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# Autism Spectrum Disorders Report

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

Prepared by:  
The Maine Department of Health and Human Services  
And  
The Maine Department of Education

With input from:  
Persons with Autism Spectrum Disorders,  
Parents, Advocates and Other Governmental Agencies

April 2013

*Coordinated by the Autism Systems Change Initiative*

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# Executive Summary

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In the last two decades, there has been a dramatic increase in the number of individuals diagnosed with Autism Spectrum Disorders (ASD) 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 the demand for services is growing rapidly. Maine is now in the final year of the three-year State Autism Implementation Grant and has accomplished much towards the goals outlined in the Autism Act Report submitted in 2011. In accordance with the Autism Act of 1984, 34-B M.R.S.A. §6001-6004, this biennial report describes the work completed since 2011, the current status of services for individuals with ASD, and initiatives underway to improve and expand systems' quality, capacity, and efficiency.

ASDs 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 done research to document, that early identification and intervention can greatly improve the long-term prognosis for individuals with ASD.<sup>1,2,3</sup> However, the reality that many adults with ASD will need some level of support throughout their lifetimes is beginning to emerge as a challenge for caregivers and adult service systems.<sup>4,5</sup>

The rapid increase in the number of individuals with ASD is escalating the need to expand Maine's ability and capacity to serve this population. In 2012, MaineCare claims data indicated that there were over 5,380 individuals with a diagnosis of ASD who received MaineCare, a 29% increase from just three years earlier and an increase of over 730% since the turn of the twenty-first century. The Department of Education's annual 2012 Child Find data also indicated a dramatic increase in students being served for Special Education under the category of autism with a 430% increase since the year 2000.

In 2008, Maine began an ASD Systems Change Initiative sponsored by the Commissioners of Education, Labor, and Health & Human Services. The ASD initiative was charged with analyzing the multiple systems of care that individuals with ASD and their families have to navigate. The work began by analyzing the early identification and early intervention systems, which revealed that it took an average span of 32 months from initial parent concern to an actual diagnosis of ASD. Stakeholder recommendations include lowering barriers to reduce the overall time between concern and diagnosis.

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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> Fernell, Elisabeth et al (2013) Early diagnosis of autism and impact on prognosis: a narrative review. Clinical Epidemiology 2013;5 33-43

<sup>4</sup> Autism Society of America (2010) Autism Through the Lifespan <http://www.autism-society.org/living-with-autism/lifespan/> Site accessed February 2, 2011

<sup>5</sup> PBS NewsHour (2011) Autism Now For Adults With Autism. Few Support Options Past Age 21 [http://www.pbs.org/newshour/bb/health/jan-june11/autism5adults\\_04-22.html](http://www.pbs.org/newshour/bb/health/jan-june11/autism5adults_04-22.html) Accessed April 3, 2013

## Executive Summary (cont.)

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In 2010, the Department of Health and Human Services (DHHS) Children with Special Health Care Needs (CSHCN) applied for and was awarded a three-year State Autism Implementation Grant (AIG) of approximately \$300,000 annually. The ASD Systems Change Initiative, staffed by the Maine Developmental Disabilities Council, was selected to assist CSHCN with the management of the grant. Utilizing the Autism State Implementation Grant for Children and Youth with ASD, Maine has improved identification rates of children with ASD. This was done by encouraging early childhood professionals, such as Part C IDEA (Individuals with Disabilities Education Act) staff, Head Start staff, public health nurses, and physicians to screen all children at 18 months of age for ASD. A training DVD and accompanying curriculum on the administration and scoring of autism screening tools was produced. Hundreds of professionals have received the training and related materials. In addition, monetary incentives to encourage professionals to screen for autism were implemented.

Another issue of concern is the long wait time to receive a diagnosis due to the long waitlists for appointments with specialists. The waitlist is largely due to an increased need for specialists in the State to provide both diagnostic services and basic follow-up care for children with ASD. To address these issues, funded by the Implementation grant, Maine sponsored two pilot projects. The first pilot tested new processes in coordination and communication between early education professionals (Part C and Section 619B IDEA) and diagnosticians to expedite the time between referral and diagnosis for children who are identified as possibly having an ASD. The second pilot added to MaineCare's existing Patient Centered Medical Home (PCMH) pilots by enhancing the model to also provide comprehensive coordination of the services individuals with ASD may utilize. Preliminary results from both pilot projects are positive.

On behalf of Improving Health Outcomes for Children (IHOC) and MaineCare Services, Maine Quality Counts has launched the First STEPS (Strengthening Together Early Preventive Service) initiative. In 2012, First STEPS focused on improving developmental, autism, and lead screenings. Twelve practices from throughout the state participated in the eight month project.

The Maine Department of Health and Humans Services and Department of Education have both made significant changes in policies and work that effect people with ASD. One major initiative that the Maine Department of Education has undertaken is to create sixteen Autism Teams and train them in evidence based practices. After the trainings, the Autism Teams will serve as a resource to schools throughout the state for technical assistance in effective evidence-based programing for students with ASD. Most of the initiatives that the Departments have undertaken are summarized within this document.

# Definition of Autism

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The definition of “autism” has evolved since Leo Kanner first identified “autistic disorders of affective contact” as a distinct developmental disorder in 1943.<sup>6</sup> Autism is a developmental disability that typically appears during the first two years of life and impacts development in the areas of social interaction, communication, and range of interests and activities. In the United States, a diagnosis of autism is typically based on criteria listed in the Diagnostic and Statistical Manual (DSM) IV.<sup>7</sup> These include impairments in each of the following three categories:

- Qualitative impairments in social interaction
- Qualitative impairment in communication
- Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities.

Increasingly, the term *Autism Spectrum Disorders* (ASD) is being used to describe a spectrum or range of conditions including Autistic Disorder, Asperger’s Syndrome and Pervasive Developmental Disorders – Not Otherwise Specified (PDD-NOS). According to the Autism Society of America, ASD are lifelong, developmental disabilities that profoundly affect the way a person comprehends, communicates and relates to others<sup>8</sup>. Characteristics and behaviors vary greatly among individuals with ASD. The way individuals experience ASD can also vary greatly in intensity and degree. Therefore, treatment and educational strategies must be highly individualized to meet each individual’s unique needs.

Currently, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, (DSM-IV-TR) includes five autism-related developmental disabilities under the broader diagnostic category of *Pervasive Developmental Disorders* (PDD). Pervasive Developmental Disorders are defined as “severe and pervasive impairment in several areas of development” characterized by patterns of unusual social interaction, communication, and behaviors/interests. The five PDD are Autistic Disorder (Autism), Asperger’s Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), which are grouped together as Autism Spectrum Disorders (ASD) and two additional lower incidence disorders, Childhood Disintegrative Disorder and Rett’s Disorder. These two lower incidence disorders are typically not included as an ASD but are included within the category of PDD.

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<sup>6</sup> Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250.

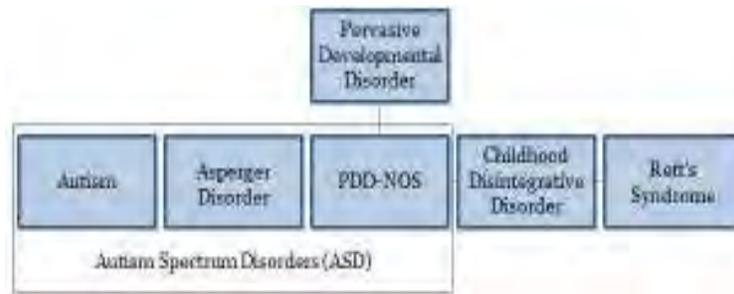
<sup>7</sup> American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: Text revision* (4<sup>th</sup> ed.). Washington, D.C.: Author.

<sup>8</sup> Autism Society of America. (2013). About autism. Retrieved April 4, 2013 at <http://www.autism-society.org/about-autism/>

4. <http://www.cdc.gov/ncbddd/autism/data.html> Accessed 2/12/3013

## Definition of Autism (cont.)

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A new edition of the DSM (DSM-5) is scheduled to be released in May 2013. The proposed new name for the category will be Autism Spectrum Disorder and will encompass all of the previously separately diagnosed disorders (Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and PDD-NOS) under one category. It is currently not being recommended that Rett's Disorder be included in the DSM-5 at all. Currently, Maine's rules and statutes reference all disorders under the PDD category but as that category may be eliminated in the new edition, Maine's rules and statutes will likely need to be updated to reflect these changes.

The proposed DSM-5 criteria also combine impairments in social interaction and communication into a single *social communication* category. This category retains the criteria of repetitive behaviors and fixated interests and behavior as well as the requirement that symptoms begin in early childhood.

**Proposed Diagnostic Criteria for Autism Spectrum Disorder**  
From: *American Psychiatric Association DSM-5 Development*

Must meet criteria I, II, and III:

(I) Clinically significant, persistent deficits in social communication and interactions, as manifest by all of the following:

- (A) Marked deficits in nonverbal and verbal communication used for social interaction;
- (B) Lack of social reciprocity;
- (C) Failure to develop and maintain peer relationships appropriate to developmental level

(II) Restricted, repetitive patterns of behavior, interests, and activities, as manifested by at least TWO of the following:

- (A) Stereotyped motor or verbal behaviors, or unusual sensory behaviors
- (B) Excessive adherence to routines and ritualized patterns of behavior
- (C) Restricted, fixated interests

(III) Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)

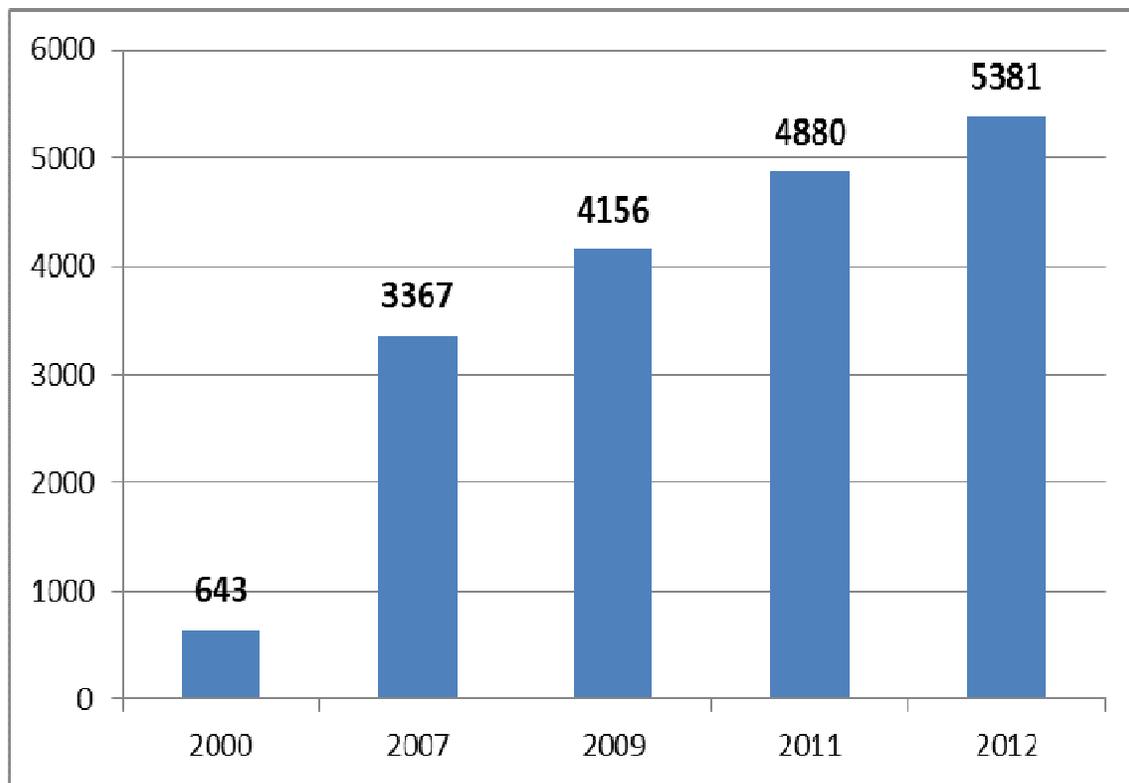
Autism was once considered a rare disorder. Now, according to the U.S. Center for Disease Control, Autism Spectrum Disorders affect 1 in 88 children, and are four times more likely to affect males than females.<sup>9</sup>

## 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 were serving 594 students under the category of autism. In 2009, schools reported 2,471 students being served in that category. The December 1, 2012 Child Count data collected by schools reported 2,989 students being served, that is a 21% increase within the last decade. In 2012, MaineCare paid claims for more than 5,381 Maine citizens diagnosed with an ASD, that is a 29% increase from just three years ago. Maine is not alone with this increase. In 2012, the U.S. Centers for Disease Control (CDC) updated its estimated prevalence numbers to 1:88<sup>10</sup>. In fact, the growing epidemic is worldwide. Studies in Asia, Europe and North America have identified individuals with an ASD with an average prevalence of about 1%. A recent study in South Korea reported a prevalence of 2.6%.<sup>11</sup>

In 2007, MaineCare paid claims for 3,367 members with an ASD. In 2012, that number jumped to 5,381. **That is an increase of 60% just within the last five years. The increase is over 730% since the turn of the twenty-first century.**<sup>12</sup>



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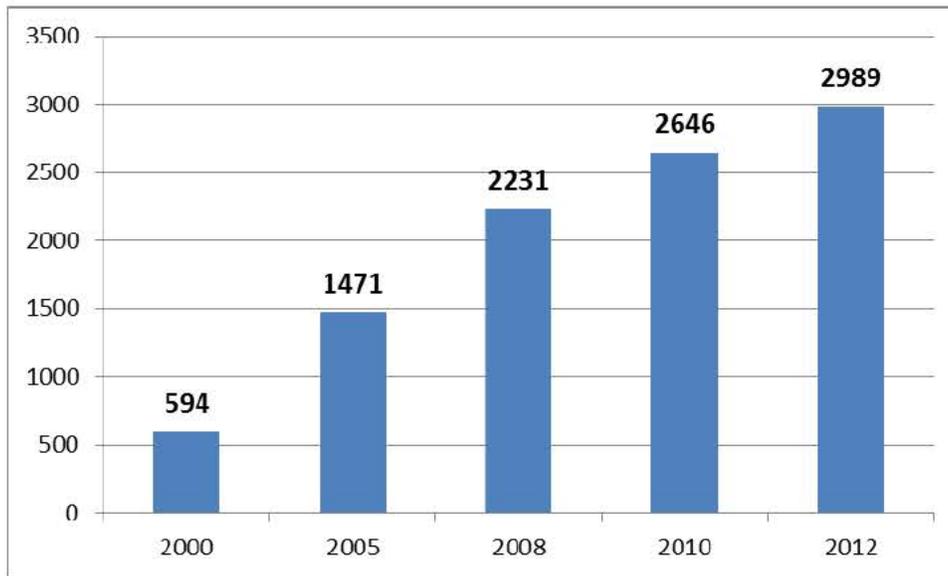
<sup>10</sup> <http://www.cdc.gov/ncbddd/autism/data.html> Accessed 3/29/2013

<sup>11</sup> Kim YS et al (2011) Prevalence of autism spectrum disorders in a total population sample. American Journal of Psychiatry 2011 Sep;168(9):904-12

<sup>12</sup> MaineCare is an income-dependent service.

## State of the State (cont.)

Department of Education (DOE) data also indicates a dramatic increase in the number of students being served for special education under the category of autism. **There has been a 34% increase within just the last five years and over a 430% increase since the turn of the twenty-first century.**<sup>13</sup>

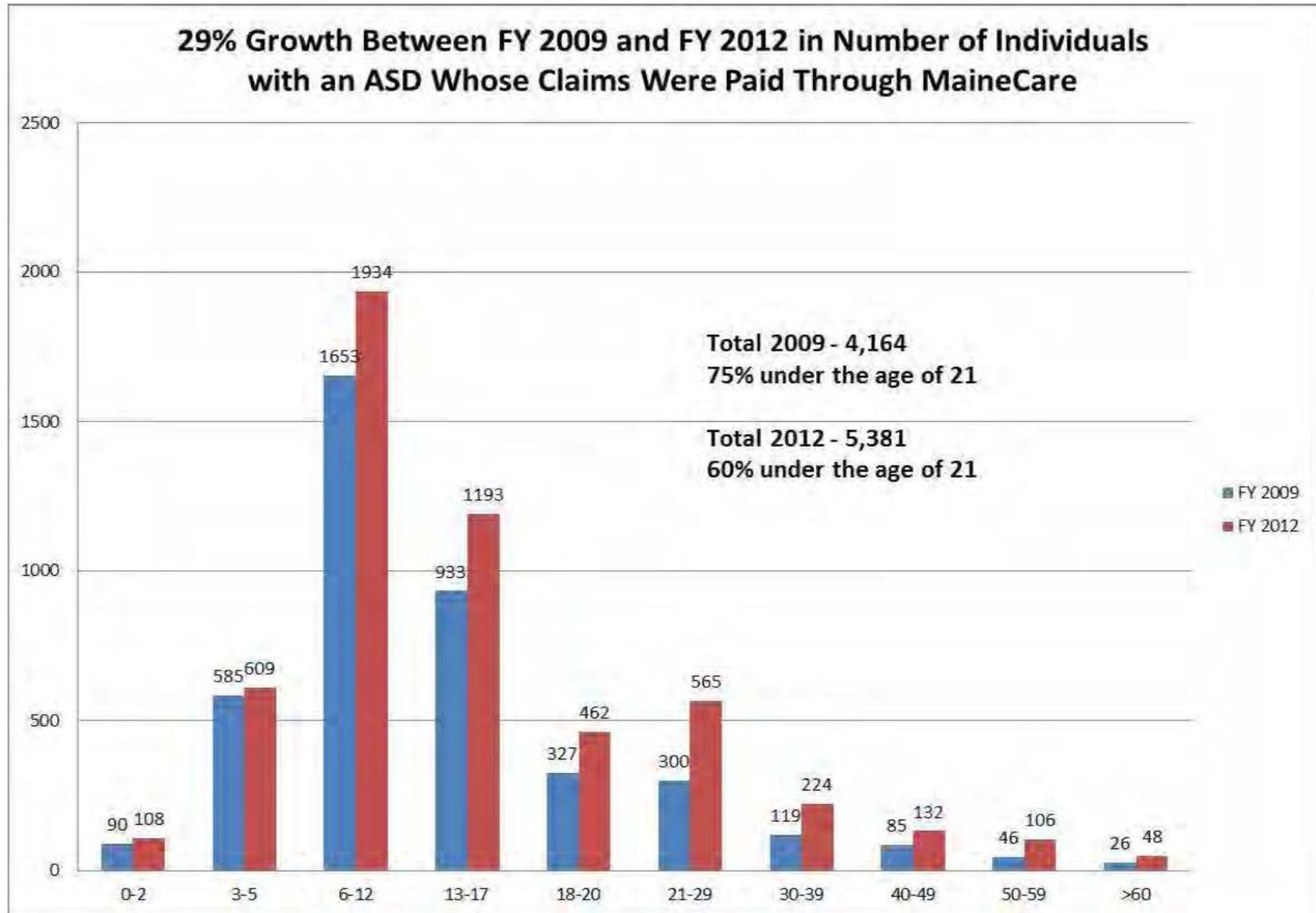


According to MaineCare claims data, there has been an increase in the number of individuals with an ASD in every age group. **In the 2011 Autism Report, youth ages 18-20 was the fastest growing group of over 100 individuals with an ASD. Today, young adults aged 21-26 are the fastest growing group of over 100, indicating that the growing population of individuals with ASD is reaching adulthood. The largest number of individuals with ASD continues to be the age group of those six through 12 years of age.**

Age	2007	2009	2012	3 yr % Increase	5 yr % Increase
0-2	91	90	108	20%	19%
3-5	470	585	609	4%	30%
6-12	1,304	1,653	1,934	17%	48%
13-17	774	933	1,193	28%	54%
18-20	239	327	462	41%	93%
21-26	184	240	429	79%	133%
27-64	296	324	620	91%	109%
65+	9	12	26	117%	189%
<b>Total</b>	<b>3,367</b>	<b>4,164</b>	<b>5,381</b>	<b>29%</b>	<b>60%</b>

<sup>13</sup> DOE Childfind data 2000-2012

*Just three years ago, 75% of the individuals with ASD who receive MaineCare were under the age of 21. Today, 60% of those individuals are under the age of 21. This indicates that the crest of the epidemic of individuals with ASD is now reaching adulthood, implying the need for significant changes in our adult services system.*



# Eligibility vs. Entitlement through the Lifespan

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Children and adults with ASD need a variety of services. However, many services are dependent upon meeting eligibility standards that 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.

## **DHHS – Aging and Disability Services**

On September 4, 2012, the Office of Elder Services and the Office of Adults with Cognitive and Physical Disabilities merged and integrated their operations, programs and services into the Office of Aging and Disability Services (OADS). This restructure realigns the Office and combines district operations under one organizational structure, creates clear lines of communication, coordinates central and regional office functions, and establishes a unified program and service model. The mission of OADS is to promote the highest level of independence for older citizens and for adults with disabilities. The safety and well-being of vulnerable adults is a priority.

OADS provides services and programs for adults with ASD who meet eligibility criteria. The statutory definition in 34-B §6002 for autism is “a developmental disorder characterized by a lack of responsiveness to other people, gross impairment in communicative skills and unusual responses to various aspects of the environment, all usually developing within the first 30 months of age... An adult with PDD is defined as an adult who:

- A. Has received a diagnosis that falls within the category of Pervasive Developmental Disorders, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, published by the American Psychiatric Association and as may be updated by rule adopted by the department in response to updates or changes in the Diagnostic and Statistical Manual of Mental Disorders; and
- B. Has been assessed as having an adaptive behavior score at a level of functional impairment as determined by the department.”

In addition to the definition of autism codified in 34-B MRSA §6002, DHHS OADS has promulgated rules regarding autism. According to these rules, an adult person with PDD is one:

1. Whose diagnosis, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association) is within the category of Pervasive Developmental Disorders, including Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, or Pervasive Developmental Disorder, Not Otherwise Specified; and manifested during the developmental period, (Developmental period is defined as age eighteen (18) years or younger), and

## Eligibility vs. Entitlement through the Lifespan (cont.)

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2. Who has been assessed as having an adaptive behavior score at least two standard deviations below the mean, as measured by an adaptive behavior scale described below. The Office will require an adaptive behavioral scale test that has been completed within two years of the date of eligibility determination and reserves the right to request further testing.

MaineCare policy Sections 21 and 29 define autistic disorder as a diagnosis that falls within the category of Pervasive Developmental Disorders (to include Autistic Disorder, Pervasive Developmental Disorders-Not Otherwise Specified, Asperger's Syndrome, Rett's Disorder, and Childhood Disintegrative Disorder), as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association), and manifested during the developmental period, in accordance with the definition of autism codified in 34-B MRSA § 6002 and accompanying rules.

MaineCare policy Section 50 defines autistic disorder as a disorder that features the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests. Autistic disorder is considered a related condition to mental retardation (see 50.01-11 for a definition of "Persons with Related Conditions").

Currently, only the following assessment tools are used by OADS to determine a person's adaptive behavior score: Adaptive Behavior Assessment System (2nd ed., known as ABAS-II), the Vineland Adaptive Behavior Scales (2nd ed., known as Vineland-II), or other substantially similar assessment tool as approved by the Office. Adaptive behavior is assessed using one of these tools in the context of a clinical interview where, as deemed clinically necessary, the examiner is able to evaluate responses from one or more participants in the testing environment. Testing must occur in the least restrictive setting available.

Case management services are available to adults who meet medical eligibility criteria for institutional care under MaineCare Section 50, Intermediate Care Facility (ICF) for Persons with Intellectual Disabilities (ICF/IID.) An ICF provides health-related care and a rehabilitative services program for individuals who do not require the degree of care and treatment that a hospital or skilled nursing facility is designed to provide, but who require care and services above the level of room and board. There are two types of ICFs: Nursing Facility and Group Home Facility.

Individuals who meet eligibility requirements and standards for admission to an ICF/IID under MaineCare Section 50 may waive their right to institutional care and apply for waiver services. Some individuals receive services under the comprehensive Home and Community Benefits 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>14</sup>. There are significant waiting lists for both waiver programs. Priority for Section 21 services is given to incapacitated and dependent adults in need of adult protective services to alleviate the risk of serious

## Eligibility vs. Entitlement through the Lifespan (cont.)

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harm resulting from abuse, neglect and/or exploitation. Members who are on the waiting list for Section 29 services are served chronologically based on the date the waiver manager determines eligibility for the waiver.

### **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 practices and include screening for autism and other ASD utilizing the guidelines recommended by the American Academy of Pediatrics (AAP). Medical practitioners who complete the forms and submit them to the Office of MaineCare Services receive an enhanced rate, if they are in private practice. Those practitioners who are part of a hospital system are reimbursed at the hospital rate.

### **School-Based Services**

A child is entitled to special education services if (1) s/he has a disability that (2) has an adverse impact and (3) which requires special education services. 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 who are covered by private insurance and/or rely on family resources, may be more restricted in their ability to access treatment and services.

From the beginning of 2012 through the present time, representatives from the Office of MaineCare Services, Department of Education, Child Development Services, Maine School Management Association, Maine Association for Special Education Directors, Disability Rights Center, Maine Developmental Disabilities Council, as well as school advocates, a Superintendent, and Special Education Directors, met to draft a plan to re-design MaineCare's policies regarding how medically necessary services will be reimbursed in school based settings. This model has been reviewed with both DHHS Commissioner Mary C. Mayhew and DOE Commissioner Stephen Bowen. The group is currently in the process of preparing a state plan amendment that proposes to incorporate all medically necessary Medicaid reimbursable services provided in a school based setting under the Early, Periodic, Screening, Diagnostic and Treatment (EPSDT) section of the Maine Medicaid State Plan. The group has also proposed that all school based services be merged into one section of policy under the current

## Eligibility vs. Entitlement through the Lifespan (cont.)

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Section 94, EPSDT of the MaineCare Benefits Manual and to create a billing guide that can be used by school districts to bill MaineCare for services they provide.

### **DHHS – Office of Child and Family Services**

In September of 2012, the Office of Child and Family Services (OCFS) underwent a restructure. The current structure is comprised of the following units: Policy and Prevention, Community Partnerships, Intervention and Coordination of Care, Accountability and Information Services, and the Medical Director/Director of Clinical Policies and Practices. Children and youth under the age of twenty-one 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 behavioral health services. If resources are available, families whose children are not MaineCare eligible can receive Individual Planning Funds 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 of 2011. There are no limits placed on the number of visits or cost that must be covered, except that service policies may limit coverage provided for applied behavior analysis therapies to \$36,000 per year. The 126<sup>th</sup> Legislature is currently considering a bill (LD-347) that would broaden the current law and provide coverage for the diagnosis and treatment of ASD for all children and youth under the age of twenty-one.

# Autism Implementation Grant (AIG)

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## DHHS – Children with Special Health Needs

According to the 2009/10 National Survey for Children with Special Health Care Needs (NS-CSHCN), nearly one in five Maine children (19.4%) has a special health care need; approximately 53,122 children with special health care needs (CSHCN). CSHCN are defined as “those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional condition and who also require health and related services beyond those required by children generally.” Maine ranks third in the U.S. in the percentage of CSHCN. More than half of CSHCN are boys (56.4%), 43.6% are girls.

Approximately 6,396 (12.5%) of children with special health care needs ages 2 – 17 years have autism spectrum disorder/developmental delays (ASD/DD). More than half of the school-aged children were not identified as having ASD/DD until entry into kindergarten or later. Children identified with having ASD/DD require a broad range of services including occupational, physical and speech therapy, prescribed medications, counseling, and specialty care, to name a few. Early identification ensures that children with ASD/DD and their families are able to access and benefit from services and has been shown to result in improved outcomes.

In 2010, DHHS CSHCN applied for and was awarded a three-year State Autism Implementation Grant (AIG) 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 ASD through early identification and provision of effective and coordinated treatment within a comprehensive medical home.

Now in the third and final year of the grant, the AIG has accomplished much towards the goal of prompt early identification, smooth entry into early intervention services, and improving the health of individuals with ASD in Maine.

## History of the ASD 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 State of Maine Strategic Interdepartmental Plan for a comprehensive, integrated system of care for persons with Autism Spectrum Disorders which focused on five tasks:

- Develop a statewide early identification and surveillance system to identify children with Pervasive Developmental Disorders (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.

## Autism Implementation Grant (cont.)

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In 2008, Maine created the Autism Spectrum Disorder Systems Change Initiative (also known as the Pervasive Developmental Disorders Systems Change Initiative) and charged the Initiative to analyze the multiple systems of care that individuals with ASD and their families utilize. The Maine Developmental Disabilities Council (MDDC) provides staff for the Initiative. The Initiative began its work by analyzing the early identification and early intervention systems. The resulting analysis showed that it took an average time span of 32 months from initial parent concern to actual diagnosis of ASD and included recommendations to accelerate that time. To continue its work to improve early identification, intervention and other health concerns, the ASD Systems Change Initiative was selected to assist CSHN with the management of the State Autism Implementation Grant.

## 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>15</sup> The most recent report from the Centers for Disease Control’s Autism and Developmental Disabilities Monitoring Network (ADDM) published in 2012 indicates that while more children are being diagnosed at earlier ages; most children are not diagnosed until after they are four years of age<sup>16</sup>. While progress is certainly being made, there is continued concern that children are not being diagnosed early enough to receive the full benefit of early intervention treatment.

*Maine Parent/Individual with ASD voices: “Early intervention helped [my son] learn the building blocks of establishing and maintaining friendships with his peers.”... This is an invaluable tool in overcoming the pathological difficulties people with ASD’s suffer from regarding social discourse, establishing and maintaining friendships and finding one’s place in their own community.”*

The American Academy of Pediatrics 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>17</sup>. In 2013, it is widely accepted that early intensive behavioral intervention results in improved outcomes for many children.<sup>18</sup> The Centers for Disease Control acknowledges that while there is currently no cure for ASD, “research shows that early intervention treatment (before school age) can have a significant impact on a child’s ability to learn new skills as well as reduce the need for costly interventions over time.”<sup>19</sup>

*Maine Parent/Individual with ASD voices: “State entities should ensure existing resources continue to reach out to families of children on the spectrum and guide those families to child service caseworkers to ensure adequate resources.”*

Along with the benefits to the children with ASD, 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 an estimated total cost of \$3.2 million per person.

<sup>15</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 3/25/2013

<sup>16</sup> CDC (2012) Community Report from Autism And Developmental Disabilities Monitoring (ADDM) Network. Morbidity and Mortal Weekly Report 2012; Vol. 61(3)

<sup>17</sup> Myers MD, Scott M (2007) Management of Children with Autism Spectrum Disorders. Pediatrics <http://pediatrics.aappublications.org/content/120/5/1162> full accessed 3/25/2013

<sup>18</sup> Fernell, Elisabeth et al (2013) Early diagnosis of autism and impact on prognosive: a narrative review. Clinical Epidemiology 2013;5 33-43

<sup>19</sup> CDC’s “Learn the Signs. Act Early.” Program guide (2013) The Importance of Early Identification of Developmental Delay and Disability, National Center on Birth Defects and Developmental Disabilities

## Early Identification and Intervention (cont.)

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A 2012 study conducted by Mandell Ph.D., Knapp, Ph.D has confirmed the high cost of providing lifelong supports to be more than \$2.3 million for a person with ASD who also has an intellectual disability and as much as \$1.4 million dollars for a person with ASD who does not have an intellectual disability<sup>20</sup>. In addition, the U.S. Centers for Disease Control and Prevention has reported that individuals with ASD have median medical expenditures 8.4 to 9.5 times higher than those without ASD.<sup>21</sup> Several studies have shown that early intervention can reduce those costs by more than half over an individual's life span.<sup>22,23,24.</sup>

### Autism Implementation Grant

The State ASD Implementation Grant that Maine received in 2010 has allowed many of the recommendations developed by the ASD Systems Change Initiative to be implemented. Over the past two years, work has been done to:

- Encourage Maine Primary Care Practitioners (PCPs) to screen all young children for ASD and to adopt the American Academy of Pediatrics Guidelines for routine periodic screening.
- Encourage early childhood professionals, such as staff from Head Start, Child Development Services, Public Health Nursing, and Home Visitors, to screen all young children for autism and report the results of the screenings to PCPs so duplication of effort can be avoided and follow-up can occur when necessary.
- Formalize payment methods to reimburse PCPs for universal screenings.
- Develop a web-based database to assist in the communication of screenings completed and facilitate access to diagnostic evaluation and early intervention services.
- Improve communication and coordination between medical diagnosticians and early childhood providers.

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<sup>20</sup> Autism Speaks <http://www.autismspeaks.org/science/science-news/autism%E2%80%99s-costs-nation-reach-137-billion-year> accessed 3/25/2013

<sup>21</sup> CDC [www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html) accessed 4/4/2013

<sup>22</sup> Ganz PhD, Michael L (2007) *The Lifetime Distribution of the Incremental Societal Costs of Autism*, Pediatrics & Adolescent Medicine. Vol. 161 No. 4

<sup>23</sup> Hockeyos(2009). *Benefit-Cost Analysis of appropriate intervention to treat autism* [https://docs.google.com/viewer?a=v&q=cache:SRSQdkw3t4QJ:www.dads.state.tx.us/autism/publications/USAutismCost-BenefitAnalysisNovember2009.pdf+cost+benefit+early+intervention+autism&hl=en&gl=us&pid=bl&srcid=ADGEESjjR0inS\\_C173htU4s\\_QagKEzGVnWzxVTOTbmt8pfTV5avpgTvs-yZfUzH-COglP2fyPEl0Nt3COk4NeVWcapfE-uz-qJD8m5QLfbs5wndkpGI8IJA5\\_oTSHenNs0eA3ko1cUDa&sig=AHIEtbS0bu7dfopgnuZTIEE7h6P-JGYGtA](https://docs.google.com/viewer?a=v&q=cache:SRSQdkw3t4QJ:www.dads.state.tx.us/autism/publications/USAutismCost-BenefitAnalysisNovember2009.pdf+cost+benefit+early+intervention+autism&hl=en&gl=us&pid=bl&srcid=ADGEESjjR0inS_C173htU4s_QagKEzGVnWzxVTOTbmt8pfTV5avpgTvs-yZfUzH-COglP2fyPEl0Nt3COk4NeVWcapfE-uz-qJD8m5QLfbs5wndkpGI8IJA5_oTSHenNs0eA3ko1cUDa&sig=AHIEtbS0bu7dfopgnuZTIEE7h6P-JGYGtA) accessed 3/25/2013

<sup>24</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.

## Early Identification and Intervention (cont.)

Below is a timeline and description of the work outlined above.

### Adoption of Universal Screening by Primary Care Physicians

- ✓ 2008      Maine Medical Professionals recommended that all PCPs:
  - Screen all children using the Ages and Stages Questionnaire (ASQ) or Parents Evaluation Developmental Status (PEDS) at 9- and 18- month well-child visits
  - Screen all children using the Modified Checklist for Autism in Toddlers (M-CHAT) screening at their 18- and 24-month well-child visits
  
- ✓ 2009      Field tested how to incorporate recommended screening tools in six medical practices
  - 3,500 children screened
  - All practices continued to screen for autism after the pilot was completed.
  
- ✓ 2010-2012      Train PCPs to utilize screening tools
  - Over 150 PCPs trained through the grand rounds process
  - Partnered with Quality Counts' Learning Collaborative where 12 additional medical practices were provided technical assistance to incorporate screening

### Adoption of Universal Screenings by Early Childhood Professionals

In hopes that this work would be sustainable in an ever-changing staffing environment, instead of providing in-person trainings on how to administer and score the M-CHAT, Maine created a DVD with accompanying curriculum. The M-CHAT video is separated into six primary chapters so that individuals can customize the training to include the information that is most relevant for their audience. The chapters are as follows:

Chapter #	Description	Duration
	Introduction	4 minutes
1	Why is universal screening for autism important?	2 minutes
2	First Signs of ASD	6 minutes
3	M-CHAT Part 1, Administration and Scoring	7 minutes
4	M-CHAT Part 2, Follow-up Interview	8 minutes
5	How to Talk to Families About Screening	4 minutes
6	Introduction to ASQ	5 minutes
	Conclusion	1 minute

## Early Identification and Intervention (cont.)

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Over 170 early childhood professionals were trained using the train-the-trainer model. Over 300 copies of the DVD and accompanying curriculum have been distributed.

Today, all Child Developmental Services sites are screening all children at 18-months of age using the M-CHAT. Further, many Head Start agencies have adopted the screening tool and starting this spring, Public Health Nursing will be trained on administering the M-CHAT.

### Formalize payment methods to reimburse PCPs for universal screenings.

Through collaborative effort between the Autism Implementation Grant (AIG), Improving Health Outcomes for Children (IHOC) and Quality Counts, MaineCare defined reimbursement codes to provide payment to PCPs for adopting universal screening of developmental disabilities and autism. Since the autism insurance mandate's passage, the AIG has been promoting the mandate which provides coverage for the screening, diagnosis and treatment of ASD for all children under the age of six.

### Web-based data system - Facilitating Autism Screening and Treatment (FAST)

Maine has developed a comprehensive data system to facilitate prompt screening, diagnosis, evaluation, and treatment for children with ASD. While not yet utilized to its fullest, the FAST system could provide a portal for early childhood professionals to communicate quickly to PCPs about screenings. In addition, PCPs are able to utilize FAST to refer children for evaluation and services. The primary goal of FAST is to improve the early identification and intervention system. An added benefit, however, will be the aggregate data it can provide for policymakers as it will facilitate collection and aggregation of data for more informed response to systemic changes. One recommendation of this report is to adopt statutory language that requires early childhood professionals, PCPs, and diagnosticians to communicate formally so that screening, diagnosis and treatment is coordinated and efficient. This process could be similar to the newborn hearing system already in statute.

### Pilot to improve communication and coordination between medical diagnosticians and early childhood providers

During the ASD 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 supported two quality improvement efforts aimed to improve coordination and communication between the two primary systems that identify children with ASD, the Department of Education's Child Development Services (CDS) and medical diagnosticians.

## Early Identification and Intervention (cont.)

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Over the last two years, CDS-REACH and Maine Medical Partners (MMP) have adjusted, tested and evaluated improvement processes. Over 100 children and their families experienced the new system and preliminary results show a 54% reduction in time has been achieved between MMP and CDS Reach's referrals.

The reduction in time is a result of early childhood professionals assisting families with necessary paperwork that needs to be completed for the first visit. In total, the multiple improved processes have shown a decrease in the time span between referral and diagnosis from 11 weeks to 9 weeks (a 19% reduction) for children aged 3 to 5 years. Similarly, CDS-Two Rivers and Eastern Maine Medical Center also adjusted, tested and evaluated improvement processes. Over 30 children and their families experienced the new system and preliminary results show a significant improvement between how the two systems communicate to coordinate early intervention plans.

Data is currently being analyzed for both quality improvement processes. In late June of 2013, a meeting will be held bringing pilot CDS sites and physicians together, along with policymakers, to discuss the results of the pilots and create a plan to implement some of the new processes that have proven effective statewide.

### ACT EARLY

The CDC's "Learn the Signs. Act Early." program's goal is to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need as early as possible.<sup>25</sup> Maine has been selected to be one of the 25 States that will receive a stipend and have a locally trained Act Early Ambassador to promote "Learn the Signs. Act Early." messages, provide free tools to track milestones, provide training to PCPs, and enhance State efforts to improve screening and referral to early intervention services. Nancy Cronin, ASD Systems Change Initiative Coordinator, working within the Maine Developmental Disabilities Council, has been appointed as Maine's Act Early Ambassador and can be reached at [nancy.e.cronin@maine.gov](mailto:nancy.e.cronin@maine.gov).

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<sup>25</sup> CDC's "Learn the Signs. Act Early." Program guide (2013) [The Importance of Early Identification of Developmental Delay and Disability](#), National Center on Birth Defects and Developmental Disabilities

## Early Identification and Intervention (cont.)

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

On February 4, 2009, President Clinton 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."

In February of 2010, Maine, in partnership with Vermont, was awarded a five-year, \$11 million demonstration grant from the Centers of Medicaid and Medicare Services (CMS) to improve the quality of care for children who are insured by Medicaid and the Children's Health Insurance Program. In Maine, the project is called Improving Health Outcomes for Children (IHOC) and the focus is on using quality measures and health information technology to improve timely access to quality care for children in Maine.

The IHOC project is building a public/private framework and system for measuring and improving the quality of child healthcare and outcomes for children in Maine and Vermont. The project is a collaboration of health systems, pediatric and family practice providers, associations, state programs, and consumers to:

1. Select and promote a set of child health quality measures
2. Build a health information technology infrastructure to support the reporting and use of quality information
3. Transform the delivery of health services using a patient centered medical home model

IHOC also provides medical practices with nationally recognized tools to enhance their ability to provide evidence-based care, and support in using data to track progress when implementing quality improvement activities. By aligning and coordinating child health quality infrastructure and quality improvement efforts, IHOC intends to improve access to actionable data for child health providers while reducing their administrative burden; improve care quality; support value-based purchasing; increase early identification of special needs; and ultimately improve child health outcomes and reduce health care costs.

## Early Identification and Intervention (cont.)

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Specifically, the State of Maine is working to:

- Collect and test child health measures, including the CHIPRA Initial Core Set of Child Health Quality Measures plus additional quality measures identified by Maine stakeholders as important to the quality of care for children.
- Align the IHOC quality measures with those of private payers, professional groups and MaineCare.
- Develop and test secure information technology linkages to collect well-child data from electronic medical records and state government information systems in support of child health quality measurement activities.
- Share quality data with payers, providers, consumers, and the Centers for Medicaid and Medicare Services; identify and communicate barriers and solutions to implementation.
- Develop and test new, secure ways for health providers to access health assessments for children in foster care.
- Conduct collaborative learning and quality improvement training activities with the Patient Centered Medical Home Pilot and other child-serving medical practices, with the goal of improving rates of preventive services for children.
- Build a child health quality improvement partnership that will promote a continuous focus on child health quality improvement after the grant ends.

Maine partnered with Vermont's Medicaid program - Department of Vermont Health Access - and the University of Vermont (UVM) because they are national leaders in building patient centered medical homes through their Blueprint for Health initiative, and they bring experience that Maine can learn from in using community health teams in health care practices. UVM is also the recognized national leader in building private/public child health collaboratives across the country and UVM faculty are the editors of the American Academy of Pediatrics (AAP) Bright Futures Guidelines. MaineCare uses the Bright Futures Guidelines as its standard of care to implement its federally mandated Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program for children and adolescents.

### **IHOC: First STEPS and the Maine Child Health Improvement Partnership**

Maine Quality Counts, on behalf of IHOC and MaineCare Services, is designing and implementing the First STEPS (Strengthening Together Early Preventive Services) Learning Initiative. First STEPS is advised by the Maine Child Health Improvement Partnership (MECHIP), a multi-stakeholder group developed through IHOC with the mission to optimize the health of Maine children by initiating and supporting *measurement-based* efforts to enhance child health care by fostering public/private partnerships.

## Early Identification and Intervention (cont.)

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First STEPS is a comprehensive effort modeled after the IHOC Collaborative to provide outreach, education, and quality improvement support to primary care practices to improve the rates of preventive services for children and adolescents. First STEPS promotes the patient-centered medical home model and includes dozens of primary care practices, including four child-serving practices who are participants in Maine's pre-existing Multi-Payer Patient Centered Medical Home Pilot. Through First STEPS, Maine Quality Counts supports primary care practices in engaging in practice change and quality improvement interventions with the goal of increasing the numbers of children insured by MaineCare (Medicaid and CHIP) who receive the required EPSDT (Early and Periodic Screening, Diagnoses, and Treatment) medical, developmental, and dental screenings as mandated by CMS and in accordance with the State of Maine's adopted standard of care for EPSDT services (the AAP's Bright Futures guidelines).

In Phase II of the three-part learning collaborative, First STEPS focused on improving developmental, autism, and lead screening. Twelve practices from throughout the state participated in the project which took place over eight months from May 2012 to December 2012. First STEPS Phase II included two day-long learning sessions (in May 2012 and September 2012); monthly coaching calls; visits by a practice coach; and monthly data collection. First STEPS Phase II promoted guideline-based work on developmental screening in the primary care setting. Practitioners were trained how to implement general developmental screening (either the PEDS or ASQ) at 9, 18, and 24 or 30 months, and autism screening (M-CHAT) at 18 months and 24 or 30 months. They were also trained in how to do the follow-up interview (M-CHAT 2) for children who did not pass the M-CHAT. Office system goals included: incorporating screening tools in the office flow; working on referral tracking for all patients; developing lists of community and medical resources for families and patients; working on care coordination and care plans for families; involving families in quality improvement efforts; and rethinking the office environment to make it more patient friendly for children with autism spectrum disorder and developmental delays. Since the completion of the pilot, Maine Quality Counts, as part of IHOC staff, continues to work with the Maine CDC and other Maine DHHS partners on how to improve the developmental screening system in the state for all children.

### **DHHS – Office of Child and Family Services (OCFS)**

#### *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, DHHS, and the Center for Community Inclusion and 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. An online Early Childhood Settings Inclusion Toolkit was developed to support families, care providers, and education providers with basic information about inclusion and quality early childhood practices that all children, including those with autism and other PDD, can benefit from.

## Early Identification and Intervention (cont.)

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### *Autism Society of Maine (ASM)*

Partly funded by the Office of Child and Family Services, the Autism Society of Maine provides youth/peer groups, family support and professionals with needed assistance through workshops, presentations, supportive activities for individuals and families, education/information, leadership and advocacy, outreach, and individual support through its Autism Information Specialist Program.

ASM distributes a quarterly newsletter advertising events and providing information related to autism as well as a hosting a free lending library. ASM provides an annual family retreat weekend and an annual meeting open to the general public. ASM's collaboration with many other family organizations keeps families updated on what is happening around the state. ASM representatives attend many state policy meetings to represent their constituents.

# Center for Community Inclusion and Disability Studies

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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. CCIDS has staff with expertise in early childhood mental health consultation who serve as a resource to early care and education and school age child care providers, families and young children by providing information, professional development and consultation to support healthy social-emotional development/wellness, improve skills and supports to children who exhibit challenging behaviors and prevent expulsions.

CCIDS, at the University of Maine, is part of a national consortium led by The Arc of the United States. The Arc was awarded a grant to develop and implement a national resource center on autism and other developmental disabilities. This four-year project began in October of 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 of 2010, with support from the Maine Department of Education. CCIDS offers technology based resources such as the Growing Ideas tipsheets and the Visual Supports Learning Links, as well as community of practice supports for practitioners.

## Maine Roads to Quality

Maine Roads To Quality (MRTQ) is part of Maine's Professional Development Network (PDN). The PDN's overriding vision is that all of Maine's children will be in quality learning environments. Its mission is to promote the quality of early care and education; address the training needs of all early care and education professionals; develop multiple ways for professionals to achieve their career goals; increase linkages between training and formal education; recognize and reward professionalism; monitor the effectiveness of the career development system, and collaborate with and unite partners to achieve their mission and goals. The PDN is a collaborative partnership between the University of Southern Maine's Muskie School of Public Service, CCIDS and University of Maine Developmental Psychology/Informatics Collaboration (DPIC). To ensure that all children will have access to and be retained in quality child care settings, CCIDS will provide consultation to the PDN in the design of their trainings and the technical assistance/consultation network by providing consultants with expertise in inclusive practice, universal design and early childhood mental health. CCIDS will take the lead in developing an inclusion credential for the PDN and Maine providers.

## Center for Community Inclusion and Disability Studies (cont.)

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### LEND

CCIDS has joined the University of New Hampshire Institute on Disability and the Geisel School of Medicine at Dartmouth as a partner in the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (NH-LEND) Program. The NH-LEND Program, with funding from the Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services, provides graduate level interdisciplinary training in neurodevelopmental and related disabilities for university students and professionals from diverse disciplines, including developmental pediatrics, early childhood education, social work, psychology, occupational therapy, health management and policy, and speech language pathology. Ultimately, this new partnership will reach an area not currently served by a LEND training program, develop infrastructure, and address regional needs, particularly in rural, underserved regions of Maine. LEND trainees are currently working on Interdisciplinary Leadership In Action projects in collaboration with Maine's ASD Systems Change Initiative. These activities included facilitation and data collection of the "*Maine Strategic Plan for Autism Spectrum Disorders and ACT Early*" stakeholders meeting held on February 26, 2013. The purpose of this meeting was to gather data in preparation for Maine's five-year ASD plan.

# Transition

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## **Sustainable Family-Centered Transition Planning Project**

The Center for Community Inclusion and Disability Studies (CCIDS) is in the second year of a three-year family-centered transition planning project for youth with ASD. This research project is funded by the National Institute on Disability Research and Rehabilitation, US Department of Education and is being conducted in collaboration with the Institute on Disability at the University of New Hampshire (UNH). Families participating in the project are provided with a package of supports that were found to be effective in another recent CCIDS/UNH collaborative research project in improving a number of transition-related outcomes for Maine and New Hampshire youth with ASD<sup>26</sup>. These outcomes include greater levels of self-determination, higher expectations for the future, and increased career maturity. Initial data on long-term outcomes indicate significantly higher rates of employment and post-secondary education than typically seen for this population. 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. Currently, the project staff are working with family advocacy organizations to develop strategies for making the supports provided in this project available to families on a sustainable basis. 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.

## **Maine EPSCoR: Increasing Access and Success in the STEM Disciplines**

CCIDS, in collaboration with Maine EPSCoR (Experimental Program to Stimulate Competitive Research), is implementing and evaluating a model for supporting the transition of Maine students with disabilities into STEM (Science, Technology, Engineering, and Mathematics)-related postsecondary educational opportunities within the University of Maine System. Participating high school students participate in workshops, family-centered planning and tours of University of Maine STEM programs. In addition, project staff try to connect participants to internship and mentorship opportunities. CCIDS is in the second year of the project and has supported more than 12 individuals on the autism spectrum.

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<sup>26</sup> Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a Family-Centered Transition Process for Students With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 27(1), 42-50

## Transition (cont.)

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### Maine State Personnel Development Grant (SPDG)

The Maine Department of Education has convened a Task Force for Effective Transition Planning. The purpose of the Task Force is to increase the percentages of SAU (School Administrative Units) special education and related services personnel who can develop and implement effective, compliant, transition plans and activities within timelines for grades 9-12, for IDEA Part C to Part B, and preschool to kindergarten for children with disabilities.

#### **Preparing for Transition, Assessment of Medical Professionals Knowledge of Health Needs for Adults with ASD**

In 2012, the Autism Implementation Grant (AIG) hired Altarum Institute, a nationally well known research firm, to conduct focus groups and assess how prepared general practitioners who provide services for adults are to provide care for the emerging population of adults with ASD. Nearly 50 family physicians were contacted during focus group recruitment, yet only two physicians were interested in participating in the group. Many representatives of medical practices stated something to the effect of “He doesn’t have any autistic patients” or “He doesn’t have time to go to any groups” as the reason for not participating in the focus group.

Due to the low number of physicians willing to participate, forming a focus group was not feasible. Instead, Altarum Institute conducted interviews with the two family physicians who volunteered to participate to capture their opinions.

*Altarum’s report documents that the knowledge the two physicians possessed about ASD had been self-taught. “Their perception is that they do not have autistic patients in their patient panel. They did contemplate after the discussion whether that was actually the case. The physicians also stated that they had heard about the increase in numbers in autistic children through the popular media and were curious to know if what the popular media was reporting was accurate.*

*During the focus group with specialists, the tone regarding knowledge was different. They were aware of patients with ASD in their practices. In fact, they were aware and discouraged by the complexity of the cases and the uncoordinated care their patients with ASD received. Some of the specialists acknowledged ASD in their training, but in a manner addressing only their area of expertise. Thus, the individual specialist is addressing one small part of a person with ASD. The physicians reported that the disjointed approach that is inherent in our health care system is especially harmful to a person with ASD.”<sup>27</sup>*

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<sup>27</sup> Altarum Institute (2012) Maine Autism Spectrum Disorders Development Project Summary of Focus Group, Group Discussion and Online Surveys

# Healthcare

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## **Patient Centered Medical Home Pilot/Health Homes Demo**

Over the last 3 years, IHOC (Improving Health Outcomes for Children) has tried to align its work with the Patient Centered Medical Home (PCMH). Maine currently has four pediatric practices included that were part of the original 25 in the PCMH pilot. There is currently a second wave of practices participating in the PCMH pilot for a total of 75 practices, including family medicine providers that care for children. There is also another group that started in January of 2013 of over 65 "Health Home Only" practices in the MaineCare pilot that include additional pediatric groups. Each of these practices is also connected with one of ten Community Care Teams (CCTs) in the state. Children with autism and developmental delays, in addition to other medical conditions, may also qualify for additional support from the CCTs. For practices in the Health Homes demo, one of the quality metrics being tracked by claims is the CHIPRA measure for developmental screening that measures the number of children who had a general developmental screening done by ages 1, 2, and 3.

## Healthcare (cont.)

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

*Developing and testing a curriculum* - 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 ASD.

*Increasing physician capacity* - In late 2011, six Maine developmental pediatricians met to discuss the curriculum utilized in 2009. It was decided that they would tailor the curriculum for the general practitioners in their distinct portions of the State. Over the next year, the developmental pediatricians will be providing training and technical assistance to ten more primary care medical practitioners.

*Increasing the skills of medical office staff* - In 2012, the AIG contracted with Dr. Carol Hubbard, Developmental Pediatrician from Maine Medical Partners, to develop a web-based training to instruct medical practice office staff on how to accommodate and integrate children and youth with ASD into their medical offices. The webinar was designed for clinical and administrative staff in medical offices to increase their knowledge about ASD and their comfort level in interacting with patients with ASD during office visits. The goal is for medical office staff to have the skills and resources to:

- Optimize the experience of office visits for patients with ASD, both children and adults
- Name the basic clinical characteristics of individuals with ASD
- Describe behavioral characteristics of patients with ASD that may make office visits challenging
- Offer strategies and approaches that would help make office visits successful
- Identify other ways to support patients with ASD and their families beyond the office setting

The webinar is complete and will be publicized throughout the final year of the grant. The webinar will remain available for medical practitioners for the foreseeable future.

## Healthcare (cont.)

### 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, and coordination of all needed services and resources to meet the needs of children and their families<sup>28</sup>. Multiple studies have emphasized that providing medical homes with thorough care coordination is crucial for children with special health needs. These medical homes have the potential to significantly improve quality of care and reduce barriers to appropriate care, because there is often no single entry point to the multiple systems of care, and the issue of existing systems that are not designed to communicate with each other regarding treatment<sup>29, 30</sup>. The ASD 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 ASD, IHOC (Improving Health Outcomes for Children) has aligned its goals with those of the pre-existing PCMH (Patient Centered Medical Home) Pilot and offers additional support towards those goals.

One of the four pediatric offices involved in the PCMH pilots is currently piloting the existing medical home model<sup>31</sup> to also provide comprehensive coordination of the services individuals with ASD may utilize. Since 2012, Husson Pediatrics has been providing enhanced coordination of medical, educational, and community-based support services to over twenty families and initial results look promising. Through the use of blind evaluators and utilizing national standardized evaluation tools, Husson Pediatrics has been:

- Evaluating the effectiveness of care coordination of services for children with ASD,
- Identifying barriers to effective and sufficient intervention for children with ASD, and
- Generating solutions to eliminate or bypass the identified barriers to improve intervention service outcomes.

### Measuring Parent Opinion on Coordination of Care in Maine

Altarum Institute conducted a web-based survey where 37 families were asked about their experiences accessing care coordination through their primary care practitioner. Survey results showed that the majority of parents (63%) reported that their physician did provide some coordination of care but 64% believed that the level of care coordination was not sufficient to meet the individual's needs.

<sup>28</sup> National Center of Medical Home Initiatives <http://www.medicalhomeinfo.org> accessed 1/5/2011

<sup>29</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>30</sup> Murphy, Nancy MD et. Al. (2011) Parent-Provider-Community Partnerships: Optimizing Outcomes for Children With Disabilities, *Pediatrics* <http://pediatrics.aappublications.org/content/128/4/795> accessed 3/29/2013

<sup>31</sup> Waisman Center, National Medical Home Initiative <http://www.waisman.wisc.edu/nmhai/> accessed 1/5/2011

## Healthcare (cont.)

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### **Measuring Health Disparities of Individuals with ASD as compared with the general population**

After analyzing the results of Altarum Institute's parent survey, it was decided that Autism Implementation Grant (AIG) funds would be utilized for a project aimed at determining if any disparities exist between the health care provided for individuals with ASD as compared to the general population. AIG contracted with a consultant who performed a thorough literature review and conducted extensive interviews with 78 family members of children and youth with ASD and 21 adults with ASD. Survey participants represent a diverse geographic, economic, age, and gender sample. The diagnosis range spread across all three ASD categories (Autism, Asperger's and PDD-NOS) and many identified as having multiple diagnoses. The sample included parents with multiple children, parents who are guardians, foster parents, and parents who were homeless.

### **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 involves educating and supporting families to engage in the medical home model. Over the last two years, the AIG has supported Maine Parent Federation (MPF) and the Autism Society of Maine (ASM) in developing and presenting a curriculum that provides information to families about medical homes. Over 90 families have received the information on medical homes. MPF sponsored a series of webinars covering the material which continues to be made available to the public. In addition, ASM has enhanced its website to include information regarding medical homes and how families can maximize use of this model in the best interests of their children.

## Education

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In 2011, Maine received a five-year State Personnel Development Grant (SPDG). The Department of Education (DOE) is now in the second year of its work to build state capacity across all SPDG funded initiatives through partnerships between the State Education Agency (SEA) and School Administrative Units (SAU). Year Three's SPDG work will be directly integrated with the SEA's operational practices of the General Supervision System (GSS) as required by the federal Office of Special Education Programs (OSEP). Its Stage I work is designed to build upon the foundation of compliance and will move into Stage II work: Effective Evidence-Based Practices (EBP) that lead to better outcomes for children with disabilities that are specific to Least Restrictive Environment (LRE), Common Core State Standards (CCSS) instructional delivery and post-secondary transition planning implementation at the SAU level. A specific emphasis is to build leadership capacity and practitioner competency leading to improved outcomes for children with disabilities regardless of the SPDG supported initiative.

The first year of Maine's 2011 SPDG work focused on the design and development of a statewide professional development (PD) model that became the framework for all SPDG funded professional development (PD) and Technical Assistance (TA) in alignment with the SEA's restructuring of its GSS activities and TA teams. This common approach allows for equitable SAU accessibility of resources and all SPDG PD activities, while providing for the unique and specific needs of a SAU, and the pooling/sharing of State, regional, and local resources. DOE's work in partnership with SAUs, agencies and institutes of higher education (IHE) has imparted an element of trust and rekindled an eagerness shared by all entities to work collectively to establish a community of practice that had eluded them in years past.

Autism Initiative - DOE anticipated that ten Autism Teams would form and participate in EBP that would improve outcomes for individuals with autism. As the project members moved through the exploration stage of implementation during year one, they formed their perception of need based

on an increase in the numbers of children with autism and an outcry from parents, educators, and Maine's Legislature that Maine's practitioners were not adequately trained to meet the needs of children with autism. In 2009, Maine's Department of Health and Human Services released its Autism Spectrum Disorders Report articulating that there "are several challenges in supporting people with Pervasive Developmental Delay (PDD)" which include "the number of people who are referred" and that "programs have not grown in the last several years and, in fact, have actually been reduced". In addition, the report identified that future programs will need to be developed to train "individuals with PDD" as they move through their post-secondary transition plan in preparation for living and working in their communities.

*Maine Parent / Individual with ASD voices: "I have had wonderful services and I have had horrible services. The issue here is capacity. We need experts in every service delivery field that know and understand ASD."*

## Education (cont.)

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This same report indicated that such focus will require a coalescence of school age and adult service approaches.

The 125<sup>th</sup> Maine Legislature passed Chapter 47, LD 715, Resolve, To Ensure That Maine Teachers and Paraprofessionals Who Work with Children with Autism Spectrum Disorders Are Appropriately and Adequately Prepared. Sec. 1 of the Resolve required the State Board of Education and the Department of Education to study teachers and paraprofessionals who work with children with autism spectrum disorders to ensure they are appropriately prepared.

In response to this charge, the Department of Education through its SPDG work, partnered with the Maine Department of Education Certification Office, served as the work group and crafted a set of recommendations. The first recommendation was to ask the State Board of Education to require 15 core credit competencies for special education teachers. The second recommendation was that ten core competencies and an additional three specialty area competencies (autism, emotional/behavioral, and blind/visually impaired and deaf/hard of hearing) should be required for Maine paraprofessionals. The paraprofessional competencies are under construction with the intent of readiness for July 2014 implementation.

Another goal of the SPDG Grant was to increase the qualifications of personnel currently serving children, birth to 20, with autism by promoting use of evidence based-practices. It was determined that there was a need for Maine to build state capacity through the Team Leader EBP PD model. Use of the capacity building model would provide equitable PD to targeted SAUs geographically spread throughout the state. A qualified purveyor and a coach/mentor to provide a high level of TA were identified and contracted. Their charge has been to use the EBP PD model and develop an Autism Team Leader EBP PD/TA model that could be readily replicated in 16 SAUs with operational implementation drivers. Implementation began in June 2012 with an invitational letter/application for participation.

Sixteen teams comprised of ten to twelve general and special education teachers, general and special education administrators, and related service personnel were established and participated in three two-day Autism Team Leader training sessions designed to build statewide experts in autism. Two of the sixteen Autism Leader Teams are part of Maine's Child Development Services (birth to five). Dr. Cathy Pratt, BCBA-D, Director of the Indiana Resource Center for Autism, delivered the initial six days of face-to-face evidence-based practice training on November 1<sup>st</sup>, 2<sup>nd</sup>, March 13<sup>th</sup>, and 14<sup>th</sup>, April 8<sup>th</sup> and 9<sup>th</sup>. Dr. Pratt's work was supported by 3-4 hours per training session of ongoing TA by Dr. Deborah Rooks-Ellis from the University of Maine through a coaching/mentor model. Dr. Rooks-Ellis will have met on site with each SAU Autism Leader Team four times over a nine month period of time for 3-4 hours per meeting to provide continued EBP PD, coaching, mentoring, and ongoing support. Each SAU's Autism Leader Team is committed to increase teacher efficacy in the delivery of educational services and supports to children with autism spectrum disorders. Each team practitioner is provided access to a Listserv which provides additional information, resources, and feedback.

## Education (cont.)

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The Listserv is used to communicate to individuals and teams about evidence-based practices, strategies, techniques, tips, ongoing progress of the teams, upcoming events, and PD materials. Technical assistance was provided for the development of the SAU's sustainability plan designed to build capacity through increased team member numbers or, depending on the size of the district, to recruit members from within the SAU for a second team. Each SAU Autism Leader Team developed a plan that focused on the children with autism in their district for the purposes of collecting data, implementing evidence-based practices, and measuring outcomes and included recruitment activities, professional development plans, materials, an implementation time line, and means of providing assistance for training new team members about their role as a Maine Autism Team Leader. Practitioners were challenged to consider how EBP and strategies can be universally implemented school-wide for other children in their district. The SPDG funded EBP practices will readily complement Positive Behavior Supports and Response To Intervention initiatives underway within the SAU, as it is the belief that these evidence-based practices for students on the autism spectrum can be universally beneficial for many students.

Parents will become contributing members to the teams as community liaisons during year three of the initiative. In addition, on April 8, 2013, the SPDG in partnership with Maine Parent Federation, Maine Autism Society, and the Center for Community Inclusion and Disability Studies provided an evening session entitled: Critical Decisions: The Journey to Adulthood for your Son/Daughter with ASD for Maine's parents of children with autism. Dr. Pratt addressed the decisions a family with a child with ASD has to make, skills that need to be taught, behaviors that need to be altered, services to be accessed that are part of the transition process to adulthood, and factors and strategies to consider.

# Office of Child and Family Services–Behavioral Health Services for Children

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## Family/Parent Support Services

The Office of Child and Family Services (OCFS) provides funding to several family organizations to provide regional family support groups, information, referrals, and training opportunities.

## Targeted Case Management

Children’s Targeted Case Management (TCM) programs 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 1,830 children and youth diagnosed with ASD received targeted case management services in FY 2011, a 15% increase from FY 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. **According to MaineCare claims data, over 170 children and youth diagnosed with an ASD lived in a residential setting in 2011, a 9% increase from FY 2009**

## Respite Care

Families of children with autism and other ASD 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.

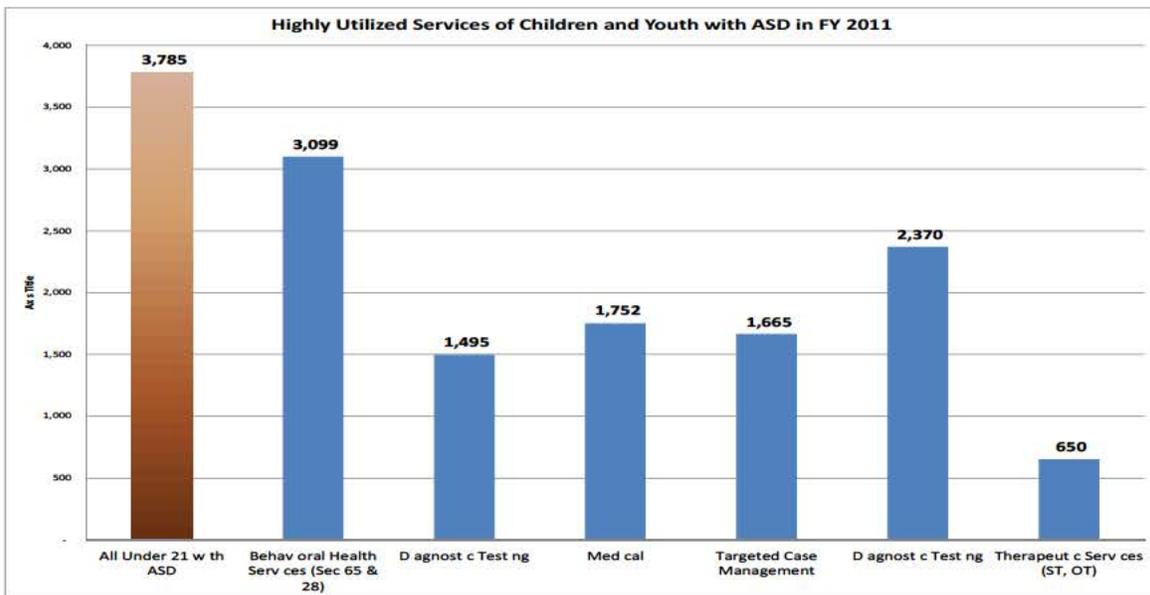
# Office of Child and Family Services (cont.)

## Home Based Services:

Rehabilitative Community Services (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.

APS Healthcare has been contracted through the Department of Health and Human Services (DHHS) to provide Utilization Review for all existing Section 28 members and new admissions from February 22, 2013 to June 30, 2013. This service was procured to increase efficiencies within this area of service. This provider has a history of providing this service for other Sections and could offer this expertise to DHHS allowing the Department to redirect its energy toward increasing accountability and the infrastructure of the Behavioral Health services system. **According to MaineCare claims data, over 1,260 children and youth diagnosed with an ASD received habilitation services in FY2011, a 20% increase from FY2009.**

Mental health treatment programs (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 1,830 children and youth diagnosed with ASD received Section 65 mental health treatment services in 2011, an increase of 22% from FY2009.**



## Office of Child and Family Services (cont.)

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

DHHS continues to develop a comprehensive waiver program that will provide a variety of services and supports for children and youth with intellectual disabilities and/or Autism Spectrum Disorders. A network of providers has been identified to serve youth under MaineCare Section 32. The rule has been updated and will be proposed by April, 2013. A system has been created that will prioritize and perform clinical reviews of the children referred to this program and oversee the collection of federally required quality measures. During the first year of the program, Maine is authorized to serve up to 40 children.

## Office of Aging and Disability Services

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Beginning in September of 2012, the Office of Aging and Disability Services (OADS) and the Office of Child and Family Services (OCFS) staff have been working collaboratively in order to better coordinate care for youth ages 16-18 that may qualify for adult developmental services. Beginning in March of 2013, all district offices will establish Early Referral teams which will serve to identify and facilitate the transition to adult services.

Supporting families is a vital component of a responsive and effective service system. In recent years, public Developmental Services systems have seen increases in the percentage of people with disabilities living in the family home. When compared to other states, preliminary data shows that Maine has a much higher percentage of people living in group homes and a much lower percentage of people living with family. Systems must keep innovating to understand and implement new approaches to supporting families and continuing to promote self-determination over the lifespan.

Simultaneously, this state is struggling with a growing population of seniors, changing expectations and limited public resources. Maine's challenge is to be innovative, to develop sustainable systems, and to serve those who have the most need and are most vulnerable.

Community inclusion and self-determination are based on the assumption that the person is a part of and connected within the community. It means the person is engaged socially, recreationally, culturally, and spiritually. The person is a productive and valued community member. The person individuates from parents and caregivers, makes informed choices, and is respected through typical interactions with others as part of a community. The person belongs.

People with ASD rely, like everyone else, on family, friends, neighbors, and local support like public transportation, public recreation, church, and medical professionals. Individuals with disabilities often need added support due to unique challenges at various times in the lifespan.

*Maine Parent /Individual with ASD voices: "A lot of my friends have gotten our own apartments this year. I believe it is always easier to learn new things when my friends are learning too. It is way less scary. I also think having a case worker like my case worker is a big help. Please help me and my friends continue to learn independent living skills. Thanks."*

*Maine Parent /Individual with ASD voices: "Lack of public transportation is the single largest stumbling block impeding young adults with autism from successfully transitioning to a more independent adult life."*

## Office of Aging and Disability Services (cont.)

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When considering support, we want to look first for local, informal support. Only where there are gaps should we add in supplemental formal supports to maximize independence, self-reliance, choice, and dignity of risk. Any supplemental formal paid support, such as those required for unique or complicated medical conditions, must be flexible and designed to meet the person where he or she is. Support may ebb and flow over the lifespan as the individual's needs change. Quality flexible wraparound support means varying services as needed (from minimal to maximum) to promote personal development, safety, stability, and inclusion.

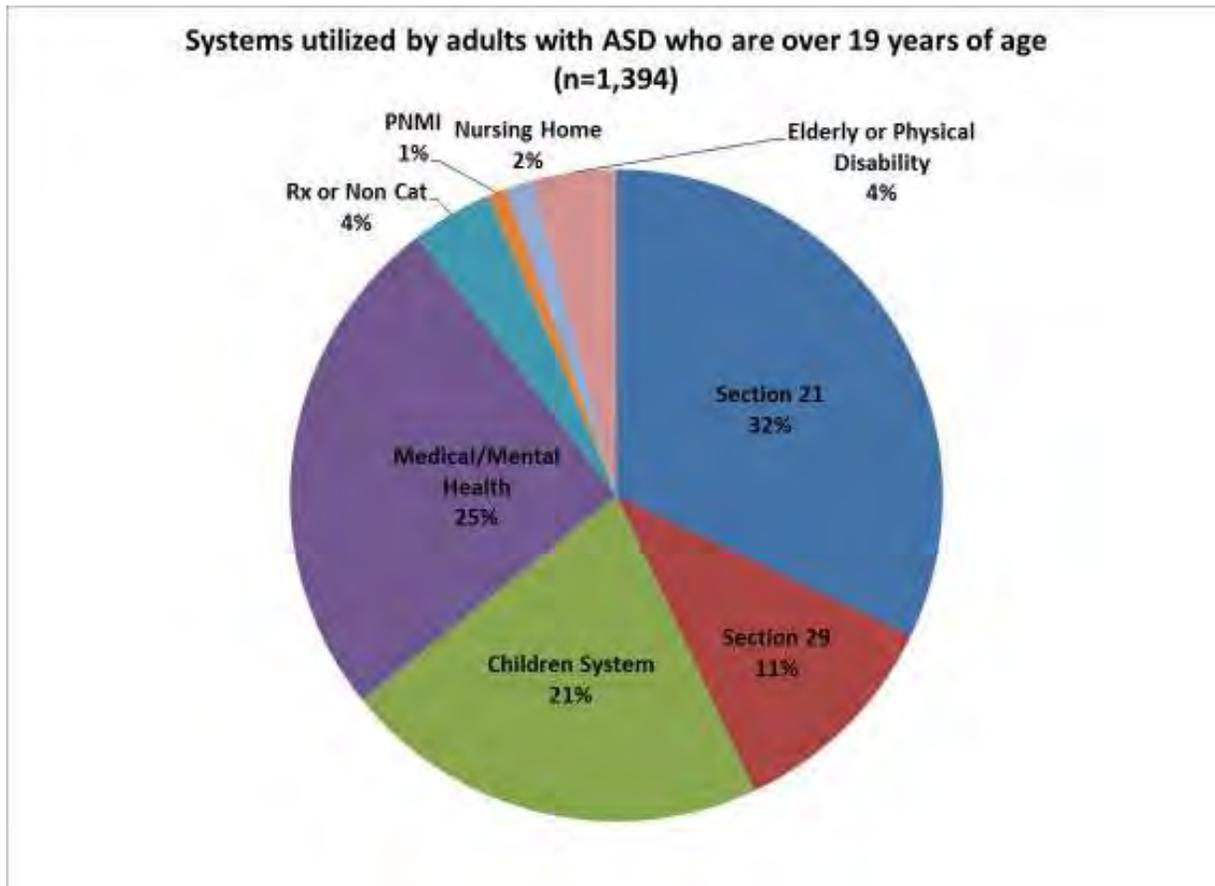
Individuals have various needs throughout their lifespan. Community inclusion, employment or related activity, and housing are critical. Quality flexible paid support stands in the background rather than being a central focus. Natural community support is the backbone of each person's autonomy and independence.

### **Targeted Case Management Services**

Each person eligible for adult Developmental Services is entitled to receive case management services. Case managers are either OADS employees or contracted community case management agencies. A case manager identifies the person's medical, social, educational, and other needs (including housing and transportation.) They identify services to meet those needs, assist the person with the development of a person-centered plan, and facilitate access to services and assure the quality of services being provided. Case management consists of intake/assessment, plan of care development, coordination/advocacy, monitoring, and evaluation.

## Office of Aging and Disability Services (cont.)

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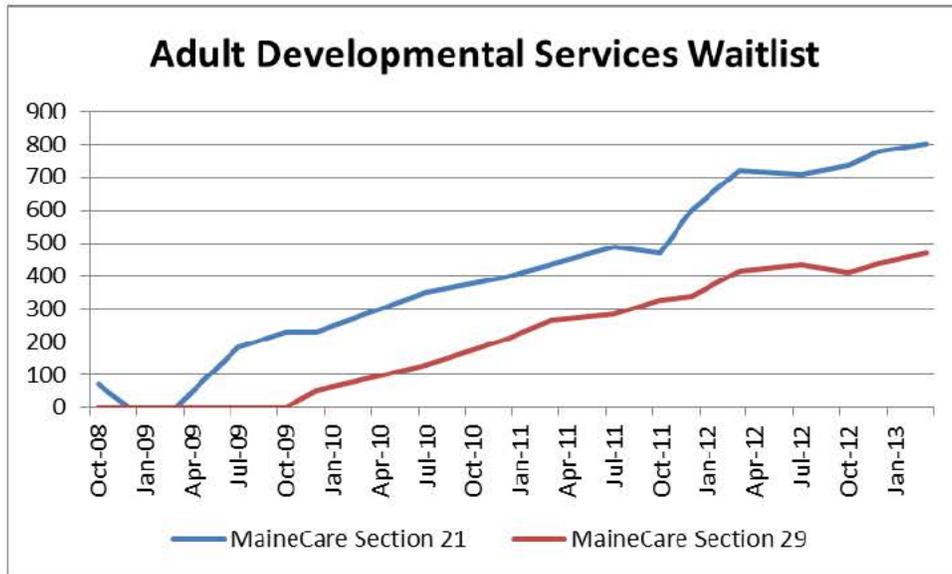
### **The Home and Community Supports Waiver (MaineCare Section 21)**

The Home and Community Supports Waiver 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 March, 2013, there were 803 individuals with developmental disabilities on the waitlist. Of that number, 168 individuals with developmental disabilities were in critical need of services; having been found to be at risk for their health and safety.

## Office of Aging and Disability Services (cont.)

### 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 March, 2013, there were 468 individuals with developmental disabilities on the waitlist, with up to 100 individuals expected to be added as the end of the school year approaches.



**Over 350 adults with PDD received services through either the supports waiver or the home and community supports waiver in 2009. In 2011, over 600 adults with ASD were receiving waiver services. That is a 71% increase in just 2 years.**

# Office of Aging and Disability Services (cont.)

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## Other Services

OADS has limited funding for professional services that are not covered by MaineCare. In addition to the services listed above, OADS provides crisis services, public guardianship and public conservatorship services, and adult protective services. Advocacy services are contracted through the Disability Rights Center.

OADS is conducting standardized assessments to determine support needs of individuals with developmental disabilities using the Supports Intensity Scale (SIS.) The first individuals being assessed are people receiving Section 21 services. SIS results will be tied to a resource allocation model and individual budgets. The name for this overall initiative, pairing the Supports Intensity Scale results with a resource allocation model is called “Supporting Individual Success.” The SIS measures the practical supports needed by an individual. Support needs measured include the areas of home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy. The SIS is strengths based and engages the consumer in a positive interview process. Case managers, guardians and direct support professionals are included in the interview.

In March of 2012, OADS staff were trained and certified to administer the SIS. Between late June and September 21<sup>st</sup> of 2012, assessments were completed on 500 individuals, using a random sample from Human Services Research Institute (HSRI). Beginning in October of 2012, OADS staff began conducting interviews with a second sample of 700 individuals. The goal is to complete interviews on 80% of individuals receiving Section 21 services by July 1, 2013. Stakeholder meetings have been held and will continue. HSRI is analyzing the results of the sample, examining the current needs of a diversified population from various geographic locations around the state. The SIS results are being compared to MaineCare costs for services provided to an individual. Analysis of the data will continue and a rate study will be conducted.

The goals of OADS are:

- To use the same tool for everyone.
- To find out what each person’s needs are for support.
- To be flexible when a person’s needs change.
- To make sure that each person gets the resources the person needs.
- To serve as many people as possible with existing resources, and reduce waitlists.
- To increase person-centeredness, self-direction, employment and community inclusion.
- To have case managers use the SIS results in Person Centered Planning.
- To look at interview results and review the cost of services provided.
- To complete a SIS interview once every three years for each consumer.

## Office of Aging and Disability Services (cont.)

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In the future, OADS will provide information about funding after a SIS interview is done. A person's support needs will be matched with a service level.

### **Continuing Education**

OADS is committed to providing continuing education to case managers and other service providers who work with adults with Pervasive Developmental Disorders (PDD).

Developmental Services recently transitioned to training Direct Support Professionals (DSP) through the College of Direct Support. The training includes a module specifically on working with people who have autism and other PDD. The module is not required as part of the DSP certificate, but it is available to anyone with access to College of Direct Support as a "self-enroll" module.

### **The Emerging Challenge**

OADS 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. Both the Home and Community Based Waiver Program and the Supports Waiver have long waiting lists. The vision of OADS includes:

- Individual and independent assessments conducted by a single assessing agency
- More flexible support to families and individuals so people can remain at home
- Management of waitlists – helping as many as possible within available resources
- Sustainability of long-term services and supports
- Further improvement in quality assessment and resource allocation
- Enhancing protective services for Maine's most vulnerable
- Incorporating assistive technology and equipment to increase independence and safety

OADS 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 persons with PDD to live and work in their communities, while at the same time doing so in the most cost effective way possible. This will require new approaches and new models of support.

## Office of Aging and Disability Services (cont.)

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### **Employment**

Maine has continued to build a strong employment system to provide efficient and effective supports for individuals with disabilities who have identified that they are interested in pursuing employment. A comprehensive Workforce Development System for employment services staff was developed in 2012. It provides basic staff certification, advanced training and a mentoring program. The Maine Business Leadership affiliate started in late 2012 and provides the business to business interaction that provides information about hiring people with disabilities. In January of 2013, OADS began gathering employment outcome data through its Enterprise Management System. It will enable the system to provide data about who is working, what businesses are employing individuals with disabilities and indicators such as rate of pay, benefits and level of paid support needed to maintain employment. Ongoing work with the Department of Labor, Bureau of Rehabilitation is essential to providing joint services to individuals during assessment, evaluation, career development and on-going support to maintain their employment.

## ASD Strategic Planning Process

On February 26, 2013, the Maine Developmental Disabilities Council, through the Autism Initiative Grant (AIG), and the University of Maine Center for Community Inclusion and Disability Studies, with help from LEND (Leadership Education in Neurodevelopment and Related Disabilities) trainees, sponsored and facilitated the ASD Systems Change Implementation Initiative Strategic Planning Meeting at Maple Hill Farm in Hallowell. A broad array of leaders and stakeholders from across the state participated in this day-long event and included representation from the Department of Health and Human Services, the Department of Education, the Disabilities Rights Center, family organizations, Pediatricians, and Mental Health Professionals.

The purpose of this meeting, in accordance with the Autism Act of 1984, 34-B M.R.S.A. §6001-6004, was to discuss and plan upcoming initiatives to improve and expand systems' quality, capacity, and efficiency for people with ASD.

The goal of the strategic planning meeting was to draft a plan that defines the work to be done to improve services for individuals with ASD in Maine. As part of the planning process, participants provided information and insights on the current status and recent progress in early identification of children with ASD, reviewed the progress in the development of a unified system of care for individuals with ASD, and identified barriers to effective supports for individuals with ASD in Maine.

An affinity diagram was utilized to gather information from participants by asking questions addressing issues effecting individuals with ASD and their families. The questions focused on the life span and included:

- What needs to happen to ensure early identification and diagnosis of ASD/PDD?
- What needs to happen to provide quality early intervention for all those diagnosed with ASD/PDD?
- What needs to happen to ensure services are coordinated and non-duplicative to serve individuals with ASD/PDD across settings?
- What needs to happen with state government to ensure that youth with ASD/PDD achieve successful community living, employment, health, and post-secondary education and training outcomes?
- What needs to happen to ensure that adults with autism across the spectrum receive care and support to live in and contribute to their communities?

Results were compiled and priority areas were determined. A series of questions were developed and widely distributed to individuals with ASD and their families in order to gather their opinions and input. Many of their responses are highlighted throughout this report. When all comments had been collected, a team of DHHS agency staff met and identified key tasks to be undertaken as part of the ASD Strategic Plan. The Commissioners of DHHS and DOE will meet in June of 2013 to prioritize tasks and determine the time frame for their implementation.

# ASD Strategic Plan

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## Policy/Systems Change

- Medical Care
  - Early Identification and Intervention
    - Develop and implement a universal screening, diagnostics, and treatment protocol that is used consistently throughout the State.
    - Improve communication to providers to prevent duplicative testing.
    - Decrease the amount of time it takes between screening and evaluation.
  - General Health
    - Increase capacity of medical professionals to work with individuals with ASD.
    - Establish medical homes for children with ASD that collaborate and coordinate with schools.
    - Develop policies, training and technical assistance opportunities to encourage providers of medical/behavioral services for adults to seek out information about ASD.
- Treatment
  - Reduce the waitlist for adult services with the ultimate goal of eliminating the waitlist.
  - Increase the number of individuals with ASD receiving career counseling.
  - Provide job sampling to individuals with ASD to discover types of employment at which the individuals would be successful.
  - Improve access to assistive technology and emerging technologies that could support greater opportunities independence.
  - Revise the behavioral health practitioner curriculum to be more focused on the variety of needs individuals with ASD and other developmental disabilities have, as opposed to individuals with mental health issues.
  - Adjust policies and rules to require in-home providers/behavioral health providers to collect data for ongoing assessment of needs and progress.
  - Adjust policies and rules to ensure appropriate choice options for treatment interventions and measure progress at the individual level to ensure effectiveness of the intervention.

## ASD Strategic Plan (cont.)

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- Improved Efficiency
  - Streamline intake and eligibility in transitioning from children's to adult services.
  - Adjust planning process to include targeted, achievable goals to be addressed at home, school, work, and in the community.
  - Adjust policies, contracts and rules to ensure that case managers assess the appropriateness of service delivery systems that serve their clients.
  - Adjust policies, contracts and rules to ensure that random check-ins occur to monitor how individuals are doing.
  - Development and requirement for use of a screening and treatment data system that crosswalks all other data systems, tracks to ensure that screening and appropriate follow up has occurred, and that can be utilized and updated by case management/care coordinator/parent navigator. (i.e. Childlink, HIN, IMMPACT II, Case E, Infinite Campus etc.)
- Collaboration between State Entities
  - Adjust internal DHHS transition process to begin earlier so that there is an increase in communication between DHHS's Office of Child and Family Services and Offices of Aging and Disability Services and Substance Abuse and Mental Health Services.
  - All State agencies develop MOU's with each other to formalize systemic improvements regarding individuals with ASD and other developmental disabilities. Develop cross-departmental standards of care for individual with ASD that will be used across silos. For example:
    - Clinically
    - IDEA and Medicaid regulations
    - Communication methods
- Joint Policy
  - DOE and DHHS implement a joint evaluation method that is accurate, well informed and includes standardized measures conducted or established by an interdisciplinary team that considers cognitive skills/levels and differential diagnosis. [This would provide one state pathway for diagnosis, evaluation, and treatment (like the newborn screening process.)]
  - Develop policies and procedures for collaborative, cross-system service planning, communication, and coordination that is both proactive and reactive.
  - Create policies to support ongoing training and collaboration amongst child and adult service systems.

## ASD Strategic Plan (cont.)

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- Identify rules, policies and practices that are barriers to natural support and adjust rules to support community inclusive practices.
- DOE and DOL collaborate to support vocational training and focus within secondary school programs.
- MaineCare
  - Require that all MaineCare providers use quality measures in their reporting.
  - Identify methods to ensure successful inclusion of individuals with ASD in both the health home initiative and any accountable care/value based purchasing effort.
  - Identify methods to pay for collateral contact.
- Planning
  - Adjust rules and policies so that transition planning uses a needs-based tool and occurs at ages 16, 17, and 18.

### Convene Workgroup To:

- Complete a literature review and identify appropriate services for individuals with ASD across age and functioning levels, compare with existing support models and develop a plan to augment existing services. Services should include home, school, community, and work supports.
- Conduct a review of current systems to identify barriers towards successful transition.
- Develop standards for treatment to be utilized across settings and systems and create a plan on how to implement those standards.
- Develop methods and a plan for implementation on how to assess pain in individuals with ASD/DD to be utilized across settings and systems.
- Define the roles of the various agencies, identify duplicative services, and create a plan to improve efficiency and quality of services.
- Evaluate the current crisis service system and adjust as necessary to meet the needs of individuals with developmental disabilities.
- Develop accountability measures to determine the appropriateness of home settings for individuals with ASD and other developmental disabilities. Ensure no dead-end placements. Always have a plan for the next stop.
- Increase availability of more supported living options (such as family home or community living) and alternative housing models (such as how technology might be utilized) with an opportunity to graduate to less restrictive environments.

## ASD Strategic Plan (cont.)

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- Investigate and promulgate rules to pool or braid funding streams to provide coordinated, streamlined services across systems.
- Investigate models like Rhode Island's nationally recognized Pediatric Practice Enhancement Project where trained parent Resource Specialists are placed into pediatric practices to assist families navigating the service systems. (This model replaces their community case management system.)

### Information Training and Technical Assistance

- Provide Training and Technical Assistance to:
  - Support staff and medical assistants within physicians' offices about ASD.
  - Medical providers
    - On school systems and the importance of working together.
    - On community support systems.
  - School staff
    - On community resources and health systems
    - On typical co-occurring physical and mental health concerns.
  - Community Support (Case Manager, Sections 65 and 28)
    - On typically co-occurring physical and mental health concerns
    - On school systems and the importance of working together
  - In-home/Community providers on how to collect meaningful data for ongoing assessment of needs and progress.
  - Families and self-advocates. Invite and support families, individuals with ASD, and other self-advocates to attend the same trainings available to educators and providers.
  - Families explaining the multiple systems of care involved in providing services for their children with ASD.
- Develop a web-based resource that:
  - Describes current assistive technology available to assist individuals with ASD and other developmental disabilities to live, work and participate in their communities.
  - Collects and maintains an up-to-date repository of best practice treatment and standards.
  - Describes strategies for community resources to include individuals with ASD and other developmental disabilities in community activities.

## ASD Strategic Plan (cont.)

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- *Sponsor public awareness campaign about:*
  - How pain can be an underlying cause for behaviors. “When behaviors change, check for pain.”
  - The need for individuals with ASD and other developmental disabilities to be included in the community

## Conclusion

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Clearly, Maine continues to make great strides to improve its service systems for children and youth with ASD. However, Maine shares with the nation the continuing struggle to adjust systems to meet the needs of the growing population of individuals diagnosed with an ASD. 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 ASD. The work outlined in this report illustrates the significant strides Maine has taken to improve the multi-agency systems of care utilized by individuals with ASD and their families, however, large gaps still remain. One major challenge is the number of youth with ASD who are transitioning into 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 necessary to assist persons with ASD to live and work in their communities, using the most cost effective means possible. This will require innovative approaches and models of support. All parties who have been involved in this work are encouraged by the continuing effort and commitment. State agency staff, advocates, university staff, educators, service providers, family members, and individuals with ASD, have made greater strides towards working together to find solutions in a collaborative, coordinated manner.

# Acronym Glossary

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<b><u>Acronym</u></b>	<b><u>Definition</u></b>
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AAP: .....	American Academy of Pediatrics
ABAS: .....	Adaptive Behavior Assessment System
ADDM: .....	Autism and Developmental Disabilities Monitoring Network
AIG: .....	Autism Implementation Grant
ASD: .....	Autism Spectrum Disorder
ASM: .....	Autism Society of Maine
ASQ: .....	Ages and Stages Questionnaire
BCBA: .....	Board Certified Behavior Analyst
CCIDS: .....	Center for Community Inclusion and Disability Studies
CCSS: .....	Common Core State Standards
CCT: .....	Community Care Teams
CDC: .....	Centers for Disease Control
CDS: .....	Child Developmental Services or College of Direct Supports
CHIP: .....	Children’s Health Insurance Program
CHIPRA: .....	Children’s Health Insurance Program Reauthorization Act
CMS: .....	Centers for Medicaid and Medicare Services
CSHCN: .....	Children with Special Health Care Needs
DD: .....	Developmental Disability
DHHS: .....	Department of Health & Human Services
DOE: .....	Department of Education
DOL: .....	Department of Labor
DPIC: .....	Developmental Psychology/Informatics Collaboration
DRC: .....	Disability Rights Center
DSM: .....	Diagnostic and Statistical Manual
DSP: .....	Direct Support Professional
EBP: .....	Evidence Based Practices
EPSCoR: .....	Experimental Program to Stimulate Competitive Research
EPSDT: .....	Early Periodic Screening Diagnosis and Treatment
FAPE: .....	Free Appropriate Public Education

## Acronym Glossary (cont.)

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<b><u>Acronym</u></b>	<b><u>Definition</u></b>
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FAST: .....	Facilitating Autism Screening and Treatment
GSS: .....	General Supervision System
HRSA: .....	Health Resources Services Administration
HSRI: .....	Human Resources Research Institute
ICF: .....	Intermediate Care Facility
ICF/ID: .....	Intermediate Care Facility for Persons with Intellectual Disabilities
ID: .....	Intellectual Disability
IDEA: .....	Individuals with Disabilities Education Act
IHE:.....	Institutes of Higher Education
IHOC: .....	Improving Health Outcomes for Children
LEND: .....	Leadership Education in Neurodevelopment and Related Disabilities
LRE: .....	Least Restrictive Environment
M-CHAT: .....	Modified Checklist for Autism in Toddlers
MDDC: .....	Maine Developmental Disabilities Council
MECHIP: .....	Maine Child Health Improvement Partnership
MEIO: .....	Maine’s Expanding Inclusive Opportunities
MMP: .....	Maine Medical Partners
MPF: .....	Maine Parent Federation
MRTQ: .....	Maine Roads To Quality
NS-CSHCN: .	National Survey for Children with Special Health Care Needs
OADS: .....	Office of Aging and Disability Services
OCFS: .....	Office of Child and Family Services
PCMH: .....	Patient Centered Medical Home
PCP: .....	Primary Care Physician
PD: .....	Professional Development
PDD: .....	Pervasive Developmental Disorder
PDD-NOS: ....	Pervasive Developmental Disorder – Not Otherwise Specified
PDN: .....	Professional Development Network
PEDS: .....	Parents Evaluation Developmental Status

## Acronym Glossary (cont.)

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<b><u>Acronym</u></b>	<b><u>Definition</u></b>
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SAU: .....	School Administrative Unit
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SIS: .....	Supports Intensity Scale
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SEA: .....	State Education Agency
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SEED: .....	Supporting Exceptional Educators Development implementation team
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SPDG: .....	State Personnel Development Grant
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STEM: .....	Science Technology, Engineering and Mathematics
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STEPS: .....	Strengthening Together Early Preventative Services
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TA: .....	Technical Assistance
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TCM: .....	Targeted Case Management
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UNH: .....	University of New Hampshire
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UVM: .....	University of Vermont
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