. I'm sure many other families relate to those kinds of sentiments, nor is it new to you."*

---

<sup>20</sup> 05-071 Chapter 101, Maine Unified Special Education Regulation. Page 53 VI-2-A

<sup>21</sup> IDEA 34 CFR 300.43 (a)] [20 U.S.C. 1401(34)]

## Transition (Continued)

---

A PDD Transition Workgroup was convened and met for three full-day sessions to examine the current system, design an improved system, and created an implementation plan. The Transition Workgroup included broad representation from advocates, families, and staff from schools. The workgroup also included staff from State agencies including representatives from DOE, Department of Labor Office of Vocational Rehabilitation and various DHHS divisions including CBHS, CSHN, and the Office of Cognitive and Physical Disability Services (OACPDS). The PDD Transition Workgroup reported that the current transition process is fragmented among departments with no integration of efforts. Each Department had the opportunity to improve collaboration to:

- Standardize eligibility requirements and inconsistent age thresholds,
- Integrate transition forms and processes, and
- Standardize priorities among programs.

The PDD Transition Workgroup recommended integrating the transition processes across all child serving programs. The process should be driven by one transition document that meets the information and planning needs of all programs involved.

Public comments on the report were positive and echoed the frustrations of working with a fragmented system. More than one family expressed how important mending the transition system is to them, but they are especially concerned about what happens to their children when they reach the adult service system.

### Current Transition Activities

- *Reference Guide For Parents:* Following the PDD Transition Workgroup recommendation, the Steering Committee has requested that a reference guide be developed to explain the transition process and the multiple service systems that youth and families might need to access. This guide has been drafted by the Maine Transition Network. A meeting will be convened early in 2009 for families and other stakeholders to review the document before it is finalized.
- *Report on Best Practice:* National research about best-practice transition planning for youth with PDDs has been collected. Work to collect information about steps/components needed to implement the tasks in the PDD Transition Workgroups plan is in process. This information will be compiled for use by the Steering Committee and various workgroups of the PDD Initiative.

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

---

**Targeted Case Management Services:** Each person eligible for OACPD 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.

**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, is still accepting new consumers.

**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 has been closed and is not accepting new applications.

**Other Services:** OACPD has limited dollars to support people for professional services that are not covered in the MaineCare program, including crisis services, advocacy services, and adult protective services.

**OACPD Continuing Education:** OACPD is committed to providing continuing education to case managers and other service providers who work with adults with PDD.

- **Understanding the World View of Adults with Autism or Other Pervasive Developmental Disorders** - This year OACPD sponsored a one-day conference to educate adult case managers, mid-level managers, and agency direct care staff. The conference objectives were to provide participants with strategies for working with adults with PDD. The conference was offered in Augusta and Bangor and over 200 participants attended.
- **Annual Crisis Services Meeting** - Deb Lipsky and Dr. Will Richards presented their new SCARED model to crisis workers. The model provides guidelines for how to work with an adult with PDD in crisis.

**The Emerging Challenge:** OACPD faces several challenges in supporting people with PDD. The number of people who are being referred is increasing and national statistics indicate that this will continue. Funding for identified programs has not grown in the last several years and, in fact, has been reduced. The Home and Community Based Waiver Program presently is not open to new admissions. OACPDs and people with Developmental Disabilities will need to work now and in the future to develop new programs that provide the flexibility, training, and the 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.

# PDD Systems Change Initiative - Activities and projects planned for launch:

---

## *In 2009*

### **Early Identification and Intervention Activities**

- Support Universal Screening pilot projects.
- Host Medical Conference on Autism
- Improve the PDD Early Intervention System
- Draft a public policy that defines components to be included in diagnostic evaluation and competencies necessary in those who diagnose

### **School Age Initiatives**

- Finalize a Reference Guide explaining the transition process and the multiple service systems that youth and families might need to access.
- Compile National Research about best-practice transition planning for youth with PDDs.
- Write Autism Evidence Based Practice Subcommittee Report

### **All Ages**

- Improve access to quality healthcare and ensure that individuals with PDD receive appropriate healthcare.

## *In 2010*

### **School Age Initiatives**

- Improve integration and coordination of plans between Departments. (For example the education plan and the in-home supports plan.)
- Improve services provided to adolescents.

### **Young Adults Initiatives**

- Improve services provided to young adults.
- Improve transition services.

### **All Ages**

- Identify ways to support individuals with PDD living in the community throughout their lives.

## *In 2011 – 2012*

Specific Initiatives in 2011 and 2012 will be determined as a result of work done in 2009 and 2010 and will focus on implementation of plans developed during those years. Those initiatives are expected to include treatment and support in the home and community for individuals with PDD throughout their lifespan.