

# Autism Spectrum Disorders Report

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

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And  
The Maine Department of Education

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

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*Coordinated by the Maine Developmental Disabilities Council*

# TABLE OF CONTENTS

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<b>EXECUTIVE SUMMARY .....</b>	<b>3</b>
<b>DEFINITION OF AUTISM .....</b>	<b>6</b>
<b>STATE OF THE STATE .....</b>	<b>9</b>
<b>ELIGIBILITY VS ENTITLEMENT THROUGH THE LIFESPAN .....</b>	<b>13</b>
<b>ASD SYSTEMS CHANGE INITIATIVE .....</b>	<b>16</b>
<b>EARLY IDENTIFICATION AND INTERVENTION .....</b>	<b>17</b>
<b>CHILDREN WITH ASD .....</b>	<b>27</b>
<b>STAKEHOLDER AGENCIES .....</b>	<b>34</b>
<b>TRANSITION .....</b>	<b>36</b>
<b>HEALTHCARE .....</b>	<b>39</b>
<b>ADULTS WITH ASD .....</b>	<b>45</b>
<b>CONCLUSION .....</b>	<b>53</b>
<b>APPENDIX A, ASD STRATEGIC PLAN .....</b>	<b>54</b>
<b>APPENDIX B, ACRONYM GLOSSARY .....</b>	<b>60</b>

# 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 has made great strides towards achieving the objectives outlined in the Maine Autism Strategic Plan, documented in the April 2013 Autism Act report. In accordance with the Autism Act of 1984, 34-B M.R.S.A. §6001-6004, this biennial report describes the work completed since the April 2013 report, the current status of services for individuals with ASD, and initiatives underway to improve and expand systems' quality, capacity, and efficiency.

## Highlights

- The number of individuals with ASD has increased over 848% since the turn of the twenty-first century.
- Healthcare pilot findings indicate that more children are being screened for early identification of ASD and other developmental disorders.
- Healthcare pilot findings indicate that enhanced care coordination for children with ASD within a medical home is effective in increasing quality and shows promise in lowering costs.
- The Maine Department of Education has created sixteen Autism Teams to train educators in evidence based practices for students with ASD.
- Maine State agencies increase the focus on the growing number of young people transitioning from children's services to the adult service system.

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</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>3 4</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 2014, MaineCare claims data indicated that there were over 6,095 individuals with a diagnosis of ASD who received MaineCare, a 46% increase from just five years earlier and an increase of over 848% since the turn of the twenty-first century.

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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> Fernell, Elisabeth et al (2013) Early Diagnosis of Autism and Impact on Prognosis: a Narrative Review. Clinical Epidemiology 2013;5 33-43

<sup>3</sup> Carpenter, Siri (2014) For Adults with Autism, a Lack of Support When They Need it Most Washington Post [http://www.washingtonpost.com/national/health-science/for-adults-with-autism-a-lack-of-support-when-they-need-it-most/2015/03/23/cd082c64-b396-11e4-854b-a38d13486ba1\\_story.html](http://www.washingtonpost.com/national/health-science/for-adults-with-autism-a-lack-of-support-when-they-need-it-most/2015/03/23/cd082c64-b396-11e4-854b-a38d13486ba1_story.html) accessed 4/10/2015

<sup>4</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 10, 2015

## Executive Summary (cont.)

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Contrary to data from MaineCare, the Department of Education's annual 2014 Child Find data indicated the first decline in the educational systems' autism category in over twenty years of increase in students being served for Special Education under the category of autism. 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. Over the last twenty years, the number of students being served under the category of autism has steadily risen until peaking in 2013 with 3,097. This is a 416% increase in 13 years. The 2014 Child Count data collected by schools reported only 2,978 students being served, which calculates at just under a 4% reduction.

In 2008, Maine began the ASD Systems Change Initiative sponsored by the Commissioners of the Departments of Education, Labor, and Health and 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.

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 for three years. Also in 2010, Maine, in partnership with Vermont, was awarded a five-year, \$11 million Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) Quality Demonstration Grant from the Centers for Medicare and Medicaid Services (CMS) to improve the quality of care for children who are insured by Medicaid and Children's Health Insurance Program (CHIP). Known as Improving Health Outcomes for Children (IHOC) in Maine and Vermont, the project's focus is on building a public/private framework and system for measuring and improving the quality of healthcare services delivered by child-serving practices.

Utilizing the Autism State Implementation Grant for Children and Youth with ASD and the IHOC First STEPS (Strengthening Together Early Preventive Services) Learning Initiative, Maine has improved identification rates of children with ASD. This was done by encouraging early childhood professionals, such as Part C (Individuals with Disabilities Education Act (IDEA) staff, Head Start staff, Public Health Nurses, and physicians to screen all children at 18 months of age for ASD. In their evaluation report of the First Steps Phase II Initiative to improve developmental, autism, and lead screening for children they reported that, based on chart review data, they found that **Developmental and autism screening rates in reporting Phase II practices more than doubled in all age groups and exceeded 75% screening targets in several age groups.**<sup>5</sup> The statewide rate of developmental screening has increased from 1-3% in 2011 to 12-17% in 2013 by ages 1, 2, and 3.

## Executive Summary (cont.)

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<sup>5</sup> Muskie School (August 2013) [IHOC First Steps Phase II Initiative: Improving Developmental, Autism, and Lead Screening for Children, Final Evaluation Report](#), page 2

Maine is also the recipient of a State Innovation Model (SIM) Grant, which seeks to achieve the Triple Aim goals of improving the health of Maine’s population, improving the experience Maine patients have with their care, and reducing the total costs of care. The model has a foundation in emerging healthcare initiatives, promising community-based demonstration projects, and evidence-based strategies that empower consumers with long-term health conditions.

Both the SIM Grant and the Autism State Implementation Grant focused on improving health outcomes. For example, research has been conducted to assess healthcare equity for individuals with ASD. Quality improvement studies have also been conducted, for example, one pilot of the AIG succeeded in improving communication and the timeliness of the screening and referral process between early childhood professionals and diagnosticians. The project resulted in reducing the period between referral and diagnosis of ASD by over 30 days.

Another pilot of the Autism State Implementation Grant 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.

This work was continued beyond the grant year through funding by the Maine Developmental Disabilities Council. Evidence indicates that this low-cost service is effective in increasing quality and appears to actually be a cost saver when factoring saved physician time, preventing higher cost emergencies and expediting early intervention, a long-term cost saver.

The Maine Department of Health and Humans Services(DHHS) and Maine Department of Education (DOE) have both made significant changes in policies and work that effect people with ASD. One major initiative that the DOE 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.

Maine has added another focus to ensure that the growing number of young people transitioning from children’s services to the adult service system is smooth and seamless. In 2013, DHHS Office of Aging and Disability Services (OADS) and DHHS Office of Child and Family Services (OCFS) built a “Youth in Transition” electronic interface. Through this mechanism, tracking and documentation of service needs begin for youth aged 16 and continue through their transition years when they move to adult services. This process captures the current services, as well as documents the projected needs of the youth.

The district coordination work provides the primary information needed to facilitate the youth’s move to adult services, and answers some of the historical shortcomings of the transition process. More recently, representatives from the Office of Substance Abuse and Mental Health Services (SAMHS) have also been included in these Transition Committee meetings in an effort to better coordinate services for consumers who may have more complex needs or co-occurring disabilities.

## **Executive Summary (cont.)**

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The committees have uncovered issues in service during transition. Maine is working to narrow and close various gaps. Differing eligibility criteria, different funding streams, different regulations, different array of services and authorizing entities all can contribute to a less than seamless transition for some. The issue has received concerted attention in past years, and the Department has recently spearheaded a renewed effort to improve the transition system as well as the individual experience.

## Definition of Autism

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According to the Autism Society of America, autism is a lifelong developmental disability that profoundly affects the way a person comprehends, communicates and relates to others<sup>6</sup>. The features of autism typically become noticeable in the first two years of life and impact development in the areas of social interaction, communication, and range of interests and activities.

The definition of “autism” has evolved continually since Leo Kanner first identified “autistic disorders of affective contact” as a distinct developmental disorder in 1943.<sup>7</sup> Kanner described eleven children who he believed had innate, biologically-based limitations that resulted in an apparent need to be left alone. He also observed a number of communication impairments that included pronoun reversals, echolalia and sometimes very limited or totally absent speech. These children also reacted very negatively to environmental changes or disruption in their regular routines. At about the same time, Hans Asperger published an article describing a group of similar individuals who he described as having “autistic psychopathy.”<sup>8</sup> Unlike the children described by Kanner, however, all of Asperger’s subjects were proficient in their use of language. Over time, the term “Asperger Syndrome” came to be used to describe individuals on a broad autism spectrum or continuum who could use their speech effectively and had no apparent intellectual deficits.

In the United States, an autism diagnosis is usually based on American Psychiatric Association criteria listed in their Diagnostic and Statistical Manual (DSM). Until recently, autism or *Autistic Disorder* was included under the broader category of *Pervasive Developmental Disorders* (PDD)<sup>9</sup>. Also included in this category were two conditions characterized by less significant social, communicative, and behavioral impairments - *Asperger’s Disorder* and *Pervasive Developmental Disorder – Not Otherwise Specified* (PDD-NOS). Also included as PDDs were two low incidence conditions - *Childhood Disintegrative Disorder* and *Rett’s Disorder*.

## Definition of Autism (cont.)

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<sup>6</sup> Autism Society of America. (2013). About autism. Retrieved April 4, 2013 at <http://www.autism-society.org/about-autism/>

<sup>7</sup> Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217-250.

<sup>8</sup> Asperger, H. (1944, 1991). *Autistic psychopathy in childhood* (U. Frith, Trans.). Cambridge, UK: Cambridge University Press.

<sup>9</sup> American Psychiatric Association. (1994). *DSM-IV: diagnostic and statistical manual of mental disorders*. Arlington, VA: American Psychiatric Association.

Increasingly, the term *Autism Spectrum Disorders* (ASD) has come to be used to label individuals with a broad range of autism-related characteristics. This was reflected in the most recent (2013) edition of the American Psychiatric Association DSM-V<sup>10</sup> that eliminated the PDD category while collapsing *Autistic Disorder*, *PDD-NOS*, and *Asperger's* into a new single *Autism Spectrum Disorders* diagnostic category. *Childhood Disintegrative Disorder* and *Rett's Disorder* were not included as ASDs, however. The new DSM-V identified two persistent deficits that need to be present for an ASD diagnosis: 1) “social communication and social interaction across multiple contexts;” and 2) “restricted, repetitive patterns of behavior, interests, and activities.” Rather than distinguishing between *Asperger Syndrome*, *PDD-NOS*, and *Autistic Disorder*, the new diagnostic scheme included criteria for identifying the “severity” of ASD symptoms. Although, technically, *Asperger's Disorder* and *PDD-NOS* have been eliminated as separate diagnoses, many individuals with ASD, family members, and professionals may continue to use these terms.

Contrary to Kanner's original conclusion, there is a growing consensus that individuals with ASD do not desire to be alone. In fact, researchers have shown that as children with ASD grow older, they often desire friendships and social interaction<sup>11</sup> but that many experience loneliness and isolation.<sup>12</sup>

Although atypical sensory responsiveness has been reported among individuals with ASD, family members and clinicians for many years, it was not included in the diagnostic criteria for PDDs. The DSM-V, in contrast, includes hyper-responsivity (unusually over-reactive) and hypo-reactivity (unusually under-reactive) to particular sensory inputs (e.g. certain sounds, sights, touch etc.) in their criteria for ASD. In many cases, individuals may be overwhelmed or have strong emotional reactions to some sensory information. Others may be unusually drawn to or preoccupied with certain sensory features such as a shiny surface or the tactile characteristics of an object.

Characteristics and behaviors vary greatly among individuals with ASD. The way individuals experience ASD can also vary greatly in intensity and degree. For example, some individuals with ASD are very proficient in their use of spoken language while others may use communication devices to compensate for limited or absent speech. In addition, individuals with ASD may vary dramatically in the ways they respond to various sensory inputs. One person, for example, might seek out the kind of deep pressure provided by a “bear hug” while another person finds such contact intolerable. Similarly one person with ASD might engage in repetitive motor behavior while another talks obsessively about a particular topic. Therefore, treatment and educational strategies must be highly individualized to meet each individual's unique needs.

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<sup>10</sup> American Psychiatric Association. (2013). *The Diagnostic and Statistical Manual of Mental Disorders: DSM 5*. Arlington, VA: American Psychiatric Association.

<sup>11</sup> Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development*, 71(2), 447.

<sup>12</sup> Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs*, 10(2), 74-81. doi: [10.1111/j.1471-3802.2010.01148.x](https://doi.org/10.1111/j.1471-3802.2010.01148.x)

## Definition of Autism (cont.)

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### DSM-V Diagnostic Criteria for ASD<sup>13</sup>

- A. Persistent deficits in social communication and social interaction across multiple contexts.
  - 1. Deficits in social-emotional reciprocity.
  - 2. Deficits in nonverbal communicative behaviors used for social interaction.
  - 3. Deficits in developing, maintaining, and understanding relationships.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following:
  - 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  - 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal/nonverbal behavior.
  - 3. Highly restricted, fixated interests that are abnormal in intensity or focus.
  - 4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Autism was once considered a rare disorder. Now, according to the U.S. Center for Disease Control, ASDs affects 1 in 68 children, and are four times more likely to affect males than females.<sup>14</sup>

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<sup>13</sup> DSM-V provides more detailed description of criteria including examples and recommendations regarding indicating the severity of symptoms.

<sup>14</sup> Centers for Disease Control <http://www.cdc.gov/ncbddd/autism/facts.html> accessed 4/10/2015

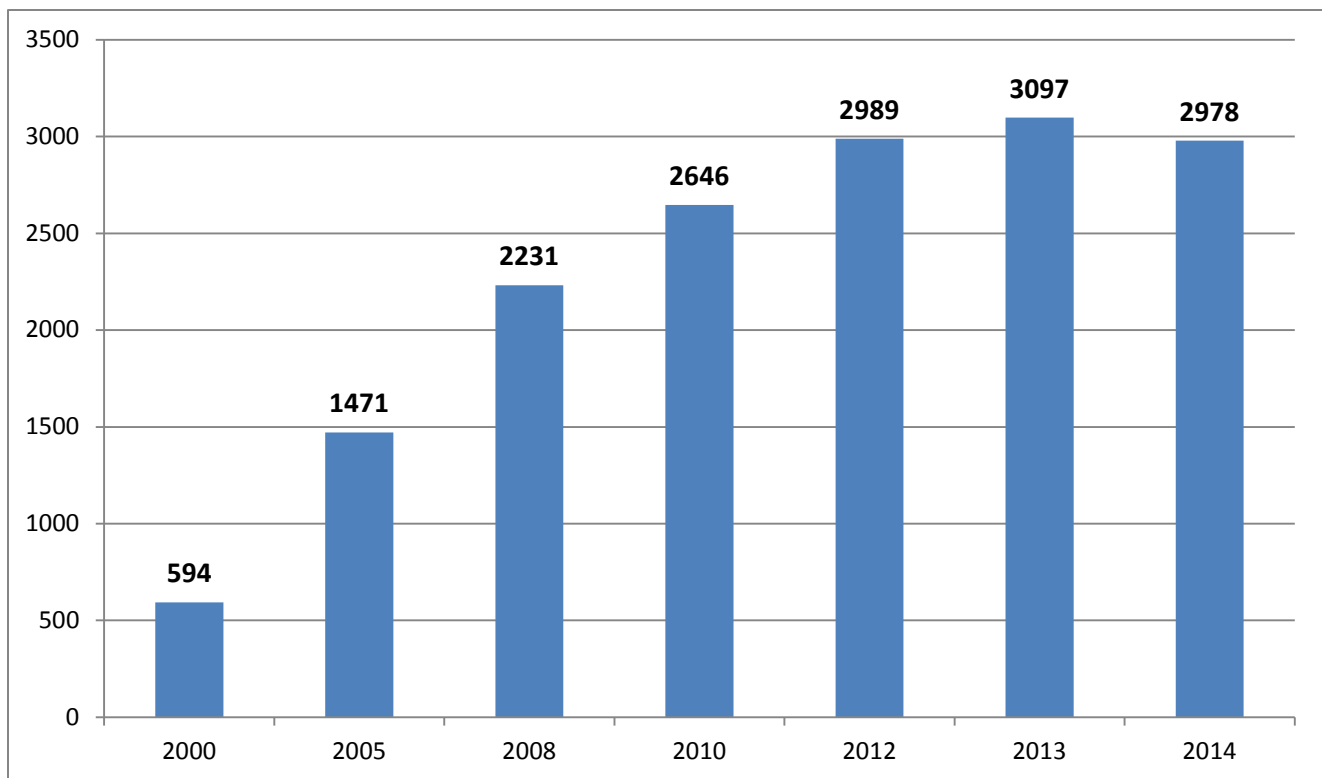


## State of the State

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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. Over the last twenty years, the number of students being served under the category of autism has steadily risen until peaking in 2013 with 3,097. This is a 416% increase in 13 years. The 2014 Child Count data collected by schools reported only 2,978 students being served, this is the first decline in the educational system autism category in over twenty years.

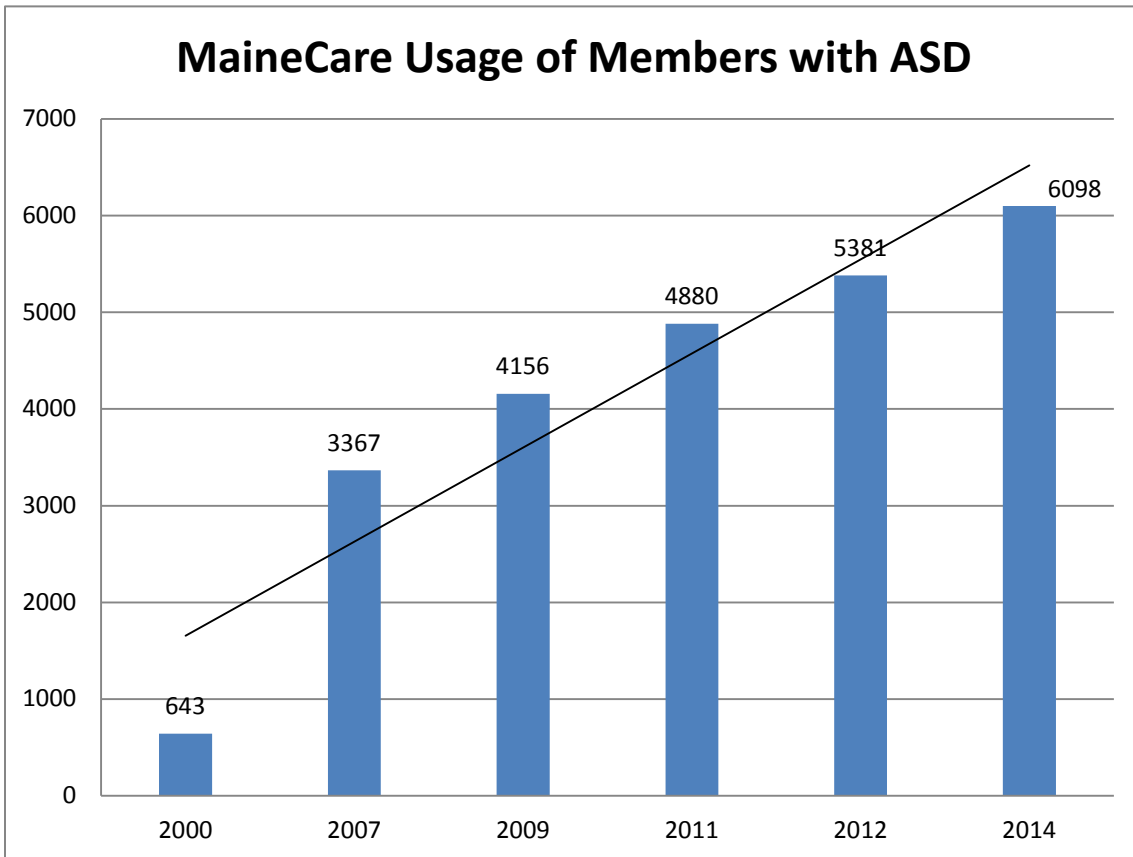


The trend of leveling numbers experienced by schools was not shown to be true by MaineCare claims data. In 2014, MaineCare paid claims for more than 6,098 Maine citizens diagnosed with an ASD, which is a 46% increase from just five years ago.

## State of the State (cont.)

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In 2000, MaineCare paid claims for 643<sup>15</sup> members with an ASD. In 2014, that number jumped to 6,098. The increase is over 848% since the turn of the twenty-first century.<sup>16</sup>



Like MaineCare, national trends continue to increase. In 2014, the U.S. Centers for Disease Control and Prevention (CDC) updated its estimated prevalence numbers again to 1:68<sup>17</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 1:100. A recent study in South Korea reported a prevalence of about 1:38.<sup>18</sup>

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<sup>15</sup>DHHS (2007) Autism Act of 1984 2007 [http://www.maine.gov/dhhs/2007\\_autism\\_report.pdf](http://www.maine.gov/dhhs/2007_autism_report.pdf) Accessed 1/23/2015

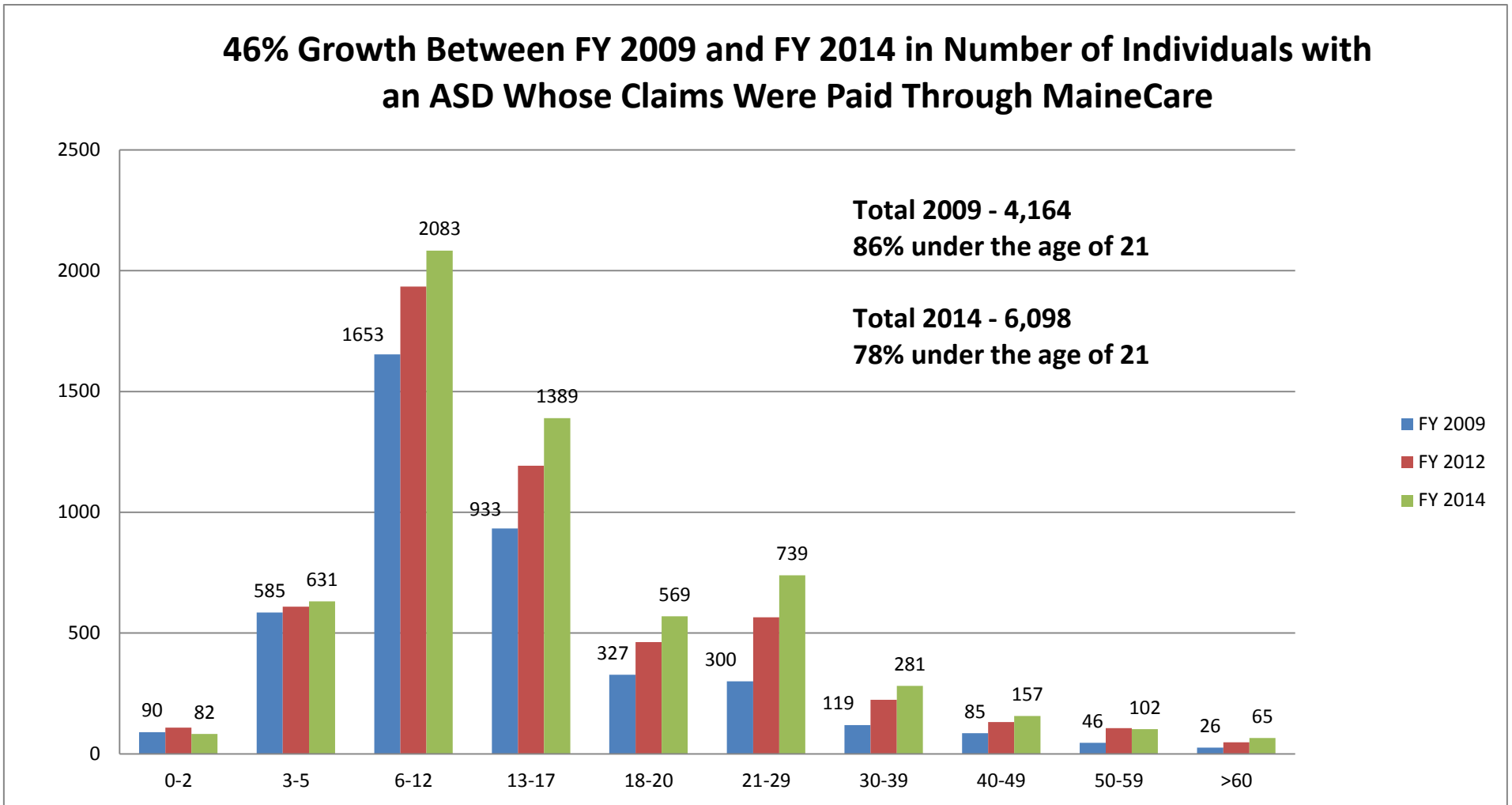
<sup>16</sup>MaineCare is an income-dependent service.

<sup>17</sup>Centers for Disease Control <http://www.cdc.gov/ncbddd/autism/data.html> Accessed 1/23/2015

<sup>18</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

## State of the State (cont.)

Just five years ago, 86% of the individuals with ASD who received MaineCare were under the age of 21. Today, 78% 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.



## State of the State (cont.)

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According to MaineCare claims data, there has been an increase in the number of individuals with an ASD in every age group except in ages 0-2. This apparent decrease in very young children contradicts other Maine research. The decrease could represent a delay in identification or, perhaps, children of this age are not yet accessing MaineCare and are receiving services through other models such as the education system. The later scenario would delay the children being identified in the MaineCare system until a later age when families seek out services that are only available through MaineCare.

The 2011 Autism Report, showed that the fastest growing age group that contained over 100 individual members was youth ages 18-20. The 2013 Autism Report identified, that the fastest growing age group had changed from 18-20 year old youth to 21-26 year old young adults. This indicates that the large increase in the numbers of children identified with ASD in the last twenty years is reaching adulthood.

Age	2007	2009	2012	2014	2 year %	5 year %	7 year %
0-2	91	90	108	82	-24%	-9%	-10%
3-5	470	585	609	631	4%	8%	34%
6-12	1304	1653	1934	2083	8%	26%	60%
13-17	774	933	1193	1389	16%	49%	79%
18-20	<b>239</b>	<b>327</b>	<b>462</b>	<b>569</b>	<b>23%</b>	<b>74%</b>	<b>138%</b>
21-26	<b>184</b>	<b>240</b>	<b>429</b>	<b>576</b>	<b>34%</b>	<b>140%</b>	<b>213%</b>
27-64	296	324	620	732	18%	126%	147%
65+	9	12	26	36	38%	200%	300%
Total	<b>3367</b>	<b>4164</b>	<b>5381</b>	<b>6098</b>	<b>13%</b>	<b>46%</b>	<b>81%</b>

# 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 for Developmental Services 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 – Office of Aging and Disability Services (OADS)

OADS provides services and programs for adults with ASD who meet eligibility criteria. The statutory definition in 34-B MRSA §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 ASD is defined in the law as an adult with PDD who:

- A. Has received a diagnosis that falls within the category of PDD, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, published by the American Psychiatric Association and 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 ASD codified in 34-B MRSA §6002, DHHS OADS has promulgated rules regarding autism. According to these rules, an adult person with PDD is one:

- A. Whose diagnosis, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association) is within the category of PDD, 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
- B. 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.

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

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

MaineCare policy for the Comprehensive Waiver (Sections 21) and the Supports Waiver (section 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 for Intermediate Care Facilities (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 intellectual disability (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/ID.) 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/ID 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 Based Waiver (MaineCare Section 21) while others receive services under the Community Supports Waiver (MaineCare Section 29), dependent upon individual needs and availability of funding. Waiting lists currently exist for both waiver programs, but it is expected by July 2015 that the Supports Waiver (Section 29) waitlist will be eliminated. Priority for Section 21 services is given to incapacitated and dependent adults in need of adult protective services to alleviate the risk of serious 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.

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

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## School-Based Services

A child is entitled to special education services if s/he has a disability that (1) 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 (OMS), Department of Education (DOE), Child Development Services (CDS), Maine School Management Association (MSMA), Maine Association for Special Education Directors, Disability Rights Center (DRC), Maine Developmental Disabilities Council (MDDC), 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. The group submitted a State Plan Amendment that proposes to incorporate all medically necessary Medicaid reimbursable services provided in a school-based setting under the EPSDT section of the Maine Medicaid State Plan. The group is also working to establish a billing guide that can be used by school districts to bill MaineCare for services they provide.

## DHHS – Office of Child and Family Services

The Office of Child and Family Services (OCFS) 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.

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

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## Insurance Mandate

The 124<sup>th</sup> Legislature passed MRSA Chapter 635, which mandates that insurance companies provide coverage for the diagnosis and treatment of ASD for all children under the age of six. The 126<sup>th</sup> Legislature expanded that law by expanding the coverage through age 10. (MRSA Title 24-A, Chapter 33, §2768) The expansion went into effect in January, 2015. 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 ASD Systems Change Initiative

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

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 Children with Special Health Care Needs (CSHCN) with the management of the State Autism Implementation Grant (AIG). The State AIG that Maine received in 2010 has allowed many of the recommendations developed by the ASD Systems Change Initiative to be implemented. Over the course of the grant, which ended late 2013, significant work was done to improve Maine’s system of care for individuals with ASD. That work is documented in this report and illustrated with a gray background.



## Early Identification and Intervention

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According to the Autistic Spectrum Disorders Report distributed by DHHS in 2007, “only about half of children with PDD in Maine are diagnosed before kindergarten.”<sup>19</sup> The most recent report from the Centers for Disease Control and Prevention’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>20</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.

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>21</sup>. Today, it is widely accepted that early intensive behavioral intervention results in improved outcomes for many children.<sup>22</sup> The Centers for Disease Control and Prevention 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>23</sup>

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>26</sup>

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>24</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>25</sup> Several studies have shown that early intervention can reduce those costs by more than half over an individual’s life span.<sup>26,27,28.</sup>

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<sup>19</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 4/10/2015

<sup>20</sup> CDC (2012) Community Report from Autism And Developmental Disabilities Monitoring (ADDM) Network. Morbidity and Mortal Weekly Report 2012; Vol. 61(3)

<sup>21</sup> Myers MD, Scott M (2007) Management of Children with Autism Spectrum Disorders. Pediatrics <http://pediatrics.aappublications.org/content/120/5/1162.full> accessed 3/25/2015

<sup>22</sup> Fernell, Elisabeth et al (2013) Early diagnosis of autism and impact on prognostic: a narrative review. Clinical Epidemiology 2013;5 33-43

<sup>23</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

<sup>24</sup> Autism Speaks <http://www.autismspeaks.org/science/science-news/autism%E2%80%99s-costs-nation-reach-137-billion-year> accessed 3/25/2015

<sup>25</sup> CDC [www.cdc.gov/ncbddd/autism/data.html](http://www.cdc.gov/ncbddd/autism/data.html) accessed 4/4/2015

<sup>26</sup> Ganz PhD, Michael L (2007) The Lifetime Distribution of the Incremental Societal Costs of Autism, Pediatrics & Adolescent Medicine. Vol. 161 No. 4

<sup>27</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\\_C173htU4sQagKEzGVnWzxVTOTbmt8pfTV5aypgTvs-yZfUszH-COGIP2fyPEI0Nt3CQk4NcVWcapfE-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_C173htU4sQagKEzGVnWzxVTOTbmt8pfTV5aypgTvs-yZfUszH-COGIP2fyPEI0Nt3CQk4NcVWcapfE-uz-qJD8m5QLfbs5wndkpgi8IJA5_oTShENns0eA3ko1cUDa&sig=AHIEtbS0bu7dfopgnuZTIEE7h6P-JGYGtA) accessed 3/22/2014

## Early Identification and Intervention (Cont.)

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In February 2010, Maine and Vermont were awarded a five-year demonstration grant from the Centers for Medicare and Medicaid Services (CMS) to improve the quality of health care for children insured by Medicaid and the Children's Health Insurance Program (CHIP). Maine's Department of Health and Human Services' (DHHS) Office of MaineCare Services (OMS) received the Improving Health Outcomes for Children (IHOC) grant in partnership with the Maine Center for Disease Control and Prevention, the Muskie School of Public Service (MSPS) at the University of Southern Maine, Vermont's Medicaid Program, and the University of Vermont. In Maine, IHOC brings together public and private health stakeholders to standardize the delivery of preventive and follow up care for children and to meet quality improvement goals of OMS.

In conjunction with the IHOC grant, Maine's DHHS has taken 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). Through the efforts of IHOC and OMS, staff billing guidance and education on developmental screening has been widely disseminated to MaineCare providers, leading to significant increases in the rate of screenings being performed.

### Office of Child and Family Services (OCFS)

OCFS currently contracts with the University of Southern Maine, Muskie School of Public Service, Maine Roads to Quality to provide training and technical assistance to early care and education providers to increase the industry capacity to provide high quality inclusive early learning settings. This is done through direct training and through sub-contracting with the Center for Community Inclusion and Disability Studies. Together they provide highly specialized assistance, training, and individualized direct service to child care programs. This increases the access and participation of children with developmental, linguistic, cultural and other diverse learning needs in community based child care programs. These services are offered to early care and education professionals.

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<sup>28</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.)

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### **Increase usage of ASD screening tools by early childhood professionals**

Over the first two years of the project, the Maine Developmental Disabilities Council (MDDC) conducted trainings to over 170 early childhood professionals in screening children for ASDs. These trainings were provided via a DVD that covered six topics, which included the importance of universal screening, the first signs of ASDs, the administration and scoring of the Modified Checklist for Autism in Toddlers (M-CHAT), the use of the M-CHAT follow-up interview tool, how to talk to families about screening, and an introduction to the Ages and Stages Questionnaire (ASQ).

Trainings were measured via a survey and effect was analyzed by an external evaluation agency, Altarum Institute. In the final evaluation report, Altarum Institute stated that both screening and referral systems appeared to have changed since the training. Of those who responded to both pre- and post- questionnaires (n= 26), most reported that they changed practices after the trainings and are now screening children for ASDs. When asked about how the training affected their knowledge about how to administer and score standard screening tools, 61.5 % reported that their knowledge had increased greatly, and an additional 30.8% said that it had increased somewhat. When asked about the impact of the training on their agencies' referral systems, the majority said that it had improved somewhat, and an additional two reported that it had improved greatly.

### **Coordinated, Comprehensive Data System -**

The 2012 Autism Act Report described a need for a comprehensive, cross agency, data system to facilitate prompt screening, diagnosis, evaluation, and treatment for children with ASD. In response to the need identified in the report, the Maine legislature's Health and Human Services Committee wrote a letter to the Department of Health and Human Services' Commissioner Mayhew dated June 12, 2013 that requested a plan to implement a comprehensive tracking data system.

DHHS worked with Maine Quality Counts and the Maine Developmental Disabilities Council to gather together State Information Technology (IT) experts who developed or maintained Maine data systems that both collect individual level or aggregate level child information. The group gathered for two full-day meetings and identified potential strategies for sharing information and interfacing medical practitioners' electronic medical records and other data tracking/collecting systems focused on developmental information.

The group of IT experts developed a high-level data base inventory that cataloged the multiple data systems that collect information about the health of Maine's children and the public services which they use. Once the data was collected it became clear that the systems could connect with each other if two barriers were overcome. The first barrier to a comprehensive, cross agency, data system lies within the multiple agencies governing statutes that manage how the data can be used and with whom the data can be shared.

## Early Identification and Intervention (Cont.)

### **Coordinated, Comprehensive Data System (Cont.)**

The committee agreed that the next step would be for each agency to identify what language would need to be changed in order to accomplish data sharing. The second barrier is cost, cost to build the connectivity as well as the time it will take to analyze policy and re-write processes to share that information across agencies.

It became clear that technology isn't the issue in putting in place a comprehensive cross agency data system, but navigating the policies that govern the sharing of information. The State Agencies Interdepartmental Early Learning Team (SAIEL) Developmental Screening Stakeholders' team is collaborating to work towards overcoming this barrier.

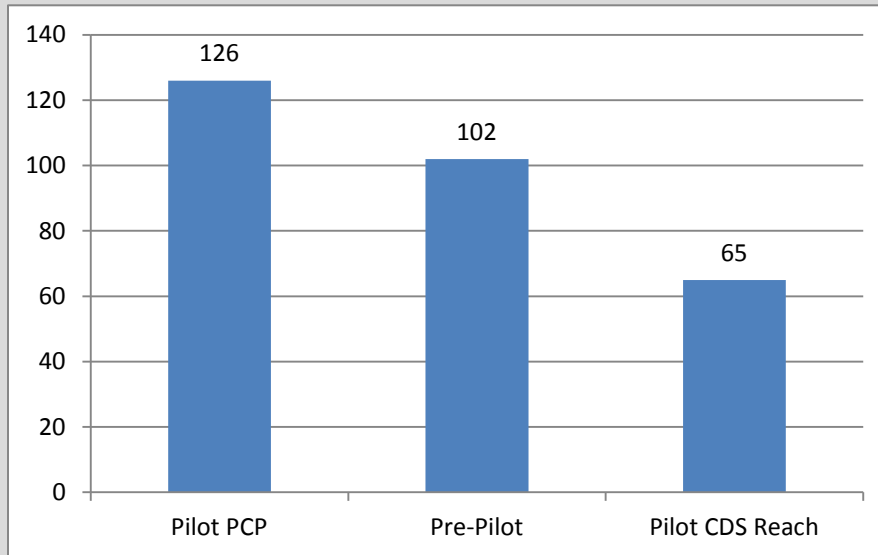
### **Pilot to improve communication and coordination between medical diagnosticians and early childhood providers**

As the population of children diagnosed with Autism Spectrum Disorders (ASDs) increases, the systems of care that serve these children—including early intervention programs, specialty medical care, special education, and primary medical care—are becoming increasingly strained. To address the issues of fragmentation and lack of coordination in these systems, the State Autism Implementation Grant (AIG) supported a quality improvement project in two sites aimed to improve coordination and communication between the two primary systems that identify with ASD, the Department of Education's Child Development Services (CDS) and medical diagnosticians. Altarum Institute was contracted as part of the grant to provide local evaluation services to the Maine DD Council. As part of this evaluation, Altarum conducted key informant interviews of the specialty medical providers and CDS offices in both pilot sites and, as far as was possible, analyzed data collected.

Both pilot sites improved communication and coordination of evaluations for children with ASD. In one site the medical practitioners and local CDS agency piloted ways to streamline the referral process to reduce the wait time between referral to diagnosis. By making a few, simple changes they were able to reduce wait time by over one month!

## Early Identification and Intervention (Cont.)

### Reduced process between referral to diagnosis by over a Month!



The other site noted a number of specific benefits of the new system, which are likely to continue beyond the life of the pilot. Most important is the increased effective communication and trust between the medical diagnosticians and the local CDS.

Overall, the pilots succeeded in improving communication and the timeliness of the screening and referral process in both sites. While the two pilot counties each addressed their own challenges through their pilot projects, it is likely that the process of planning the pilot—including CDS and medical diagnosticians meeting to discuss the process; making explicit the expectations of all parties regarding documentation, communication, and timelines; and coming to agreement about ongoing communication and information-sharing—were as useful in improving the system as the pilot project itself. Thus, one possible systems change activity would be to conduct meetings in each county with the CDS agencies and providers of specialty care to walk through this process and identify areas where the system could be improved or streamlined. These pilots show that the mere process of discussing the process, identifying areas for improvement, and making each party's needs and expectations explicit is likely to contribute to an improved system. The pilots demonstrated that small process changes can improve coordination and communication between CDS and specialty providers, both essential elements of the system of care for children with ASDs. The ongoing challenge will be in sustaining these improvements in the pilot sites and replicating them in the rest of Maine's counties.

## **Early Identification and Interventions (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 2010, Maine, in partnership with Vermont, was awarded a five-year, \$11 million CHIPRA Quality Demonstration Grant from the Centers for Medicare and Medicaid Services (CMS) to improve the quality of care for children who are insured by Medicaid and CHIP. Known as Improving Health Outcomes for Children (IHOC) in Maine and Vermont, the project's focus is on building a public/private framework and system for measuring and improving the quality of healthcare services delivered by child-serving practices. IHOC is a collaboration of health systems, pediatric and family practice providers, professional associations, state agencies and programs, quality improvement groups, and consumers working 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, and
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, improving care quality, supporting value-based purchasing, increasing early identification of special needs, and ultimately improving child health outcomes and reducing health care costs.

Specifically, the State of Maine is working to:

- Collect and test child health measures, including the CHIPRA Core Set of Child Health Quality Measures, plus additional measures identified by Maine stakeholders as important to the quality of care for children.
- Align the IHOC quality measures with State and national quality improvement, incentive payment, and value-based purchasing initiatives.

## Early Identification and Interventions (Cont.)

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### IHOC (Cont.)

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 CMS; 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 practices in the Patient Centered Medical Home Pilot and other child-serving 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. OMS 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 (QC), on behalf of IHOC and MaineCare Services, designed and implemented 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.

First STEPS is a comprehensive effort modeled after the Institute for Health Improvement’s “Model for Improvement” framework to provide outreach, education, and quality improvement support to increase rates of preventive services for children and adolescents. First STEPS promotes principles of the patient-centered medical home and includes dozens of primary care practices, including the four child-serving practices who are participants in Maine’s pre-existing Multi-Payer Patient Centered Medical Home Pilot.

## **Early Identification and Interventions (Cont.)**

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### **IHOC: First STEPS (Cont.)**

Through First STEPS, QC 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 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 four-phase 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 through December, 2012. First STEPS Phase II included two day-long learning sessions (in May 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-3) 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. Developmental screening rates more than doubled for children ages 1 to 3 and more than tripled for 2 year olds in the First STEPS practices.

Since the completion of First STEPS Phase II, Maine Quality Counts and IHOC have continued to work with the Maine CDC and other Maine DHHS partners on ways to improve the developmental screening system in the state for all children, called the Developmental Systems Integration Project (DSI). First STEPS 2014 focused on spreading the lessons learned from Phase II to more child-serving primary care practices in Maine. Quality Counts provided three regional trainings in March and April, 2014 for thirty-one PCMH/Health Homes practices and two trainings in August, 2014 for fourteen Federally Qualified Health Centers (FQHC) through the Maine Primary Care Association. Practices who attended a First STEPS 2014 training were able to receive a validated developmental screening toolkit, at no cost, as part of the CHIPRA grant to assist them in immediate implementation. In addition to the regional training, a six month learning initiative was offered to practices if they wanted to participate in a full Maintenance of Certification (MOC) project. Nine practices completed the full MOC project which included monthly data collection, plan-do-study-act cycles, and webinars by content experts. One way that MaineCare is tracking the increase of developmental screening is through claims.



## Early Identification and Interventions (Cont.)

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### IHOC: First STEPS (Cont.)

The First STEPS Learning Initiative was evaluated by the University of Southern Maine Muskie School of Public Service. In their evaluation report of the First Steps Phase II Initiative to improve developmental, autism, and lead screening for children, they reported that, based on chart review data, they found that **Developmental and autism screening rates in reporting Phase II practices more than doubled in all age groups and exceeded 75% screening targets in several age groups.**<sup>29</sup> The statewide rate of developmental screening has increased from 1-3% in 2011 to 12-17% in 2013 by ages 1, 2, and 3.

### Developmental Systems Integration Initiative

Beginning in 2013, Maine Quality Counts for Kids (QC) started to partner with the State Agencies Interdepartmental Early Learning Team (SAIEL), the interdepartmental sub-agency established by the Commissioners of the Maine Department of Education and the Maine Department of Health and Human Services. Together, QC and SAIEL are leading the Developmental Systems Integration (DSI) initiative in order to improve general developmental screening rates for children so that early identification and referral can occur statewide more seamlessly for all children ages 0-3 years. QC was a natural partner in this work because of their leadership role for the IHOC First STEPS work with practices in 2012 and 2014, focused on increasing developmental and autism screening in the primary care practices through a federal CHIPRA grant.

The original goal of the DSI initiative, which aligned with the IHOC First STEPS work, was to increase the number of MaineCare children who receive general developmental screening by age 1, age 2, and age 3 by 3% per year using baseline data gathered in 2011. These data from 2011 MaineCare claims showed a rate of developmental screening of 2.1% by age 1, 3.4% by age 2 and 0.5% by age 3 based on the federal CHIPRA measure. By 2016, the goal was to show an increase in general developmental screening of 11.1% by age 1, 12.4% by age 2 and 9.5% by age 3 based on a federal CHIPRA metric and the American Academy of Pediatrics guidelines on general developmental screening. In 2013, MaineCare claims indicated that rates had exceeded the 2016 projected targets. New goals were established to increase developmental screening rates by 15% by December, 2015 and 20% for all ages by December, 2016.

DSI successes in improving health care quality for children ages birth to 3 through expansion of developmental system integration activities include: convening monthly DSI-SAIEL steering committee meetings and hosting three day-long DSI Stakeholder meetings in November, 2014; January, 2015 and May, 2015 with over 50 participants attending. The DSI team at QC also developed and implemented a survey across early childhood disciplines (300+ respondents), providing information about developmental systems integration practices including how information is communicated and referrals are conducted. After the survey was complete, the DSI-SAIEL team developed intent statements to guide DSI work.

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<sup>29</sup> Muskie School (August 2013) IHOC First Steps Phase II Initiative: Improving Developmental, Autism, and Lead Screening for Children, Final Evaluation Report, page 2

## Early Identification and Interventions (Cont.)

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### Developmental Systems Integration Initiative (Cont.)

They also achieved broad-based consensus that general developmental screening for children ages birth to three would be conducted using an evidence-based, parent-completed tool throughout all the disciplines using either the *Ages and Stages Questionnaire-3* (ASQ-3) or the *Parents Evaluation of Developmental Status* (PEDS), and recommended the updated autism screening tool, the *Modified Checklist for Autism in Toddlers-Revised* (M-CHAT). As a group, they determined that the critical ages for screening should follow the American Academy of Pediatrics periodicity, identifying the critical ages for developmental screening to be at 9, 18 and 30 months and autism screening at 18 and 24 months.

In addition, the DSI-SAIEL team worked to create a cross-disciplinary terminology chart to define surveillance, screening, evaluation and assessment for children ages birth to three and developed common metrics to begin to collect developmental screening data across the disciplines. The DSI-SAIEL team continues to work to understand essential elements of release of information and referral processes, and has draft of a universal consent/referral form to be used by medical practices. They are in the process of identifying materials to promote the message of the importance of developmental screening to families including using materials from the National Center for Disease Control outreach materials through the “Birth to Five, Watch Me Thrive” ([www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive](http://www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive)) and the “Learn the Signs, Act Early” ([www.cdc.gov/ncbddd/actearly/downloads.html](http://www.cdc.gov/ncbddd/actearly/downloads.html)) campaign. DSI has planning the launch of 3 community pilots in the spring of 2014 under the Developmental Screening Community Initiative. With this pilot, they hope to test how to better share information across community partners including primary care providers, Early Head Start, Maine Families Home Visiting, Child Development Services, Public Health Nursing, and Child care providers. They will be working with community teams in Bangor, Waterville and the Midcoast area (Bath/Brunswick) for 9 months to test information sharing, strategies to close the referral loop, and ideas on how to make sure that children receive recommended early intervention services.

Finally, DSI is working to improve efforts to reduce health care costs through enhancing systems. Through concept mapping and the development of schematics, the DSI team began the process of determining roles and responsibilities of the different disciplines in terms of surveillance, screening, evaluation and assessment services for children ages birth to three to recognize missed opportunities and areas where duplication was an issue. The DSI-SAIEL team also worked with the Maine Developmental Disabilities Council, to convene a group of IT technicians to examine the different data systems in Maine’s DOE and DHHS which collect child developmental health information, and to identify possibilities for connectivity and/or integration. In addition, QC staff as part of IHOC/First STEPS and DSI worked to align measures with SIM measures alignment group so that developmental screening is included in the metrics list. QC DSI staff also continued to highlight the need for consistent payment across public and private insurers as well as to reinforce the message that, in 2011, the Affordable Care Act included a modifier 33 code covering the cost of preventive services on the American Academy of Pediatrics Bright Futures Schedule without a co-pay or deductible.

### Children with ASD

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## **DHHS/MECDC/Division of Population Health – Children with Special Health Needs Program**

According to the 2009/10 National Survey for Children with Special Health Care Needs, 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 Disabilities (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.

Nancy Cronin, Executive Director of the Maine Developmental Disability Council and Toni Wall represent Maine on the national Maternal and Child Health Bureau, Autism Screening and Referral, Diagnosis, and Services Expert workgroup. The mission of the workgroup is “to improve the system of care for children with autism spectrum disorder and developmental disabilities.”

### **Education**

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, Common Core State Standards 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.

# Children with ASD (Cont.)

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## Education (Cont.)

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.

In the third and fourth years of the grant, the Department increased the percentages of highly qualified special education teachers and related services personnel in the State by working to decrease the percentage of employed but not fully qualified personnel through: a scholarship program for 23 special education teachers and related services personnel; funding for tuition, books and fees

*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.”*

for 40 special education teachers currently in a 2-3 year service obligation working with children with disabilities; funding for tuition, books and fees for 29 special educators (included occupational therapists, speech-language therapists and teachers of the visually impaired (TVI)); and the design of a statewide induction and retention plan for special educators. The Department also provided funding for tuition, books and fees for an orientation and mobility specialist (O/M) and maintained its partnership with the University of Massachusetts (UMASS) to provide funding for tuition, books and fees for Maine students enrolled in the UMASS TVI and O/M preparation program. In addition, recommendations were submitted to the Commissioner of Education for paraprofessional core competency training aligned with the Maine Autism Leader Team Evidence-based Practice Professional Development System. Throughout this period, a great deal of training has been provided to school administrative units (SAUs) or Child Development Services (CDS) sites (for children birth–two) statewide on: least restrictive environment requirements and the progress of children with disabilities in the general curriculum; instructional usage of the Common Core State Standards in English-language arts (ELA) and mathematics for children with disabilities; developing and implementing transition plans for children with disabilities from 9<sup>th</sup> grade to post-secondary education/employment; the evidence-based Early Intervention Model (EIM) for children age birth –two with disabilities; and effective planning for children with disabilities for their transition from IDEA, Part C to IDEA, Part B and to preschool and kindergarten. Training was also provided for 63 parents throughout Maine’s nine superintendent regions on the development and implementation of effective kindergarten and post-secondary transition plans.

# Children with ASD (Cont.)

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## Education (Cont.)

### Autism Initiative

DOE anticipated that ten Autism Teams would form and participate in EBP that would improve outcomes for individuals with ASD. 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.

The Department of Education has also utilized federal IDEA funding (separate from SPDG funds) for the establishment of the Maine Autism Institute for Education and Research (MAIER) through an agreement with the University of Maine’s College of Education and Human Development. The Institute was established to build statewide sustainability for the training and professional development initiated under the 2011 SPDG grant, to increase Maine’s ability to deliver necessary and highly effective services to children age 3-20 with Autism Spectrum Disorders, as well as to provide evidence-based professional development and coursework for those working with children with autism spectrum disorders. The Institute will reach stakeholders by means of an Advisory Board, training, a website, and regional collaboratives as a foundation for effective services and supports statewide.

Specifically, with respect to training, MAIER (in partnership with the Maine Department of Education and Child Development Services), will implement the Early Start Denver Model for young children with autism spectrum disorders. The Early Start Denver Model (ESDM) is an evidence-based intervention specifically developed for very young children with autism. ESDM is a play-based intervention that fuses behavioral and developmental principles into an integrated approach. ESDM can be implemented in different natural settings such as the home or the daycare/preschool by trained therapists as well as parents within play and daily routines. ESDM aims to reduce the symptoms of autism and target all developmental areas. Partnered implementation with families and children will begin January 6, 2015 for CDS Peds, CDS Reach, CDS First Step, CDS Two Rivers, and CDS Aroostook; and for remaining sites in February, 2015.

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

# Children with ASD (Cont.)

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## Education, Autism Initiative (Cont.)

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 evaluate whether 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 recommendations for the paraprofessional competencies were submitted to the Commissioner of Education in the fall of 2014.

Another goal of the SPDG Grant was to increase the qualifications of personnel currently serving children, birth to 20, with ASD 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, November 2, March 13, and 14, 2013 and April 8 and 9, 2014. 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.

## Children with ASD (Cont.)

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### Education, Autism Initiative (Cont.)

The Listserv is used to communicate to individuals and teams about evidence-base 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

#### 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 Wraparound Principles to develop and coordinate individual support plans and monitor services provided to children and their families and/or guardians. This program's usage by member appears to steadily be increasing. **According to MaineCare claims data, approximately 2,049 children and youth diagnosed with ASD received targeted case management services in FY 2014, a 12% increase from FY 2011 and a 32% since FY 2009.**

# Children with ASD (Cont.)

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

### 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 intellectual disabilities and/or ASD. **According to MaineCare claims data, over 165 children and youth diagnosed with an ASD lived, at least part of the year, in a residential setting in 2014, this number is slightly lower than the 2011 data showed.**

### Respite Care

Families of children with 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. Families seeking service may select the respite provider; however the provider must be trained and eligible to provide the service.

### Home Based Services

Rehabilitative Community Services (MaineCare Section 28) for eligible children and youth with developmental disabilities or ASD, 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.

Since June 2013, site reviews have been conducted at all Section 28 agencies to monitor compliance with regulations and contracts. This includes eight (8) agencies providing Applied Behavior Analysis. **According to MaineCare claims data, over 1,530 children and youth diagnosed with ASD received Section 28 services either in schools, homes, or the community in 2014.**

Effective December 1, 2013, the Department of Health and Human Services added to APS Healthcare's ongoing responsibilities for Utilization Review. APS assumed additional responsibilities to provide Waitlist Management, Classification, and Prior Authorization for Section 28 Community Based Rehabilitation and Community Support Services. This created an integrated, comprehensive Utilization Management system for children receiving this service.



## Children with ASD (Cont.)

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

#### Mental Health Treatment Programs (MaineCare Section 65)

This service is for children and youth with serious emotional disturbance, and is designed to 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 2,019 children and youth diagnosed with ASD received Section 65 mental health treatment services in 2014, an increase of 10% from FY 2011 and a 29% increase from FY 2009.**

# Stakeholder Agencies

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## Autism Society of Maine

Partly funded by the Office of Child and Family Services, the Autism Society of Maine (ASM) 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 and Sibshops for siblings.

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 and summer camp for children with ASD. 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.

## University of Maine Center for Community Inclusion and Disability Studies

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) is Maine's University Center for Excellence in Developmental Disabilities, and part of a national network of centers congressionally authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. 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 nationally. 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 staff with expertise in early childhood mental health consultation serve as a resource by providing information, professional development and consultation to support healthy social-emotional development and prevent expulsions of children who exhibit challenging behaviors.

After The Arc of the United States was awarded a four-year grant in 2010 to develop and implement a national resource center on autism and other developmental disabilities, CCIDS provided 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 complemented and enabled the expansion of the Maine Autism Spectrum Resource Center launched by CCIDS in June, 2010, with support from the Maine Department of Education. CCIDS also offers free online resources such as Growing Ideas Tipsheets and Resources for Guiding Early Childhood Practices, Visual Supports Learning Links, and community of practice supports for practitioners.

## Stakeholder Agencies (Cont.)

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### CCIDS (Cont.)

#### Maine Roads to Quality

Maine Roads to Quality is part of Maine's Professional Development Network (PD). The PD'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 PD 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 PD 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 PD and Maine providers.

#### New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program at the University of Maine

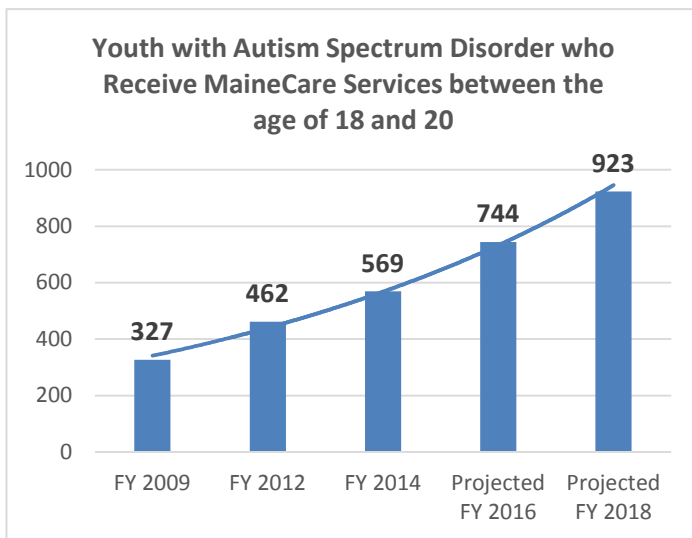
The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) has joined the University of New Hampshire Institute on Disability and the Geisel School of Medicine at Dartmouth as a partner in the New Hampshire Leadership Education in Neurodevelopmental and Related Disabilities (NH LEND) Program. The NH LEND Program, with funding from the Maternal and Child Health Bureau, Health Resources and Services Administration, 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 have worked 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.

# Transition

## Multi State Agency Efforts for Seamless Transition

Young people transitioning from children’s services to the adult service system can be vulnerable to gaps in service. Differing eligibility criteria, different funding streams, different regulations, different array of services and authorizing entities all can contribute to a less than seamless transition for some. The issue has received concerted attention in past years, and the Department of Health and Human Services has recently spearheaded a renewed effort to improve the transition system as well as the individual experience. In 2012, internal staff from DHHS’s Office of Child and Family Services (OCFS) and DHHS’s Office of Aging and Disability Services met at the district level to plan for and coordinate transition activities for individual consumers. With parental permission, the two offices shared information to develop a plan to support smooth transition to adult services for youth nearing the end of high school. In 2013, OADS/DS and OCFS built a “Youth in Transition” electronic interface. Through this mechanism, tracking and documentation of service needs begin for youth at age 16 and continue through their transition years until the move to adult services. This process captures the current services as well as documents the projected needs of the youth. The district coordination work provides the primary information needed to facilitate the youth’s move to adult services, and answers some of the historical shortcomings of the transition process. More recently, representatives from SAMHS have also been included in these Transition Committee meetings in an effort to better coordinate services for consumers who may have more complex needs or co-occurring disabilities.

Transition Committee members continue to reach out to partners in the Department of Education and local schools to identify youth who may need long term services and supports, and begin their transition planning well before they are ready to leave school. While this approach is demonstrating success, more attention is needed to create systemic solutions so that the transition pathways are clear, parents will know what to expect in this arena, and eligible consumers receive the necessary services in a timely manner. Below is a chart that shows the projection of youth with ASD entering adulthood through 2018. These changing numbers are creating challenges to the adult service system as the population that they serve must adapt to include more individuals with ASD than any time in prior history.



## Transition (Cont.)

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

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) recently completed the second of two research projects testing the effectiveness of a family-centered transition planning project for youth with ASD. This most recent project was funded for three years by 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 were provided with a package of supports that were found to be effective in an earlier CCIDS/UNH collaborative research project in improving a number of transition-related outcomes for Maine and New Hampshire youth with ASD<sup>30</sup>. These outcomes included greater levels of self-determination, higher expectations for the future, and increased career maturity. Initial data on long-term outcomes indicated significantly higher rates of employment and post-secondary education than typically seen for this population. Participating families learned about practical strategies for person-centered planning, networking, and for utilizing a variety of adult service options and resources. In addition, project staff facilitated individual planning meetings and provided support for students to investigate career options. CCIDS hopes to be able to expand the project to a broader range of participants in coming years and to work with family advocacy organizations to make the model sustainable.

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

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS), in collaboration with Maine EPSCoR (Experimental Program to Stimulate Competitive Research), implemented and evaluated 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 participated in workshops, family-centered planning and tours of University of Maine STEM programs. CCIDS has supported more than 15 individuals on the autism spectrum in this project. The project produced a publication, *Increasing Access and Success in the STEM Disciplines: A Model for Supporting the Transition of High School Students with Disabilities into STEM-related Postsecondary Education*, that contains information and instructional activities related to the following: self-advocacy and self-determination; exploring STEM careers; disability disclosure; the accommodations process in college; identifying assistive technology; mentoring relationships and internships; and using student-and family-centered planning to prepare for college.

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<sup>30</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.

### **Raising Expectations**

A public outreach campaign has been developed to raise the expectations of and for individuals with developmental disabilities, their families, and the general public. Too often, families, as well as members of the general public, are not encouraged to expect more of a child with a disability than to move into a group home and engage in a day program as he enters adulthood. The Maine Developmental Disabilities Council (MDDC) believes that while there is a need for these services, children with developmental disabilities should expect and be expected to grow up to be active, valued members of their community.

The MDDC has engaged with the civil rights teams at two area high schools. Initial focus groups with students at these schools were held to document their perception of individuals with disabilities and their opinions about what lives are like for individuals with developmental disabilities after high school. Posters with messages aimed at raising the expectations and perceived value of individuals with developmental disabilities have been hung in the schools. At the end of the school year, a follow-up focus group will be held with the students to determine whether the posters have effected a change in attitudes and perceptions.

# HealthCare

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## State Innovation Model (SIM)

Maine is also the recipient of a State Innovation Model Grant (SIM), which seeks to achieve the Triple Aim goals of improving the health of Maine’s population, improving the experience Maine patients have with their care, and reducing the total costs of care. The model has a foundation in emerging healthcare initiatives, promising community-based demonstration projects, and evidence-based strategies that empower consumers with long-term health conditions. Quality Counts (QC) is working in close partnership with MaineCare to support implementation of Stage A of the MaineCare Health Homes (HH) initiative which promotes transformation in primary care practices designed to improve care for members with chronic illness. The State aligned the HH model in Maine to the 10 Core Expectations of the multi-payer Maine Patient Centered Medical Home Pilot (PCMH), and of the 75 primary care practices in the PCMH Pilot, 73 are also MaineCare Health Homes, and there are an additional 119 single-payer MaineCare Health Homes that joined the PCMH Learning Collaborative under SIM. SIM funding allows QC to provide Quality Improvement outreach and support directly to these practices, and to expand the existing PCMH Learning Collaborative to include the single payer Health Homes. In the second year of participation in the Health Home initiative, MaineCare requires practices to implement three screenings in the primary care workflow: depression, substance abuse and pediatric developmental screening. QC partners with IHOC’s First STEPS to provide technical assistance to support practices in implementing the pediatric developmental screenings. Over 77 practices received training on developmental and autism screening in 2014 as a result of the work of First STEPS, DSI, and SIM efforts. SIM is also supporting one of the three community pilot sites in the Developmental Screening Community Initiative.

## Developmental Disabilities Health Initiatives

The SIM Grant currently supports MaineCare’s workforce development for healthcare providers working with adults that have Intellectual / Developmental Disabilities (I/DD) and Autism Spectrum Disorders. In 2015 the Maine Developmental Disabilities Council joined the SIMS work to increasing the knowledge and ability of direct service providers, caregivers, case managers and physicians to coordinate and provide appropriate healthcare for individuals with Developmental Disabilities (DD). This will be accomplished by developing and disseminating information providing a technical assistance “hot line” for ongoing support.

A new add-on to the Section 21 waiver will be skilled nursing allowing Developmental Disability Nurses to be reimbursed for their work. This will fill a large gap in the reimbursement structure. However, the pool of DD Nurse’s in Maine are limited. The Maine Developmental Disabilities Council (MDDC) will contract to increase the number of nurses certified as DD Nurses. The skilled nursing reimbursement will cover individuals with DD who already have serious, identified health conditions. Through this project, MDDC will evaluate whether or not providing an “as needed” DD Nurse to identify if behavioral changes are actually an indication of a health condition. The DD Nurse will talk to caregivers and direct service providers to troubleshoot behavioral and medication issues then, when appropriate, assist with the complex navigation of medical services.

## **HealthCare (Cont.)**

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### **Developmental Disabilities Health Initiatives (Cont.)**

In addition, the DD Nurse will be available for primary care physicians to assist in communication and coordination of services with the DD system.

The project will test the hypothesis that earlier intervention of behavioral issues by health professionals will identify and treat medical problems before they become a crisis and the individual is either in need of emergency care or long term skilled nursing.

The initiative plans to put into place a three pronged approach to address the care of individuals with I/DD. A curriculum that shows changes in behavior can be indicative of health problems. It will also leverage Maine Quality Counts Health Homes Learning Collaborative to educate Primary Care providers about the connection between physical health issues and behavioral issues, and the potential misinterpretation of symptoms that sometimes result in an inappropriate use of mental health crisis services instead of addressing physical pain. The third piece to this project is to provide case managers, guardians, direct care staff, and PCPs with technical assistance. A variety of methods will be utilized to disseminate information and a needs assessment will be conducted to evaluate what future training or systemic improvements are needed.

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

Over the course of the grant, IHOC (Improving Health Outcomes for Children) has aligned its work with the Patient-Centered Medical Home (PCMH) pilot, which originally started with 25 medical practices and has since been expanded to over 170 practices in the Health Homes pilot throughout Maine, including pediatric practices and family medicine practices that care for children. Each of these practices in the demonstration 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 demonstration, one of the quality metrics being tracked by claims is the CHIPRA developmental screening metric that measures the number of children who had a general developmental screen. This metric was added to the MaineCare PCCM Utilization Review reports in the fall of 2013. As of January 2014, practices in the Health Homes pilot were required to offer developmental screening to children by ages 1, 2, and 3 years. In order to meet this requirement, additional training has been supported by the State Innovation Model (SIM).



## HealthCare (Cont.)

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

One of the four pediatric offices involved in the PCMH pilots is currently piloting the existing medical home model 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. The medical home care coordination project is located at Husson Pediatrics, a large general pediatric practice in central Maine. The practice has approximately 7,500 patients with a larger percentage of patients having DD than most family practices. The project consists of the use of a care coordinator who works with families, usually by phone, to address care coordination needs. This project began enrolling children in June 2012 and will continue through FFY15. The goal of the project is to evaluate the effectiveness of coordination of services for children with DD, to identify barriers, if any, for effective intervention for these children; and to generate possible solutions to these barriers as they arise to improve services and outcomes for children with DD.

Husson Pediatrics reported that they have thus far successfully enrolled and enriched the lives of over 70 patients and their families. They stated that the reason this pilot was of interest to them is that the current system of treatment for ASD is both confusing and unwieldy. Parents are not intuitively knowledgeable about what services are available and what services are covered by the medical and educational models. Community case managers do serve as guides through these difficult and confusing landscapes of treatment, but those professionals may not have the expertise in all the models and services available and have little to no knowledge about the medical needs of children with ASD.

The care coordinator telephones the family within 24 hours of the receipt of a referral to enroll the child in the pilot and begin the care coordination process. She then continues to interact with the family over time, reporting that families generally need care coordination at four critical times:

- *When a Developmental Screening is received by the practice, the care manager reviews the screening and provides a brief analysis of the results with, when appropriate, potential needs for early intervention*

Results thus far indicate that this practice is saving significant time for the physician as the care coordinator reviews the screening prior to the well child check.

- *Upon initial referral for evaluations by the Primary Care Physician (PCP) because of concerns regarding developmental delays*

The care manager can help parents better understand the process of diagnosis and what they can expect at each step. This eases anxiety and provides the parents with information they will need for informed decisions along the way. Parents have an incredible amount of stress around the possibility of autism as a diagnosis and the delays they see in their child. Knowledge from the care manager is power and relieves anxiety.

## HealthCare (Cont.)

### Comprehensive Medical Home (Cont.)

- *After the diagnosis is received the parents need guidance and support navigating the multi-layered systems*

Once the diagnosis is given, parents embark on the journey of working with multiple interventional services from multiple providers. They have many questions about services, Individual Education Plans, medical versus educational services, and how to access them all – and make it work with their schedule. The care coordinator regularly guides parents through this process.

- *During times of crisis*

Often parents experience a time when their child goes through a transition and they find themselves in crisis: the child is not sleeping and keeping the whole family up at night; the child becomes aggressive; the school is telling parents that the current interventions are not working, or sensory issues increase. Parents have turned to the care coordinator to find out where to go next. Talking with them on the phone has often been sufficient to determine the need and prevent an office visit. The patient's need may be a new Occupational Therapy evaluation to determine sensory needs, an earlier appointment for medication management, or a referral to speech therapist to assist with supports in communication, among others.

#### **Results Thus Far:**

- **Over 300 screenings reviewed by care coordinator.**
  - Physicians report that they find great value in the care coordinator reviewing incoming documents. The care coordinator's synopsis of each evaluation, current services, and potentially needed services/referrals has helped them understand many of the service reports, decreased their work loads, and assisted them in a higher quality of care to patients with DD.
- **In the past two years 70 children have received this enhanced service.** Well over half of these children were under the age of five. Outcomes include:
  - Expedited appointments at a diagnostic clinic for early identification,
  - Expedited access to evidence based, medically necessary services,
  - Prevention of Emergency Room visits by identifying complex medical issues early,
  - Provision of Family support, and the
  - Elimination of duplicative services and enhanced quality of services by coordinating educational and medical plans.

**Preliminary evidence indicates that this low-cost service is effective in increasing quality and appears to actually be a cost saver when factoring saved physician time, preventing higher cost emergencies and expediting early intervention, a long-term cost saver.**

## HealthCare (Cont.)

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### ASD Health Equity

Individuals with Autism Spectrum Disorders (ASD) are significantly more likely to have unmet healthcare needs and difficulty accessing healthcare services than those with other disabilities. Minority status, living in a rural location, and low income can exacerbate these disparities. Other obstacles to effective healthcare for individuals with ASD include the following: (1) severity of symptoms associated with ASD; (2) lack of knowledge or skill by medical practitioners; (3) lack of access to comprehensive healthcare supports or a medical home; and (4) lack of access to health insurance for needed supports and services. Individuals with ASD of all ages are likely to have a range of co-morbid medical and psychological conditions, making the need for comprehensive healthcare imperative.

The MDDC funded a research activity to collect information about the experience of accessing healthcare from 85 parents of children with ASD and 22 adults with ASD or their guardian who live in Maine as compared to the recommendations for the general population and existing research. A consultant conducted structured in-person interviews to collect information and the Center for Community Inclusion and Disabilities Studies, primary researcher Alan Kurtz, analyzed the method and data collected, he then reported results. This work yielded extensive data about quality of health and healthcare of Maine Citizens with ASD. A link to the report can be found (<http://www.maineddc.org/uploads/Accessing%20Healthcare%20Report.pdf>)

This research revealed a number of possible positive trends in healthcare for individuals with ASD in Maine. These included the following:

- A much earlier median age of identification and diagnosis among the youngest cohort of children;
- High ratings of overall health;
- Satisfaction with the PCP;
- Satisfaction with the ability of the PCP to meet the patient and family's individual needs;
- A relatively good understanding of ASD among PCPs;
- High ratings of PCP responsiveness and communication;
- Relatively little difficulty finding a PCP; and
- Access by most patients with ASD to regular healthcare, routine care and screening.

## HealthCare (Cont.)

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### ASD Health Equity (Cont.)

The research points to a number of areas of concern, however. These include the following:

- Difficulty by a small number of respondents in finding a PCP who could meet their needs;
- Poor communication among some medical providers;
- Failure of medical practices to make requested accommodations, especially those related to difficulty in waiting rooms;
- A very high rate of gastrointestinal issues;
- Frequent failure of PCPs to notice or act upon a possible relationship between gastrointestinal and behavior issues;
- Lack of communication with PCPs about using alternative therapies;
- Lack of support and planning for families related to the transition to adult healthcare;
- Difficulties that some patients had with completing routine care and screening procedures; and
- Inability of some individuals with ASD to communicate pain or illness in ways that are universally understood.

Perhaps the most encouraging finding from this study is that the median age of diagnosis with ASD for children was 4 and 2.9 for children who were 8-years old or younger at the time of the survey. The median age for adults who were diagnosed as children was 7.5. The lower median age of diagnosis in the successive cohorts suggests a substantial improvement in early identification and diagnosis in Maine over time. Furthermore, it is also nearly half the median age of 5.7 reported in a 2009 population-based study (Shattuck et al., 2009). Consistent with previous research, some parents and guardians complained that their PCP was too slow in responding to their concerns about their child's early development (e.g., Carbone et al., 2010; Jensen & Spannagel, 2011). **This appears to have improved dramatically however, especially in the last eight years.** Indeed, the parent of two children with ASD noted a significant improvement in her pediatrician's practices between the birth of her two children. **It is reasonable to assume that these results can be attributed, at least in part, to the efforts made through the Maine ASD Systems Change Initiative to improve screening and early identification practices.** Other factors may play a role, however. There is some evidence that early identification and diagnosis have improved nationwide, possibly as the result of the national Act Early network (Association of University Centers on Disability, 2014), in which Maine participated. (Kurtz, et al (2014) Accessing Healthcare, The Experience of Individuals with ASD in Maine pg 63-64).

## Adults with ASD

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### Office of Aging and Disability Services

The mission of the DHHS, Office of Aging and Disability Services (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.

Beginning in September, 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. All district offices have 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.

*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.”*

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.

# Adults with ASD

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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.

*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.”*

## Targeted Case Management Services

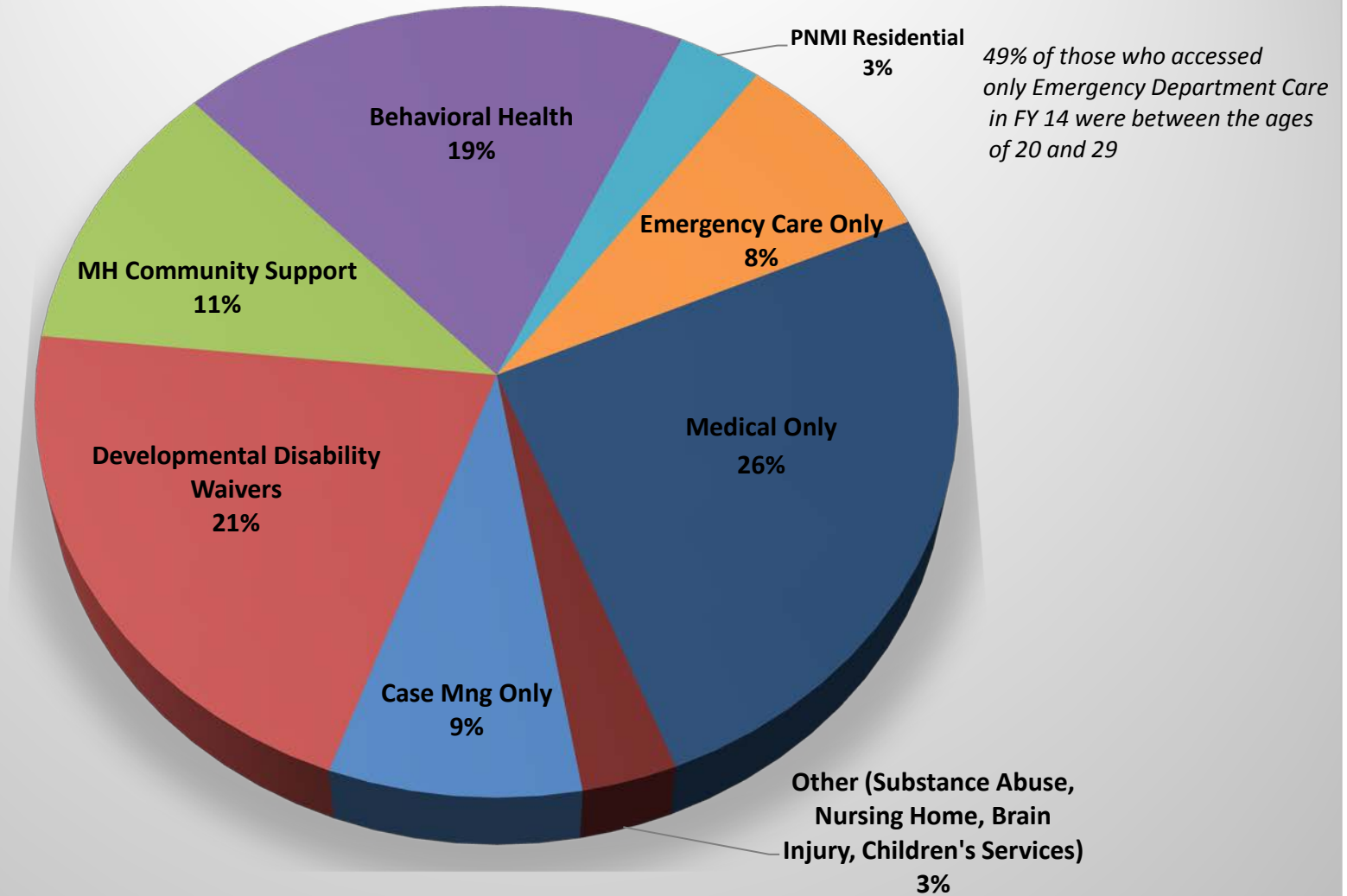
Each person eligible for adult Developmental Services is entitled to receive case management services. Case managers are either OADS employees or employees of contracted community case management agencies. A case manager identifies the person's medical, social, educational, and other needs, for example, housing and transportation. They identify services to meet those needs, assist the person with the development of a person-centered plan, 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. **Case Management was a billed service in FY '14 for over 360 adults with ASD.**

## 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 intervention. This waiver program has been closed and there is a waitlist for this service. As of March, 2015, there were 1,041 individuals with developmental disabilities on the waitlist. Of that number, 13 individuals with developmental disabilities were in critical need of services, having been found to be at risk for their health and safety.

## Adults with ASD (Cont.)

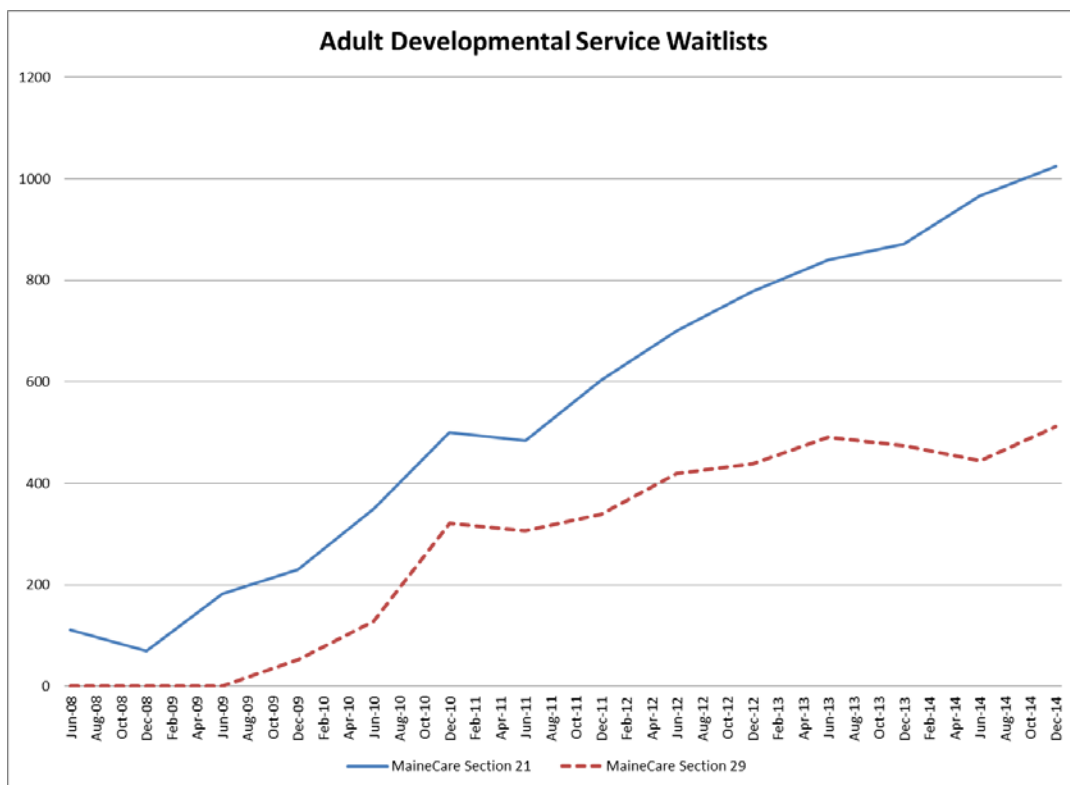
Primary System Usage for Adults with ASD over 20 years old n=1,344



# Adults with ASD (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, 2015, there were 517 individuals with developmental disabilities on the waitlist, however, it is anticipated that all these individuals on this waitlist will be offered services by July, 2015.





## Adults with ASD (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 the Comprehensive Waiver Services (Section 21). SIS results will be tied to a resource allocation model and individual budgets. The name for this overall initiative, pairing the Supports Intensity Scale (SIS) results with a resource allocation model, is called **“Supporting Individual Success.”** The Supports Intensity Scale 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, 2012, OADS staff were trained and certified to administer the SIS. Between late June and September 21, 2012, assessments were completed on a pilot sample of 500 individuals, with assistance from Human Services Research Institute (HSRI). Beginning in October, 2012, OADS staff began conducting interviews following intensive training and feedback from the pilot sample. In March, 2014, DHHS’s “single assessing agency,” Goold Health System took over the SIS assessment to provide an independent assessment. The goal is to complete interviews on 100% of individuals receiving the Comprehensive Waiver Services (Section 21) no later than July 1, 2015. 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 has been completed. All aimed at instituting a fair, equitable, comprehensive system of support for persons with ID/ASD.

The goals of the **“Supporting Individual Success”** initiative 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.

# Adults with ASD (Cont.)

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## Other Services (Cont.)

- 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.
- To provide a basic services “budget” from which each member can choose through the Person Centered Planning process, the array of services and supports that meets their own needs and goals.

## Continuing Education

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

Developmental Services provides training to Direct Support Professionals (DSP) through the College of Direct Support. The training includes a module specifically on working with people who have ASD. 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 ASD. The number of people who are being referred is increasing and national statistics and State education data indicate that this will continue. Both the Comprehensive Waiver Program and the Supports Waiver have had lengthy 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 and reduction 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, and
- Incorporating assistive technology and equipment to increase independence and safety.

OADS continues to work with people with developmental disabilities and their families to develop new programs that provide the flexibility, training, and level of support needed to assist persons with ASD to live and work in their communities, while at the same time doing so in the most cost effective way possible. This requires new approaches and new models of support.

## Adults with ASD (Cont.)

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### Employment

Research demonstrates, and is corroborated by experience, that participation in integrated community employment is strongly correlated with positive outcomes: being a homeowner or lease holder, having strong social supports, being engaged in other aspects of community life, and utilizing fewer paid supports. Significant progress has been made in the clinical understanding of the technical aspects of accessing and maintaining integrated community based employment for persons with any type of disability. Despite this progress, employment rates of persons with developmental disabilities continue to be very low and systems of support have not systemically institutionalized this understanding.

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, 2013, OADS began gathering employment outcome data through its Enterprise Management System. It enables 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.

### Developmental Disability Council Employment Demonstration Projects

In FY '14, the Maine Developmental Disabilities Council (MDDC) funded two projects to test novel approaches to support individuals with developmental disabilities in obtaining and retaining competitive employment.

One project was aimed at addressing the barriers to obtaining permanent, community based employment for older students who are within one to two years of transitioning out of school (aging-out). Contractors engaged students, families and education staff to be involved in all aspects of career exploration and work placement. The Division of Vocational Rehabilitation's work exploration curriculum was employed with participants for determining characteristics of jobs desired by each individual. Family groups were convened to describe services available and to identify ways that families can be of support. After the exploration process, jobs were found and youth supported within those jobs.

The second project demonstrated the operationalization of Customized Employment in which Employment Specialists are provided with specialized training to enable them to increase the employment options and outcomes for persons with significant and complex support needs.

# Adults with ASD (Cont.)

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## MDDC Employment Demonstration Projects (Cont.)

### **One individual's (de-identified) experience with the Customized Employment Project:**

*When John was a young child he had an accident which resulted in a lifelong developmental disability. Regardless of his disability, John's family instilled in him a strong work ethic and never let his disability be an excuse for idleness. John had a limited but steady work history. However, he had been out of work for over two years. He wanted to be an important contributor to a small business that didn't involve "fast food" and knew he would find such a business with the assistance of the Customized Employment Project. The Customized Employment Coordinator arranged an informational interview and meeting with the owner/operator of Bangor Laundromat and Drycleaner. John was hired. A task list was negotiated, VR contributed 10 hours of job coaching plus funding for a non-rolling laundry cart, folding board, and pouch for quarters (all accommodations for Chris' limited use of one hand), and the employer purchased plastic gloves that Chris could easily maneuver on his hands. The employer refused any wage subsidies or other employer benefits. John is doing well with natural supports from his colleagues and is pleased to be able to get to his job by taking the city bus.*

Results of Employment Projects include:

- Eight additional individuals became employed
- Three adults with developmental disabilities are employed and no longer need formal supports
- 28 persons with developmental disabilities engaged in the projects although they have not yet attained employment
- 137 people had the opportunity to learn about individualized employment for people with developmental disabilities

## 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 by individuals with ASD and their families. However, large gaps still remain. One major challenge continues to be 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.

# Appendix A

## ASD Strategic Plan

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The 2013 Autism Act Report documented Maine's ASD strategic plan. A meeting will be convened by stakeholders February 2016, three years after the initial plan was drafted to update and amend the plan. The 2017 report will document the next three-year plan. Much has been accomplished. Below is the FY '13-16 plan with bookmarks to where in this report the work accomplished can be found.

### 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.
      - *See Increase usage of ASD screening tools by early childhood professionals (page 19)*
      - *See IHOC: First STEPS and the Maine Child Health Improvement Partnership (pages 22- 25)*
      - *See Developmental Systems Integration Initiative (pages 25-26)*
    - Improve communication to providers to prevent duplicative testing.
      - *See Pilot to improve communication and coordination between medical diagnosticians and early childhood providers (pages 19-21)*
      - *See Developmental Systems Integration Initiative (pages 25-26)*
    - Decrease the amount of time it takes between screening and evaluation.
      - *See Pilot to improve communication and coordination between medical diagnosticians and early childhood providers (pages 19-21)*
      - *See Developmental Systems Integration Initiative (pages 25-26)*
  - General Health
    - Increase capacity of medical professionals to work with individuals with ASD.
      - *See Pilot to improve communication and coordination between medical diagnosticians and early childhood providers (pages 19-21)*
      - *See Improving Health Outcomes for Children in Maine and Vermont (pages 22-23)*
      - *See State Innovation Model (SIM), Developmental Disability Health Initiatives (pages 39-40)*
      - *See Comprehensive Medical Home for Children and Youth with ASD Pilot (pages 41-42)*
      - *See ASD Health Equity (pages 43 -44)*

## ASD Strategic Plan (Cont.)

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- Establish medical homes for children with ASD that collaborate and coordinate with schools.
  - *See State Innovation Model (SIM), Developmental Disability Health Initiatives (pages 39 – 40)*
  - *See Comprehensive Medical Home for Children and Youth with ASD Pilot (pages 41-42)*
- Develop policies, training and technical assistance opportunities to encourage providers of medical/behavioral services for adults to seek out information about ASD.
  - *See State Innovation Model (SIM), Developmental Disability Health Initiatives (pages 39 – 40)*
- Treatment
  - Reduce the waitlist for adult services with the ultimate goal of eliminating the waitlist.
    - *See Office of Aging and Disability Services (pages 45 – 50)*
  - 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.
    - *See Employment (page 51)*
    - *See Developmental Disabilities Council Employment Demonstration Projects (page 51 – 52)*
  - 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.
- Improved Efficiency
  - Streamline intake and eligibility in transitioning from children’s to adult services.
    - *See Multi State Agency Efforts for Seamless Transition (page 36)*
    - *See Education (pages 27 – 31)*
  - Adjust planning process to include targeted, achievable goals to be addressed at home, school, work, and in the community.

## ASD Strategic Plan (Cont.)

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- Improved Efficiency
  - Adjust policies, contracts and rules to ensure that case managers assess the appropriateness of service delivery systems that serve their clients.
    - *See Multi State Agency Efforts for Seamless Transition (page 36)*
  - 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.)
    - *See Coordinated, Comprehensive Data System (pages 19-20)*
- 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.
    - *See Multi State Agency Efforts for Seamless Transition (page 36)*
    - *See Education (pages 27 – 31)*
  - 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.
    - *See Multi State Agency Efforts for Seamless Transition (page 36)*
    - *See Education (pages 27 – 31)*
  - Create policies to support ongoing training and collaboration amongst child and adult service systems.



## ASD Strategic Plan (Cont.)

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- Joint Policy
  - 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.
    - *See State Innovation Model (SIM), Developmental Disability Health Initiatives (pages 39 – 40)*
  - 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.
  - *See ASD Health Equity (pages 43 -44)*
- Develop standards for treatment to be utilized across settings and systems and create a plan on how to implement those standards.
  - *See ASD Health Equity (pages 43 -44)*
- Develop methods and a plan for implementation on how to assess pain in individuals with ASD/DD to be utilized across settings and systems.
  - *See ASD Health Equity (pages 43 -44)*
- 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.

## ASD Strategic Plan (Cont.)

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### Convene Workgroup To:

- 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.
  - *See Office of Aging and Disability Services (pages 45 – 50)*
- Investigate and promulgate rules to pool or braid funding streams to provide coordinated, streamlined services across systems.
  - *See Multi State Agency Efforts for Seamless Transition (page 36)*
- 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.)
  - *See Coordinated, Comprehensive Data System (pages 19-20)*

### Information Training and Technical Assistance

- Provide Training and Technical Assistance to:
  - Support staff and medical assistants within physicians’ offices about ASD.
    - *See State Innovation Model (SIM), Developmental Disability Health Initiatives (pages 39 – 40)*
  - 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.
      - *See Education (pages 27 – 31)*
  - 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
      - *See State Innovation Model (SIM), Developmental Disability Health Initiatives (pages 39 – 40)*

# ASD Strategic Plan (Cont.)

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## Information Training and Technical Assistance

- 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.
    - *See University of Maine Center for Community Inclusion and Disability Studies (page 34-35)*
  - 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.
- 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
    - *See Raising Expectations (page 38)*

## Appendix B

### Acronym Glossary

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<u>Acronym</u>	<u>Definition</u>
AAP: .....	American Academy of Pediatrics
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
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
DSI.....	Developmental Systems Integration Project
DSM: .....	Diagnostic and Statistical Manual
DSP: .....	Direct Support Professional
EBP: .....	Evidence Based Practices
EIM: .....	Early Intervention Model
EPSCoR: .....	Experimental Program to Stimulate Competitive Research
EPSDT: .....	Early Periodic Screening Diagnosis and Treatment
ESDM.....	Early Start Denver Model
FAPE: .....	Free Appropriate Public Education
FY.....	Fiscal Year
FFY .....	Federal Fiscal Year

## Acronym Glossary (cont.)

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<b><u>Acronym</u></b>	<b><u>Definition</u></b>
HH.....	MaineCare Health Homes
HSRI: .....	Human Services 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
I/DD .....	Intellectual/Developmental Disability
IHOC: .....	Improving Health Outcomes for Children
IT .....	Information Technology
LEND: .....	Leadership Education in Neurodevelopment and Related Disabilities
M-CHAT: .....	Modified Checklist for Autism in Toddlers
MAIER.....	Maine Autism Institute of Educators and Research
MDDC: .....	Maine Developmental Disabilities Council
MECDC .....	Maine Center for Disease Control
MECHIP: .....	Maine Child Health Improvement Partnership
MRSA .....	Maine Revised Statutes
MSPS .....	Muskie School of Public Service
NH-LEND .....	New Hampshire Leadership Education in Neurodevelopment and Related Disabilities
O/M .....	Orientation and Mobility Specialist
OADS: .....	Office of Aging and Disability Services
OCFS: .....	Office of Child and Family Services
OMS .....	Office of MaineCare 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
PEDS: .....	Parents Evaluation Developmental Status

## Acronym Glossary (cont.)

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<b><u>Acronym</u></b>	<b><u>Definition</u></b>
QC .....	Maine Quality Counts
SAIEL .....	State Agencies Interdepartmental Early Learning Team
SAMHS .....	Office of Substance Abuse and Mental Health Services
SAU: .....	School Administrative Unit
SIM.....	State Innovation Model
SIS: .....	Supports Intensity Scale
SEA: .....	State Education Agency
SPDG: .....	State Personnel Development Grant
STEM: .....	Science Technology, Engineering and Mathematics
STEPS: .....	Strengthening Together Early Preventative Services
TA: .....	Technical Assistance
TCM: .....	Targeted Case Management
TVI.....	Teachers of the Visually Impaired
UMASS .....	University of Massachusetts
UNH: .....	University of New Hampshire
UV	
M: .....	University of Vermont