Maine Department of Education

Department of Health and Human Services
Maine People Living Safe, Healthy and Productive Lives

Autism Spectrum Disorders Report

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

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

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

May 2017

Coordinated by the Maine Developmental Disabilities Council

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Executive Summary

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 current Maine Autism Strategic Plan, documented in the April 2013 Autism Act report.

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. 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. This has become especially clear as large numbers of youth with ASD transition into adult service system.

Highlights 2015-2017

- The number of individuals with ASD has increased over 1,019% since the turn of the twenty-first century.
- Healthcare project has demonstrated long term systems change in implementing screening for early identification of ASD and other developmental disorders.
- Hundreds of medical practitioners receive training on identifying underlying medical conditions which may present as challenging behavior.
- The Maine Department of Education has partnered with Maine Autism Institute for Education and Research (MAIER) to provide professional development to thousands of educators.
- Maine State agencies increase the focus on the growing number of young people transitioning from children's services to the adult service system.

The rapid increase in the number of individuals with ASD has put pressure on Maine's capacity to serve this population. In 2016, schools served 3280 students identified with ASD, a 59% increase from five years ago and an 86% increase from ten years ago. In 2016, DHHS served 6,312 individuals with a diagnosis of ASD through Maine Care, a 29% increase from five years ago and an 87% increase from ten years ago. Some DHHS services were particularly impacted: of children receiving Section 28 services, twice as many were identified with ASD in 2016 than in 2014; in 2016, 61% of individuals received services through Section 21 were diagnosed with an ASD.

From 2014-2017, the State of Maine continued to focus on improving services that impact the lives of individuals with ASD. Highlights include:

Executive Summary (Cont)

Department of Health and Human Services: Has utilized its State Innovation Model (SIM) Grant to address the healthcare needs of persons with developmental disabilities by seeking to achieve the "Triple Aim: goals of 1. improving the health of Maine's population, 2. improving the experience Maine patients have with their care, and 3. reducing the total costs of care. Successes include:

- Developmental and autism screening rates have more than doubled in all age groups.
- Supporting the Developmental Disabilities Health Project to increase the knowledge and ability of caregivers, medical practitioners, and physicians to coordinate and provide appropriate healthcare for individuals with intellectual and developmental disabilities (I/DD) by training hundreds of medical practitioners and direct service professionals to identify and address underlying medical conditions. Evaluation of the data has demonstrated that 76% of participants have changed at least one thing about the way they provide healthcare to individuals with I/DD.

Department of Education: Established the Maine Autism Institute for Education and Research (MAIER), which has:

- Provided professional development regarding implementation of evidence-based practice to over 2000 educators.
- Developed and distributed the "Road Map to Services", a guide for Maine families, and of Early Start Maine.
- Undertaken the Early Start Maine initiative, which is comprised of nationally certified Early Start Denver Model (ESDM) providers and delivers training, consultation, and ongoing support to early intervention providers statewide who are working with toddlers with autism.

Department of Labor: To meet the rising needs of youth with ASD, Department of Labor, Vocational Rehabilitation has partnered with University of Maine, Center for Community Inclusion and Disability Studies, and Maine Developmental Disabilities Council to pilot a program to provide work opportunities for youth, many of whom have ASD. This pilot has run for two years and is showing promising results.

In accordance with the Autism Act of 1984, 34-B M.R.S.A. §6001-6004, the following report describes the current status of services for individuals with ASD, the state's efforts to address its strategic plan since April 2014, and initiatives underway to improve and expand systems' quality, capacity, and efficiency.

Definition of Autism

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[1]. 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.[2] 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 total absence of 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."[3] 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 2013, autism or *Autistic Disorder* was included under the broader category of *Pervasive Developmental Disorders* (PDD)[4]. In addition, 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*.

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[5] that eliminated the PDD category while collapsing *Autistic Disorder*, *PDD-NOS*, and *Asperger's* into a new single *Autism Spectrum Disorders* diagnostic category. However, *Childhood Disintegrative Disorder* and *Rett's Disorder* were not included as ASDs. The new DSM-V identified two persistent deficits that need to be present for an ASD diagnosis: A. "social communication and social interaction across multiple contexts;" and B. "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

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[1] Autism Society of America. (2013). About autism. Retrieved April 30, 2017 at http://www.autism-society.org/about-autism/

[2] Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250.

[3] Asperger, H. (1944, 1991). *Autistic psychopathy in childhood* (U. Frith, Trans.). Cambridge, UK: Cambridge University Press.

[4] American Psychiatric Association. (1994). *DSM-IV: diagnostic and statistical manual of mental disorders*. Arlington, VA: American Psychiatric Association.

[5] American Psychiatric Association. (2013). *The Diagnostic and Statistical Manual of Mental Disorders: DSM 5*. Arlington, VA: American Psychiatric Association.

Definition of Autism (cont.)

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 [6] but that many experience loneliness and isolation.[7]

Unlike the previous version, the DSM-V 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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[6] Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447.

[7] 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

Definition of Autism (cont.)

DSM-V Diagnostic Criteria for ASD[8]

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 stereotypes, 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.[9]

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[8] DSM-V provides more detailed description of criteria including examples and recommendations regarding indicating the severity of symptoms.

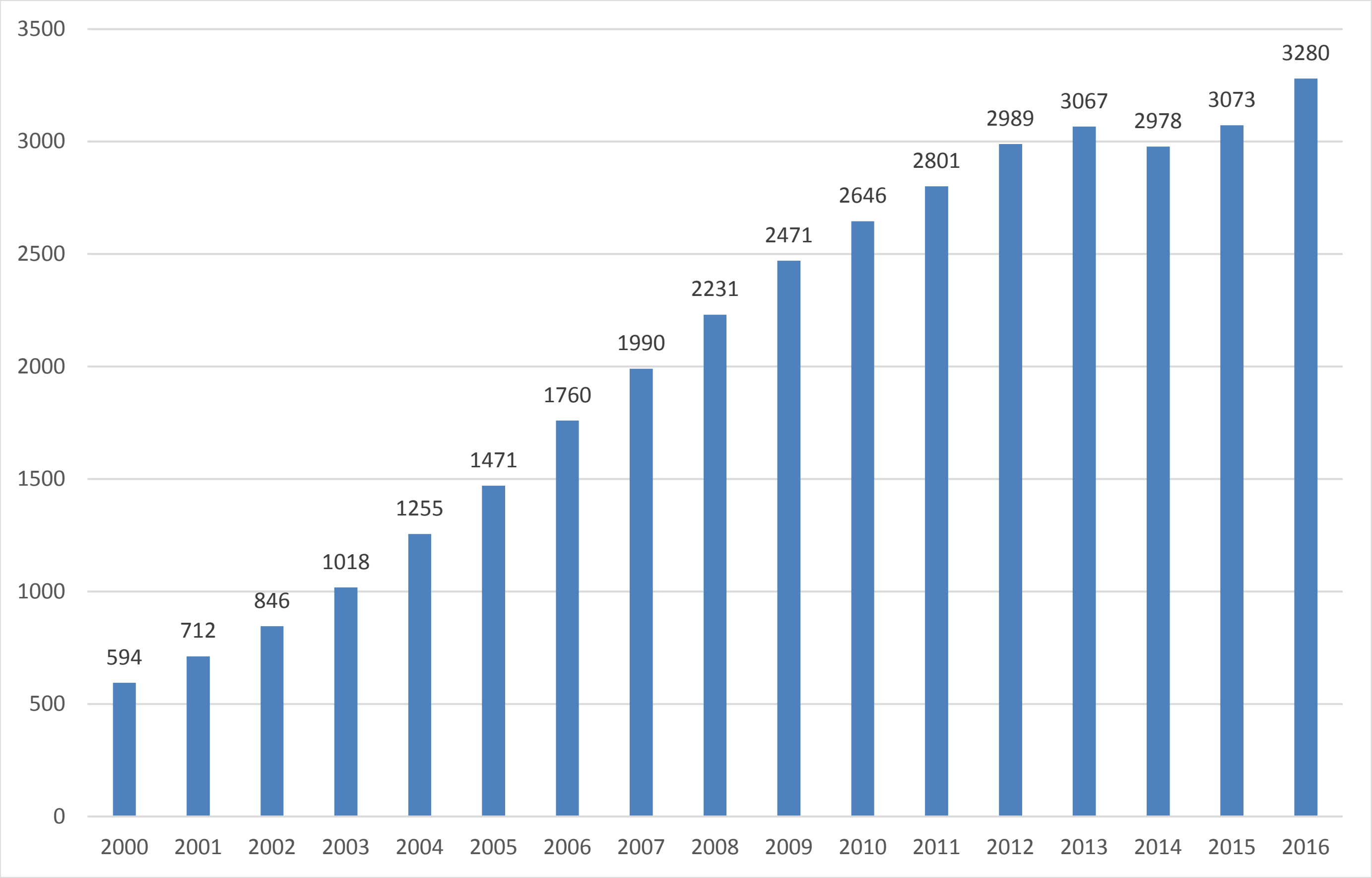
[9] Centers for Disease Control https://www.cdc.gov/ncbddd/autism/data.html accessed 4/30/2017

State of the State

In 1984, there were fewer than 40 individuals identified as having autism in Maine. To provide services to them, the 111th Legislature passed the Autism Act of 1984.

Increasing numbers of students with ASD

At the turn of the 21st 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 increased over 500% until an apparent leveling out from 2013 to 2015. 2016 Child Count data collected by schools reported 3,280 students being served, a 7% increase from the previous year. It is unclear if this increase is the beginning of another upward trend or an isolated incident where the numbers will level out again next year.



In 2000, MaineCare paid claims for 643[10] members with an ASD. In 2016, that number had jumped to 6,312. **The increase is over 882% since the turn of the twenty-first century.[11]** The rate of growth appears to be slowing however. The increase over the last decade is 87%, with an average increase of approximately 14% annually.

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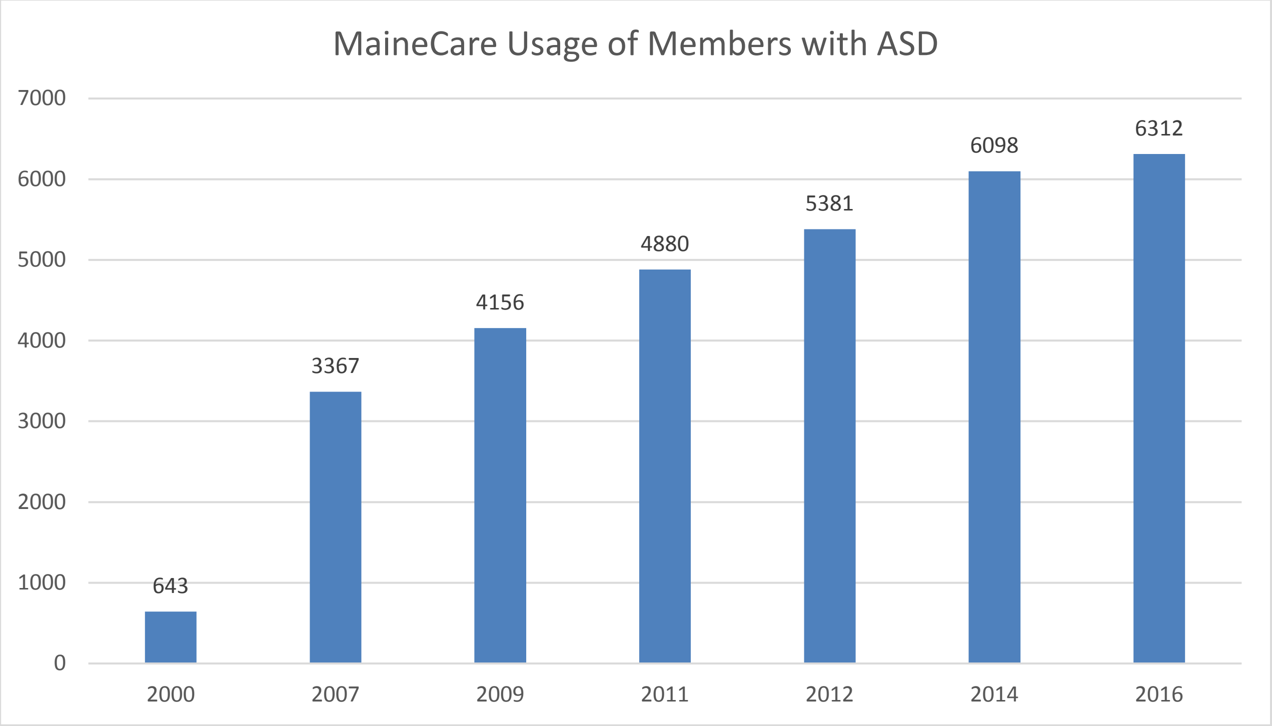
[10] DHHS (2007) Autism Act of 1984 2007 http://www maine.gov/dhhs/2007_autism_report.pdf Accessed 4/30/2017

[11] MaineCare is an income-dependent service.

State of the State (cont.)



At a national level, the increase in ASD appears to be slowing down. The U.S. Centers for Disease Control (CDC) has continued reporting prevalence numbers steady at 1:68[12] since 2014. The CDC, however, continues to focus on the public health epidemic of ASD. One reason for this is the significant economic impact. Recent research documents that:

- The total costs per year for children with ASD in the United States were estimated to be between $11.5 billion - $60.9 billion due to a range of direct and in-direct costs, from medical care to special education to lost parental productivity.[13]
- On average, medical expenditures for children and adolescents with ASD were 4.1–6.2 times greater than for those without ASD.[14]
- In addition to medical costs, intensive behavioral interventions for children with ASD cost $40,000 to $60,000 per child per year.[15]

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[12] Centers for Disease Control https://www.cdc.gov/ncbddd/autism/data.html accessed 4/30/2017

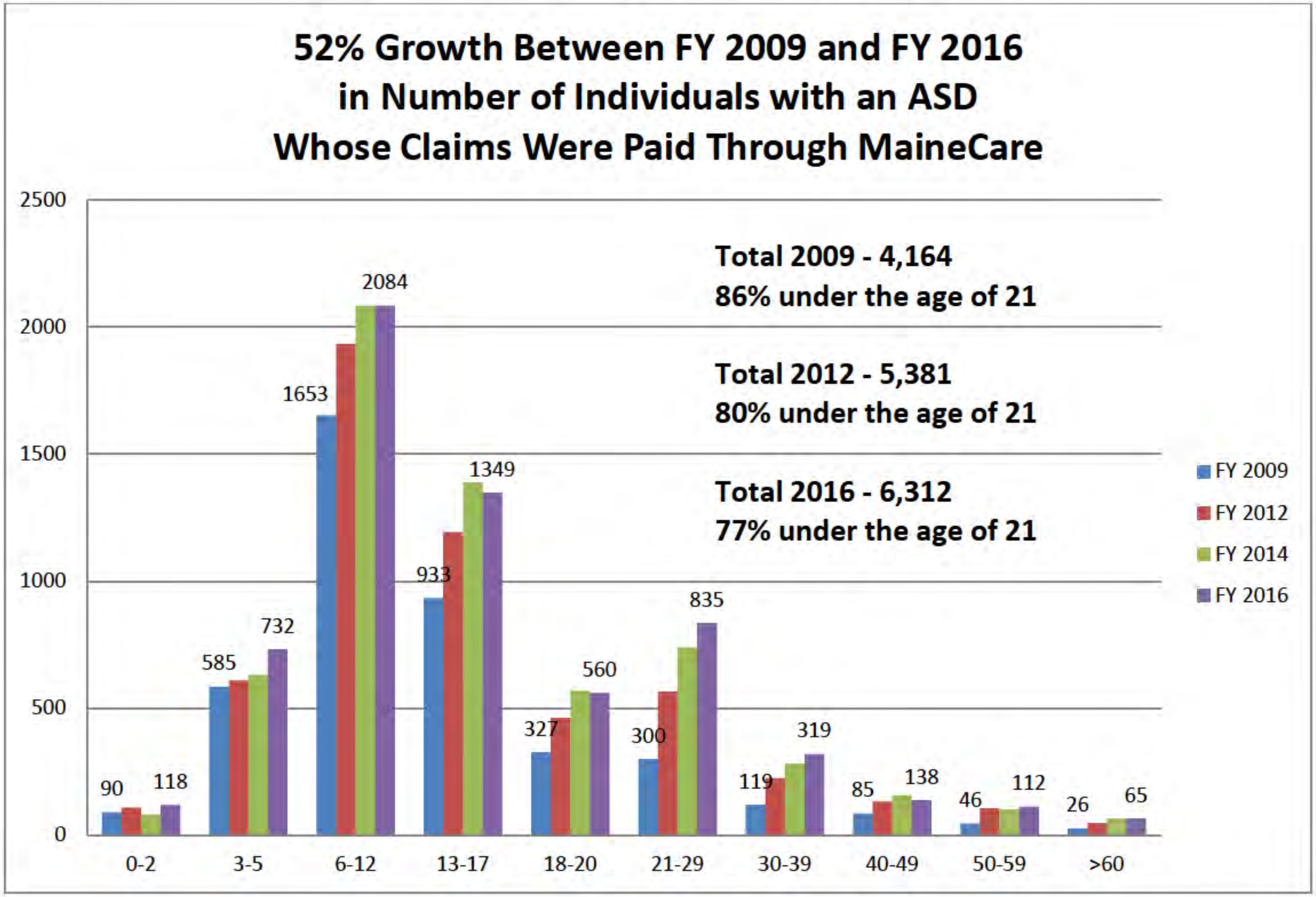
[13] Lavelle, TA et al (2014) The Economic Burden of Childhood Autism Spectrum Disorders *Pediatrics* 2014 Mar;133(3):e520-9. doi: 10.1542/peds.2013-0763. Epub 2014 Feb 10

[14] Shimabukuru TT et al (2008) Medical expenditures for children with an ASD in a privately insured population *J Autism Dev Disorder* 2008 Mar;38(3):546-52. Epub 2007 Aug 10.

[15] CDC http://www.cdc.gov/ncbddd/autism/data html#references accessed 4/30/2017

State of the State (cont.)

Seven years ago, 86% of the individuals with ASD who received MaineCare were under the age of 21. Today, that number is 77%. 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.)

According to MaineCare claims data, there has been a stablizing trend in the number of individuals with an ASD in most age groups. Exceptions include age 0-2, which has demonstrated a notable increase, and age 3-5, which has demonstrated a less pronounced increase.

These numbers are somewhat lower than other Maine data that demonstrate an even higher rate of early identification. This disparity could represent a genuine delay in identification. It could also indicate that children of this age are not yet accessing MaineCare and are receiving services through other payers such as private insurace or through the education system, which would delay 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 documented that the fastest growing age group had changed from 18-20 year old youth to 21-26 year old young adults. The current 2016 Autism data shows a steady increase of individuals with ASD reaching young adulthood. This increase further indicates that the crest of the epidemic of autism has reached young adults.

Age	2007	2009	2012	2014	2016	2 yr % Increase	4 yr % Increase	7 yr % Increase	9 yr % Increase
0-2	91	90	108	82	118	44%	9%	31%	30%
3-5	470	585	609	631	732	16%	20%	25%	56%
6-12	1,304	1,653	1,934	2,083	2,084	0%	8%	26%	60%
13-17	774	933	1,193	1,389	1,349	-3%	13%	45%	74%
18-20	239	327	462	569	560	-2%	21%	71%	134%
21-26	184	240	429	576	644	12%	50%	168%	250%
27-64	296	324	620	732	790	8%	27%	144%	167%
65+	9	12	26	36	35	-3%	35%	192%	289%
Total	**3,367**	**4,164**	**5,381**	**6,098**	**6,312**	**4%**	**17%**	**52%**	**87%**

Eligibility vs. Entitlement through the Lifespan

Persons with ASD can benefit from a variety of services to ameliorate the impact of disability. Their ability to access those services is impacted by factors including payment source, provider type and availability. Each discrete service, across the lifespan, requires recipients to meet unique eligibility standards.

Once children meet eligibility criteria, they have the legal right to obtain an array of medically and educationally necessary services that the system is obligated to provide. Practically speaking, this means that children and families are generally able to access any needed supports for which they are eligible and that services provided to children are separate from those provided to adults.

Upon reaching adulthood and exiting school, the system no longer has a broad obligation to provide a comprehensive array of services. Adults must establish eligibility for each needed service. This transition is often not anticipated or well understood by persons with ASD and their families. Adults are often able to receive healthcare based upon categoric eligibility for Medicaid. Those who meet eligibility criteria are able to receive case management and vocational rehabilitation services. Adults may be eligible for and in need of additional services, but access to these services is not a right and is generally limited by funding constraints.

Entitlement to Services for Children

Medical Services

MaineCare is required to provide preventive care, screening and "medically necessary" treatment for all MaineCare eligible children pursuant to federal Early Periodic Screening Diagnosis and Treatment (EPSDT) requirements under Medicaid. In order to be covered under EPSDT, the treatment must be a currently allowable MaineCare benefit or a benefit that is not currently covered but is "coverable" according to federal law. 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.

In the fall of 2016, MaineCare published a MaineCare School Based billing Guide. This Guide describes the MaineCare benefits covered in a school based setting and provides instructions and rules related to reimbursement. The Guide can be found online at http://www.maine.gov/dhhs/oms/provider/school.html. This Guide is a "living document" and will be updated regularly. MaineCare continues to work with staff from the Department of Education (DOE), Child Development Services (CDS), and outside entities to improve the delivery of school based services to MaineCare members.

Early Intervention Services (Part C)

A Maine child is eligible for Early Intervention services if they demonstrate a -2.0 standard deviation delay in one developmental domain or a -1.5 standard deviation delay in two developmental domains or has a diagnosed medical or physical condition that has a high probability of resulting in a developmental delay.

Part B (ages 3-20) Eligibility Criteria

A child is entitled to special education services if (1) s/he has a disability that (2) has an adverse impact and (3) which requires special education services. The federal Individuals with Disabilities Education Act

(IDEA) specifies that every child who receives special education services is entitled to a Free Appropriate Public Education (FAPE) that is individually designed to meet the child's educational needs.

Office of Child and Family Services (OCFS)

Children and youth under the age of twenty-one must meet the eligibility requirements of the relevant behavioral health service to obtain that service; for example, they 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 Rehabilitative and Community Services (section 28). If resources are available, families whose children are not MaineCare eligible can receive Individual Planning Fund services and Respite Services.

Insurance Mandate

The 124th 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 126th 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 of 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.

Eligibility for Adult Services

The 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 Pervasive Developmental Disorders, as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, published by the American Psychiatric Association and as may be updated by rule adopted by the department in response to updates or changes in the Diagnostic and Statistical Manual of Mental Disorders; and

B. Has been assessed as having an adaptive behavior score at a level of functional impairment as determined by the department.

Assessment tools are used by OADS to determine a person's adaptive behavior score include the 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 tools as approved by OADS.

Each service has highly specific definitions and eligibility criteria.

Eligibility vs. Entitlement through the Lifespan (Cont.)

MaineCare Section 50, Intermediate Care Facility (ICF) for Individuals with Intellectual Disabilities (ICF/IID.) 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. An ICF/IID 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. Maine operates two types of ICF/IIDs: Nursing Facility and Group Home Facility. These residential treatment facilities are considered "institutional" settings by the Federal government and were designed to meet the intensive, active treatment needs of persons with intellectual disabilities.

Case management (Section 13) is available to adults who meet medical eligibility criteria for institutional care under MaineCare Section 50, Intermediate Care Facility (ICF) for Individuals with Intellectual Disabilities (ICF/IID.)

Individuals who meet eligibility requirements and standards for admission to an ICF/IID under MaineCare Section 50 may waive their right to institutional care and apply for waiver services. Some individuals receive services under the Comprehensive Home and Community Based Waiver (Section 21) while others receive services under the Community Supports Waiver (Section 29), dependent upon individual needs and availability of funding. Section 21 and Section 29 define “autism” 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.

Waiting lists currently exist for Section 21. Priority 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 applying for MaineCare Section 29 services are served chronologically based on the date the waiver manager determines eligibility for the waiver.

Early Identification and Intervention

Maine Autism Institute for Education and Research

One effort to build capacity of highly trained professionals implementing evidence-based practice to work with students with autism was the inception of the Maine Autism Institute for Education and Research (MAIER). The Maine Department of Education used federal IDEA funds for the establishment of the MAIER which launched in January 2014 as a partnership between the Maine Department of Education-Office of Special Services and the University of Maine College of Education and Human Development. MAIER was created to build statewide capacity to improve outcomes for individuals with autism spectrum disorder through leadership, training, professional development, collaboration, and research. MAIER offers advanced course work in autism spectrum disorders through the University of Maine.

Since inception, MAIER has provided evidence-based professional development opportunities attended by approximately 2100 general educators, special educators, and related service providers who support thousands of students across Maine, including students diagnosed with an autism spectrum disorder. MAIER professional development also includes the Maine Autism Leader Team trainings and supporting coaching efforts as previously mentioned.

MAIER's Maine Family Partnership (MFP) is dedicated to providing outreach to individuals and families affected by autism spectrum disorders across the state of Maine. Together, MAIER staff and families work to identity issues of concern for Maine families and collaborate on projects to promote greater awareness and acceptance; develop tools and resources; address access to services; and support research efforts. Alongside community partners such as the Maine Discovery Museum, York Wild Kingdom, and Kiddos in Lewiston, MFP provides free opportunities for children and families to connect by offering 2-3 free educational and social events each year. Individuals with autism, parents and family members, and caregivers are welcome to join MFP.

MAIER's *Maine Parent Guide to Autism Spectrum Disorders* is available online and in print. This parent-friendly guide, a "roadmap" of sorts, was developed to assist families as they navigate the autism journey. In three booklets, the *Parent Guide* leads families from the initial question of "Does my child have autism?" to steps for obtaining needed assessments, connecting with educational and social services, and finding resources based on their needs. It includes an in-depth description of early childhood and special education services in Maine, a guide for transitioning from high school to adult services, and a Resource Guide that includes contact information for many services and supports across the state. The *Maine Parent Guide to Autism Spectrum Disorders* is enriched with personal stories, reflections, and suggestions from Maine parents, lending a personal touch that reflects their experiences and knowledge gained from their own journeys. Family photos capture the joys and challenges of raising a child with ASD. Copies of the *Maine Parent Guide to Autism Spectrum Disorders* can be downloaded from the MAIER website or by contacting MAIER for a print copy (207.581.2352) or by e-mail (maineautisminstitute@maine.edu).

Early Identification and Intervention (cont.)

Early Start Maine

In partnership with Maine DOE and Child Development Services, MAIER works to build sustainability for the training and professional development of primary service providers to improve Maine's ability to deliver necessary and highly effective services to young children with autism spectrum disorders through the ***Early Start Maine*** initiative. The Early Start Maine team is comprised of nationally certified Early Start Denver Model interventionists. The Early Start Maine team provides training and supervision to Maine's early intervention providers to improve Maine's ability to deliver necessary and highly effective early intervention to young children, birth to age 3, with autism spectrum disorders.

Developed by psychologists Geraldine Dawson, Ph.D. and Sally Rogers, Ph.D., the Early Start Denver Model (ESDM) is an evidence-based early intervention treatment package designed to promote language, learning, and engagement for young children 12-48 months of age with autism spectrum disorder (ASD). ESDM is supported by the principles of developmental psychology and applied behavior analysis (ABA). Teaching interventions are delivered within play-based, relationship-focused routines. The ESDM curriculum is designed to address all areas of the child's development using ABA based teaching strategies that involve interpersonal exchange and positive affect, shared engagement with real-life materials and activities, adult responsiveness and increasing parent sensitivity to child cues, and focus on developing the child's verbal and nonverbal communication skills.

ESDM aims to reduce the symptoms of autism and target all developmental areas. Monies spent on early intervention will result in improved outcomes for children and dollars saved on special education services. MAIER has on staff five ESDM certified providers who oversee the training and supervision for 30 primary service providers working with young children in the home environment. In addition, the team completes the assessment and program planning for all children who participate in the Early Start Maine initiative.

ESDM has served a total of 73 families.

When families exit the program (to transition to Part B services), they are invited to complete an outcome survey. Most (89%) do. 100% of respondents indicated agreement and strong agreement with the progress and developmental growth of their child when participating in ESDM intervention. Below are open-ended responses from the family surveys. Contact MAIER for more information.

Imported from the electronic survey:

> *This is a wonderful model and was very beneficial to our daughter's growth and development. It's almost scary to think about where she would be today if she hadn't been fortunate enough to receive these services. It truly made a difference. I wish nothing but success for this program and all the future kids you will be helping.*
>
> *I wish there was more connection and communication between CDS and the school systems for when children leave the ESDM model to go to schooling programs. We were always being told new additions to information once both sides heard one anothers.*
>
> *My son had many issues with social interaction and with language. In the year I was in the program he made a lot of positive progress now playtime is very enjoyable and he goes to preschool where he has made new friends.*
>
> *We couldn't be more thankful. Our son has learned so much and we can see just how PROUD he is of himself with these newly acquired skills. We'd love him no matter what, but there's a new joy in his eyes that makes our hearts melt.*
>
> *This helped open up my child in so many areas that weren't open to him before and they helped us learn and modify thing to help him learn. This is a wonderful program and I'm happy with the results we got from this.*

Data sources to determine child progress and developmental growth are used including entrance and exit forms of the Measure of Engagement, Independence, and Social Relationships (MEISR) tool used by CDS, the ESDM curriculum assessment, the Child Outcomes Survey, the Autism Impact Measure, and parent report. Preliminary efficacy data indicate that children receiving ESDM showed significant improvements in child outcomes and autism diagnosis, as compared to children receiving the community intervention. Of the 27 children who have exited ESDM services, three were not eligible for Part B services because of significant improvement in behavior and outcomes. Preliminary results indicate the importance of early detection of and intervention in autism.

Office of Child and Family Services (OCFS)

Early Childhood Services focus on increasing access to and quality of child care services, supporting Head Start programs, coordination of child care licensing, technical assistance, training, and employer incentives. The Associate Director of the Policy & Prevention Team is responsible for the oversight, integration, and coordination of Early Childhood Services to support Maine's Families.

Early Identification and Intervention (cont.)

Child Developmental Services (CDS)

Child Developmental Services (CDS) Early Intervention conducts comprehensive developmental evaluations and completes hearing and vision screenings for all children as part of those evaluations. The M-CHAT (Modified Checklist for Autism in Toddlers) is completed with children who fall within the appropriate age range (16 – 30 months) at intake and as part of the annual Individual Family Service Plan (IFSP) review, as well as at the discretion of the early intervention team over the course of services. Those children for whom the M-CHAT indicates "refer" are, with parental consent, referred for a diagnostic evaluation. Referrals for a diagnostic evaluation may also be made in the absence of an M-CHAT "refer" result if the early intervention team identifies concerns.

CDS Early Intervention utilizes Routines-Based Early Intervention (RBEI)(McWilliam, 2010) to provide services to eligible infants, toddlers, and their families. This approach focuses on improving the engagement, independence, and social relationships of infants and toddlers in daily routines and activities by building caregiver capacity to meet their child's needs. For those children who receive an ASD diagnosis, CDS also offers the Early Start Denver Model (ESDM), an intensive, evidence-based Applied Behavioral Analysis (ABA) intervention provided in the child's natural environment, and supplements that intervention with RBEI. In order to address situations in which ESDM is determined to be inappropriate (i.e. due to lack of parent availability or interest), CDS has also developed modules which support the integration of ABA strategies into RBEI services.

IHOC: First STEPS and the Maine Child Health Improvement Partnership

Maine Quality Counts (QC), on behalf of Improving Health Outcomes for Children (IHOC) and other MaineCare Services initiatives, designed and implemented the First STEPS (Strengthening Together Early Preventive Services) Learning Initiative between 2011 and 2015. First STEPS was funded from February of 2010 to February 2015, by a Federal CHIPRA (Children's Health Insurance Program Reauthorization Act) Quality Demonstration Grant from the Centers for Medicare and Medicaid Services (CMS). Its goal was to improve the quality of care for children who are insured by Medicaid and CHIP (Children's Health Insurance Program) and was known as Improving Health Outcomes for Children (IHOC) in Maine and Vermont. First STEPS was 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 focused on improving developmental, autism, and lead screening. Twelve practices from throughout the state participated in the project which took place over eight months from May 2012 to December 2012. First STEPS included two day-long learning sessions (in May 2012 and September 2012); monthly coaching calls; visits by a practice coach; and monthly data collection. First STEPS 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.

The First STEPS Learning Initiative was evaluated by the University of Southern Maine, Muskie School of Public Service. This report, based on chart review data, 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."** [16] The Statewide rate of developmental screening has increased from 1-3% in 2011 to 12-17% in 2013 by ages 1, 2, and 3. Since the completion of First STEPS, Maine Quality Counts 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 Initiative (DSI).

Developmental Systems Integration Initiative

Beginning in 2013, Maine Quality Counts for Kids (QC) started to partner with the State Agency Interdepartmental Early Learning and Development Team (SAIEL), the interdepartmental sub-agency established by the Maine Department of Education and the Maine Department of Health and Human Services commissioners. QC was a natural partner in this effort because of their leadership role for the IHOC First STEPS[17] work with practices in 2012 and 2014, focused on increasing developmental and autism screening in the primary care practices through a federal CHIPRA[18] grant. QC is 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.

The original goal of the DSI initiative 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. The 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

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[16] Muskie School (August 2013) IHOC First Steeps Phase II Initiative: Improving Developmental, Autism, and Lead Screening for Children, Final Evaluation Report, page 2

[17] IHOC First STEPS=Improving Health Outcomes for Children First Strengthening Together Early Preventative Services

[18] CHIPRA=Children's Health Insurance Program Reauthorization Act Grant

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. Table 1 reflects that MaineCare Developmental Screening Rates over time.

Table 1. Developmental Screening Rates based on MaineCare Claims Data

Age	FFY 2011	FFY 2012	FFY 2013	FFY 2014	FFY 2015	FY 2016 GOAL
Age 1	1.7%	3.3%	12.50%	18.5%	23.79%	21.7% (+20%)
Age 2	2.5%	5.8%	17.11%	25.6%	28.38%	22.5% (+20%)
Age 3	1.1%	1.6%	11.93%	19.0%	20.79%	21.1% (+20%)

DSI successes in improving health care quality for children ages birth to three include: convening monthly DSI-SAIEL steering committee meetings and hosting three (3) day-long DSI Stakeholder meetings in Nov. 2014, Jan. 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.

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 2016, the Survey of Well Being of Young Children (SWYC) was added as an additional screening tool. It is an option for practices because it is available at no-cost and includes some components of screening for social-emotional issues.

DSI worked to improving Patient Experience of Care by Engaging Providers in Coordination Efforts to Increase Linkages and Referrals. DSI created 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. In addition, DSI worked to identify and distribute materials on developmental screening to families through different partners. DSI tested 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) and the "Learn the Signs, Act Early" (www.cdc.gov/ncbddd/actearly/downloads.html) campaign. In 2016, with the State Innovation Model (SIM) Project, QC distributed materials to 550 primary care practices on why developmental screening is important, using materials from "Learn the Signs. Act Early" and DSI partner brochures. Materials were also distributed to over 10 partner organizations on the DSI Steering Committee.

In addition, DSI is working to improve efforts to reduce health care costs through enhancing systems. The DSI-SAIEL team worked with 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 2015-16, DSI investigated the National Help Me Grow model which promotes developmental screening, early intervention, and care coordination for children's ages 0 to 8 years to see if this model would help improve screening rates and facilitate coordination of services among existing groups. Maine became a Help ME Grow (HMG) Affiliate state after the September 2015 technical assistance site visit in order to gain access to national resources during the planning phase. In the spring of 2016, four sub-groups were convened to explore with approximately 10 participants each: Child Health Care Provider Outreach, Community & Family Engagement, Centralized Access Point and Data Collection and Analysis. Sixteen meetings were held with over 320 hours of time from participants. The final report around HMG exploration was completed in August of 2016 with 15 key points for consideration of HMG state implementation as part of the DSI work.

Next Steps: The DSI team is committed to using the lessons learned from the DSI teams to plan for systems of change that incorporate plans for improvement in developmental systems integration. Work will continue on improving developmental screening rates (with the target of increasing rates by 24% by September 2017) and sustaining leadership provided by the DSI Steering Committee. Other specific, targeted strategies in FY2017 will include:

- Continue to explore Help Me Grow model with a focus on centralized access and resource specialist training.
- Continue to support cross-disciplinary developmental screening pilot in Cumberland County.
- Distribute developmental screening materials more broadly to child care providers and Early Head Start/Head Start.
- Evaluate messaging to families for cultural and linguistic competence.
- Continue to examine statewide data on rates of developmental screening, information sharing, and closing the feedback loop once referrals are made.
- Continue to work with organizations on collection of data especially with new data systems and staff to get more accurate, timely information.
- A statewide webinar series on child health for child health providers that will have focused sessions on developmental screening.

Maine Developmental Disabilities Council (MDDC)

Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970 to "engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose of the DD Act; and contribute to a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system of community services, individualized supports and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive and be integrated and included in all facets of community life."

Maine Developmental Disabilities Council (MDDC) is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self-determination, and independence, and acts to effect positive change. MDDC has a vision that all people are included, supported, and valued in communities that provide opportunities to participate and succeed as they choose. MDDC acts to effect positive change through advocacy, capacity building, training, demonstration projects, and support for other inclusive and collaborative systems change activities.

Medical Home Pilot

Over the last five years, MDDC began an enhanced care coordination pilot at Eastern Maine Medical Center (EMMC) Pediatrics (formerly Husson Pediatrics). The EMMC Pediatrics Project has demonstrated the capacity to adapt and strengthen patient-centered medical home models to fit the population of children with ASD/DD. The project has documented significant positive outcomes for children and families including, but not limited to, expedited implementation of services, prevention of less than recommended services, prevention of duplication of services, prevention of emergency room care, decreased timelines, discrepancies reconciled, access to insurance, and improved planning. The project has also documented significant benefits to health care professionals. Evaluation of the project noted that “physicians report that they find great value in the care coordinator reviewing incoming documents,” developing summaries and being able to spend the time to assist families in the coordination of care[19]. Positive outcomes include a better understanding of service reports, decreased workloads, more time to spend with children, and assistance in providing a higher quality of care to patients with ASD/DD.

In addition to medical providers and families, an unexpected group has benefited from the EMMC Pediatrics Project, specifically Targeted Case Managers. As the American Academy of Pediatrics brief on Patient- and Family-Centered Care Coordination reports, “Case Managers work with and guide services intrinsic to their specific agency, often within the constraints of eligibility criteria. In contrast, care coordinators work with and guide the team process, which includes and is driven by the needs of patients

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[19] Cronin, N (2014) *Autism Implementation Grant Final Report* Accessed on 5/3/2016 at http://www.maineddc.org/uploads/Autism%20Implementation%20Grant%20Final%20Close%20Out%20Report.pdf

and families for services across the community."[20] Many Case Managers have contacted the EMMC Pediatrics Care Coordinator to obtain assistance coordinating care across the social, medical, and educational service systems.

In FY17, MDDC has allocated funding to EMMC for a cost/benefit analysis to measure the benefit gained to hospitals for providing the service. MDDC hopes that this research will yield a pathway to sustain the project and provide incentive to other health practices to adopt the evidence informed technique.

Learn the Signs, Act Early

The Center for Disease Control (CDC)'s "Learn the Signs. Act Early." program's goal is to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need as early as possible.[21] Maine has been selected to be one of the States that will receive a stipend and have a locally trained Act Early Ambassador to promote "Learn the Signs. Act Early." messages, provide free tools to track milestones, provide training to PCPs, and enhance State efforts to improve screening and referral to early intervention services. Nancy Cronin, Executive Director of MDDC and long-term lead of the ASD Systems Change Initiative, has been appointed as Maine's Act Early Ambassador and can be reached at nancy.e.cronin@maine.gov.

Augmenting Early Intervention

In FY16, MDDC contracted with the University of Maine at Orono to utilize a team of undergraduate and post-graduate students to develop an informational booklet on domains of early childhood development. The booklet will include, at minimum, sections on each of the following:

- Background information/developmental milestones per domain.
- Information for parents on what they can do to assist their child(ren) when they identify a delay within the domain.
- Systemic information regarding resources, eligibility, and procedures.
- Frequently Asked Questions

It is the hope that this booklet will provide families of young children a roadmap to access needed services and supports their children may need.

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[20] American Academy of Pediatrics (2014) Policy Statement *Patient- and Family-Cenetered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems*. Pediatrics 2014;133;e1451; originally published online April 28, 2014; DOI: 10.1542/peds.2014-0318

[21] 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

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

According to the 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.

The 2014 MCH Assessment Report documented that parents of Maine CYSHN with functional limitations were more likely than others to report challenges in accessing services.
Only 39.8% reported that services were organized in ways that they could use vs. 58.1% for parents of children accessing other services. This data confirms a study done in 2009[22] documenting the challenges families experience in accessing services for CYSHN through multiple departments, agencies, and programs.

Prescription usage is common and at a high rate for individuals with DD of all ages. The Office of MaineCare (Medicaid) produces an Annual Survey of Children Served by MaineCare in order to monitor the quality of services to determine if any subpopulations have any unmet needs (December 2013). This survey showed that prescription medication use is the most frequent medical response to behavioral health concerns (24%), followed by use of medical services (20%), and treatment and/or counseling services (20%).

CYSHN has clearly documented the need for improved care coordination and is identified in the 2015 Title V Five-year Needs Assessment which emphasized the need to concentrate efforts on improving health homes for children and youth with special healthcare needs in Maine.

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[22] Golnik, A., et al (2009) Medical Homes for Children with Autism: A Physician Survey *Pediatrics*, 123(3), 966-971

Children with ASD (cont.)

Education

In 2011, Maine received a federal State Personnel Development Grant (SPDG). The Department of Education (MaineDOE) is now finishing the fifth year of its work to build state capacity through partnerships between the state education agency (SEA) and school administrative units (SAU).

The first year of Maine's 2011 SPDG work focused on the design and development of a statewide professional development model that became the framework for all SPDG funded professional development and technical assistance in alignment with the SEA's restructuring of its general supervision activities and technical assistance teams. This common approach allows for equitable SAU accessibility of resources and all SPDG professional development activities, while providing for the unique and specific needs of an SAU, and the pooling/sharing of State, regional, and local resources.

Autism Initiative

The Maine Department of Education and the University of Maine College of Education and Human Development partnered to provide extensive training to school-based Autism Leader Team. Approximately 400 professionals comprising 42 statewide Maine Autism Leader Teams (MALT) have been trained to implement evidence-based practices to support individuals with autism spectrum disorder. These teams are comprised of 10-12 administrators, general educators, special educators, and related service providers and include early intervention teams, school-based teams, district-wide teams, and one team representing Maine's educational services for deaf and hard of hearing individuals.

> *My "ah-ha" moment from the first day of MALT training was when we had to assess our school districts progress on the indicators. We found that we are doing a lot of things well, but have some definite areas of improvement. It was a great place to start in order to build our action plan for our school district.*

> *The combination of the 6 days of training with follow-up in between with a coach has resulted in our MALT team moving forward with accomplishing goals we had identified at the beginning of the year. I feel the integration of people across grade levels and professions is an effective model for this type of training.*

Each Autism Leader Team participated in six days of training designed to build statewide capacity of professionals to implement evidence-based practices to lead to long term and sustainable improvement in both teaching practice and student outcomes. Leader teams 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. Plans included recruitment activities, professional development plans, materials, an implementation timeline, and means of providing assistance for training new team members about their roles. Parents are contributing members of the Leader teams as community liaisons. The training 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.

Maine Autism Leader Teams demonstrate success in many ways. For example, many teams have implemented the use of district-wide visual supports, a tool that benefits all students. Teams self-report improved student outcomes and a solid understanding of data collection and data use. Other teams report an increase in autism awareness and acceptance by staff, students, families, and community. Teams share resources through websites and district webpages. Teams have conducted needs assessment surveys, which are used to plan staff training and presentations. Additional successes included a focus on generalization goals for students with ASD, increased support for paraprofessionals to be trained in evidence based practices (EBPs), use of video-modeling to support student learning, and increased district-wide consistency and continuity for students with ASD across programs, settings, and grades.

> *I am very grateful to have had the opportunity to participate in the training this year. It has been so useful to take the learning back to staff. We have created a web page and have appreciated the guidance to make that a reality. We will be using the modules to train staff, as well as information shared by teachers who attended the training and have been implementing it in their classrooms. I want to set a school wide expectation for peer training across grades, as we have seen incredible results in one of our Kindergarten classes with it.*

As a sustainability strategy, Maine Autism Leader Teams are provided professional development based on "high need." In 2015-2016, 15 Leader teams participated in six days of training designed to provide special and general educators with evidence-based practice in literacy instruction, supporting classroom staff, and promoting positive behavior for students with ASD. Teams also participated in projects designed to increase their literacy expertise and implementation of practices learned. Ten teams continued on with Level 2 literacy training with an additional two days of training and ongoing coaching through 2016-2017.

225 education technicians were provided professional development in "*Working with Students with Challenging Behaviors*" with a specific emphasis on evidence-based interventions to develop pro-social and adaptive skills, including behavior intervention plans, educational and behavioral accommodations for children with ASD.

Legislative Action

The 125th 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. Section 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 are appropriately prepared. The Department of Education is in the process of revising

Chapter 115. Proposed revisions involve a requirement of specific core competencies for all special education teachers.

Office of Child and Family Services (OCFS)

Family/Parent Support Services

The Office of Child and Family Services (OCFS) continues to provide 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 develop and coordinate individual support plans and monitor services provided to children and their families and/or guardians. OCFS will be implementing the Children's Behavioral Health Services (CBHS) Planning Process. The new process includes concepts from Person-Centered Planning. The Child and Adolescent Needs and Strengths assessment (CANS) is an integral part of the new Planning Process. The new process will include a standardized format for Individual Plans of Care that will be used in children's Targeted Case Management, and in children's Behavioral Health Homes. A group of stakeholders is assisting with the forms and procedures for the new CBHS Planning Process, as well as updating the 2005 Children's Targeted Case Management Practice Guidelines. Tentative implementation date for new CBHS Planning process is July 1, 2017.

The utilization of children's Targeted Case Management services has been steadily increasing. According to MaineCare claims data, approximately 3,116 children and youth diagnosed with ASD received Targeted Case Management services in FY2016, a 52% increase from FY2014 and a 124% since FY 2009.

Residential Treatment

At times, children are in need of short-term, out-of-home residential services to stabilize behaviors and learn coping skills in order to return to their homes and communities and be safe and successful. Residential programs are available that specialize in the care of children and youth with intellectual disabilities and/or ASD. According to MaineCare claims data, **over 270 children and youth diagnosed with an ASD lived, at least part of the year, in a residential setting in 2016, this number is a 64% increase from FY2014 data.**

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.

Children with ASD (cont.)

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 (ABA) practices to help maintain or improve the functional abilities of children in service.

According to MaineCare claims data, over 3,195 children and youth diagnosed with ASD received Section 28 services either in schools, homes, or the community in 2016. That is twice the number of children that were served by Section 28 in FY2014.

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 communities. The programs work is 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 4,200 children and youth diagnosed with ASD received Section 65 mental health treatment services in FY2016, an increase of 52% from FY2014 and a 227% increase from FY2009.**

Stakeholder Agencies

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 also provides Autism and Safety training across the state to law enforcement, firemen, and other first responders.

ASM distributes a quarterly newsletter advertising events and providing information related to autism as well as hosting a free lending library. ASM provides an annual family retreat weekend, 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 (UCEDD), and part of a national network of centers congressionally authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. UCEDDs have played key roles in every major disability initiative over the past four decades. Many issues, such as early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation have been directly benefited by the services, research, and training provided by the UCEDDs. CCIDS faculty and staff provide a wide range of technical assistance, training, and research 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.

CCIDS offers free online resources such as Growing Ideas Tip sheets, Resources for Guiding Early Childhood Practices, Visual Supports Learning Links, training curricula, and community of practice supports for practitioners.

Maine Roads to Quality

Maine Roads to Quality is part of Maine's Professional Development Network. The Network's overriding vision is that <u>all</u> 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. Maine Roads to Quality 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 provides consultation in the design of their trainings and to technical assistance/consultation network by providing consultants with expertise in inclusive practice, universal design, and early childhood mental health. CCIDS is taking the lead in developing an inclusion credential for childcare providers.

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

CCIDS partners with the University of New Hampshire Institute on Disability and the Geisel School of Medicine at Dartmouth on the New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program. The NH-ME 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. This partnership reaches an area not served by any Maine LEND training program, develops infrastructure, and addresses regional needs, particularly in rural, underserved regions of Maine. LEND trainees complete community leadership placements at the Maine Developmental Disabilities Council, Maine Child Development Services, Maine Office of Aging and Disability Services, Maine Coalition for Housing and Quality Services, and Center for Community Inclusion and Disability Studies as well as clinical placements at Child Development Services, Pediatric Specialty Care Developmental Clinics at Eastern Maine Medical Center, Edmund N. Ervin Pediatric Center at MaineGeneral Health, and Seacoast Child Development Clinic at the University of New Hampshire.

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

Funded on July 1, 2016, The Maine LEND program is a collaboration between the University of New England and Maine Medical Center to extend services, infrastructure, and opportunities to individuals living with neurodevelopmental and related disabilities throughout the state of Maine. Its goals are to train healthcare providers, parents, educators, and others to improve the health of children with Autism Spectrum Disorder (ASD) and other Neurodevelopmental Disabilities (ND). The Maine LEND program is a five year (with on-going funding after successful reapplication) collaborative agreement through the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, and provides graduate level interdisciplinary training in neurodevelopmental and related disabilities for graduate students and professionals from diverse disciplines. The 2016 inaugural cohort of LEND long-term (9 month) trainees is comprised of physical therapy and occupational therapy graduate students and practitioners, nurses, a social worker, and family members of individuals with autism.

Transition

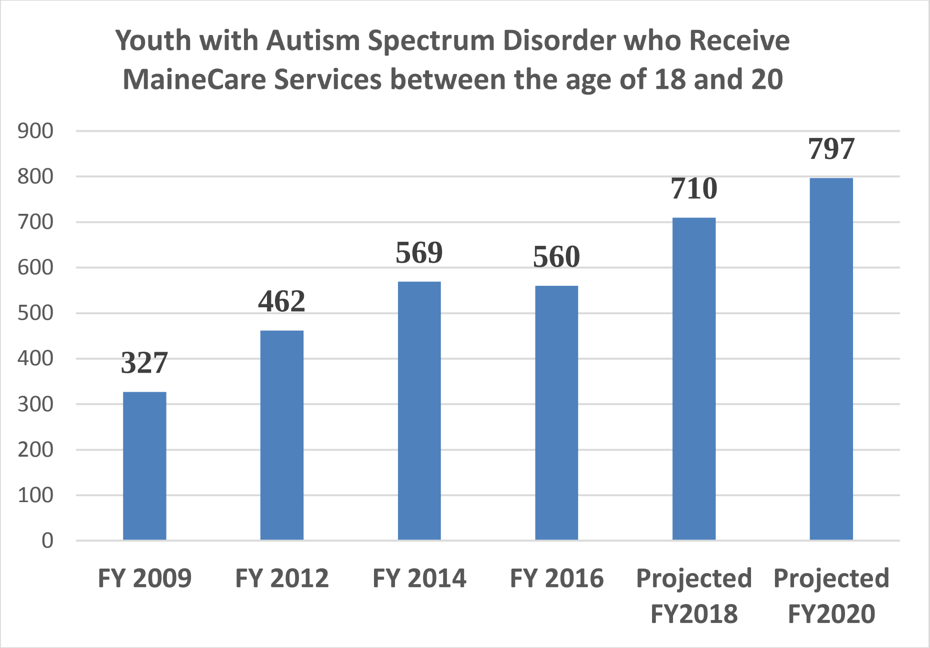
Multi State Agency Efforts for Seamless Transition

In 2016, DHHS Office of Child and Family Services (OCFS), in partnership with other state agencies, private service providers, and valued community members published: ***High School and Beyond: A Guide to Transition Services in Maine.***

This Guide was developed with the assistance of youth and families to provide resource and planning information to youth and young adults, their families, and their supports to address the many different areas of transition planning.

The Guide can be found at:
https://content.govdelivery.com/attachments/MEHHS/2016/06/30/file_attachments/578674/MSK.HDBK-update%25286.23.16%2529.pdf

OCFS is committed to ensuring that all youth they serve can successfully transition to adulthood. Some youth we serve may also receive supports and services from a variety of public and private agency providers. In order to improve the transition process for these youth, the **Youth in Transition Steering Committee** was developed. The various Public and Private Partners who serve on the Youth in Transition Steering Committee focus on improving collaboration and efforts to improve the outcomes for transition-aged youth, and help ensure a smooth, well-coordinated transition process.



The mission of the Youth in Transition Steering Committee is to support youth in transition ages 14-26 who have a diagnosis of Intellectual Disability or Autism Spectrum Disorder (ASD) and who are entering, exiting, or navigating State service systems. These service systems span the State Departments of Health and Human Services, Education, Corrections, and Labor. The primary goal of this Committee is to connect youth in transition to a paid employment experience before graduating or exiting high school.

The Youth in Transition Steering Committee has identified the following strategies for systems change:

- Align efforts and increase coordination, understanding, and efficiency among different organizations across the state working on similar goals.
- Identify and improve systemic issues that hinder employment and education, including policies and practices across departments.
- Provide recommendations to state commissioners around findings on an ongoing basis.
- Collaborate closely with Employment First Maine.

In addition to the Youth in Transition Steering Committee, OCFS is committed to partnering with local collaborations and community networks across the State to ensure improved transition opportunities and resources for youth and their families within their local communities.

CCIDS - Sustainable Family-Centered Transition Planning Project

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS) completed 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 was 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[23.] 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.

Currently, several CCIDS staff are completing a transition curriculum for youth with ASD and other disabilities, family members, teachers, and other professionals. The curriculum builds on the experiences and findings of staff in their transition research projects. Topics covered in the curriculum include authentic person centered planning strategies, supporting self-determination, accessing natural supports, assistive technology to support employment and independent living, employment supports, creative use of funding, and the range of supports, funding, and services available to youth with ASD and other developmental disabilities in Maine. CCIDS will share the curriculum with parent advocacy organizations and assist in delivering training.

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[23] 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

CCIDS - Maine EPSCoR: SEANET (Sustainable Ecological Aquaculture Network)

The University of Maine Center for Community Inclusion and Disability Studies (CCIDS), with funding from Maine EPSCoR/SEANET is partnering with the Community Environmental Health Laboratory (CEHL) at MDI Biological Laboratory to train and engage middle/high school students with ASD and other developmental disabilities from coastal Hancock County school districts in intertidal census work. CEHL works to identify and help remedy threats to public health and water quality on and around Mount Desert Island. Enrolled students are offered paid internships and receive training in the identification of invasive species, such as green crabs; data collection and data management. Student interns, supervised onsite by mentors, follow a scientific protocol and receive a variety of hands-on worksite skills.

CCIDS - Summer Work for ME

Beginning in the summer of 2015 and continuing for the summer of 2016, through a contract with the Maine Developmental Disabilities Council, the Summer Work for ME project provided Bangor area high school students with ASD and other developmental disabilities with a range of paid work experiences to help them gain insight into their own strengths and interests and cultivate career awareness. The project leveraged funding from the Maine Department of Labor, Bureau of Rehabilitation Services to provide job coaching for the students at the work sites through Vocational Rehabilitation program situational assessment dollars. Transition counselors from Vocational Rehabilitation examined how the melding of work sites into situational assessments for several students yields them the information needed for assessing clients. Community Rehabilitation Provider KFI took the lead on the development of the work sites at Eastern Maine Community College and the hiring and training of job coaches. Students worked four (4) hours per day, four (4) days each week (M-Th) and attended a three (3) hour job skills training workshop provided by project staff and a teacher from the students' school. Evidence-based practices for increasing student levels of self-determination were incorporated into each of the project components.

Education

Maine State Personnel Development Grant (SPDG)

The Maine Department of Education 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, and for the transition of IDEA Part C (birth to 3 year olds) to Part B (3-5 year olds), and preschool to kindergarten for children with disabilities. The percentage of compliant transition plans rose from a low of 54% in the 2014-15 school year to a high of 88.96% in the 2015-16 school year. The Maine DOE believes that its success as reflected in significantly improved State Performance Plan/Annual Performance Reports is that the Maine DOE took its technical assistance directly to the teachers. Maine DOE developed a model of small group technical assistance focused on high school special educators that has dramatically improved results.

There has been tremendous improvement over the past 5 years in the availability of services and supports for children on the autism spectrum. Teachers and paraprofessionals have access to quality professional development and technical assistance. Secondary level students are benefitting from well-designed transition plans. Schools have teams of skilled educators who can be accessed to support a school or teaching team or individual teacher who is working with a child on the spectrum. In the words of someone who has watched the evolution of educator skills, support systems, access to programs and information, and the increasing ability of schools to support students on the spectrum, “Maine is a great place to raise a child who is on the autism spectrum.” We have more work to do but we have made tremendous gains.

HealthCare

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 Project

Caregiver Education

The goal of the Developmental Disabilities Health Project is to ameliorate health disparities and improve care of individuals with intellectual and developmental disabilities (I/DD). The project has addressed this through two strategies: education of informal and professional caregivers of persons with I/DD and exploration of the applicability of Patient Centered Health Homes for people with I/DD through development of an expert committee to identify and evaluate competencies for providers of health care to individuals with I/DD (based on existing core competencies of general health homes).

Over the last three years, Maine Developmental Disabilities Council (MDDC) has addressed the educational strategy by deploying nurses with extensive expertise to develop curricula and provide trainings to caregivers and healthcare providers of persons with I/DD. This has increased the knowledge and ability of caregivers, medical practitioners, and physicians to coordinate and provide appropriate healthcare for individuals with I/DD. Hundreds of medical practitioners and direct service professionals have been trained and received tools to identifying underlying medical conditions. At the 3 month post training evaluation, 76% of respondents reported having changed their communication style, 22% had made changes to plans of care, 25% initiated pain assessments, and 22% made other changes such as the way they treat behaviors, speak to individuals, and look for signs and symptoms of pain. Evaluation assisted with identification of other areas of need, including emerging issues of dementia and diabetes care for people with I/DD. Based on this feedback, the DD Health Project is expanding training opportunities of the treatment of individuals with DD and diabetes. This curriculum has been developed, reviewed by experts and is about to be delivered across the State.

Exploring Patient Centered Medical Homes for Individuals with IID/DD

Prescription usage is common and at a high rate for individuals with ASD of all ages. Maine DHHS Office of Continuous Quality Data Snapshot recently demonstrated that more individuals with I/DD are placed on antipsychotic medications than individuals within the mental health system.[24] These types of medication are often used to control negative behaviors but are rarely indicated for use in the I/DD population. The Office of MaineCare (Medicaid) produces an Annual Survey of Children Served by MaineCare in order to monitor the quality of services to determine if any subpopulations have any unmet needs (December 2013). This survey showed that prescription medication use (24%) is the most frequent medical response to behavioral health concerns, followed by use of medical services (20%), and treatment and/or counseling services (20%).

One possible solution to help mitigate that that the DD Health Project is exploring is the applicability of Patient Centered Health Homes for people with I/DD. This promising Medicaid model of improving care and managing costs generally "carves out" persons with I/DD due to their medical complexity. MDDC brought together an interdisciplinary "Core Expectations Committee": a group composed of experts from across the state committed to improving healthcare for people with I/DD. The committee reviewed evidence based literature, established and promising practices, and health disparities experienced by the population with I/DD through the lens of systemic barriers. The committee then evaluated each of the ten areas of competency established for (general) Patient Centered Health Homes to identify gaps and areas of need that would need to be addressed in order for the general model of Health Home to be able to meet the specific needs of Mainers with I/DD. In reviewing the work of the Core Expectations Committee, it became clear that a Patient Centered Health Home for individuals with I/DD differs somewhat from a conventional health home. Because a health home consists of the bio-psycho-social knowledge and healthcare professionals receive little training specific to individuals with I/DD, providers and caregivers need to understand and look at the total of these three aspects of the individual and know how they should deal with their health problems. Over the next couple of years the DD Health Project will continue the work of developing a model to pilot a Patient Centered Health Home for people with I/DD.

Maine Parent Federation, Inc.

Children and Youth with Special Healthcare Needs provides funding to the Maine Parent Federation (MPF) to support the Family Support Navigator (FSN) program which links families of children and youth with special healthcare needs/disabilities in Maine with an experienced person for information and support. The Navigator is a parent who has personal experience navigating the various systems of care. The FSN program provides families with information and resources on topics that include specific disabilities, early intervention services, special education, health care, insurance options, Social Security, transition, adult services, and any other services or circumstances facing a family of a child with special healthcare needs.

The FSN program serves children with special healthcare needs/disabilities (including those receiving a diagnosis of Autism Spectrum Disorder) and their families from birth through 21 years of age.

In the last 18 months of the program, Maine Parent Federation has worked directly with 193 families. From October 2015 to September 2016 parent requests for any type of information on ASD made up about 22% of requested support. This was the greatest percentage of all the disabilities to which support was provided.

Maine Parent Federation's Family Support Navigator program has been an extremely successful program and the program currently receiving the highest demand from families.

Adults with ASD

Office of Aging and Disability Services (OADS)

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 of 2012, the Office of Aging and Disability Services (OADS) and the Office of Child and Family Services (OCFS) staff have been working collaboratively in order to better coordinate care for youth ages 16-18 that may qualify for adult developmental services. 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.

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 based on the individual needs of each person, 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.

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 and where they want to go. 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.

Adults with ASD (cont.)

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

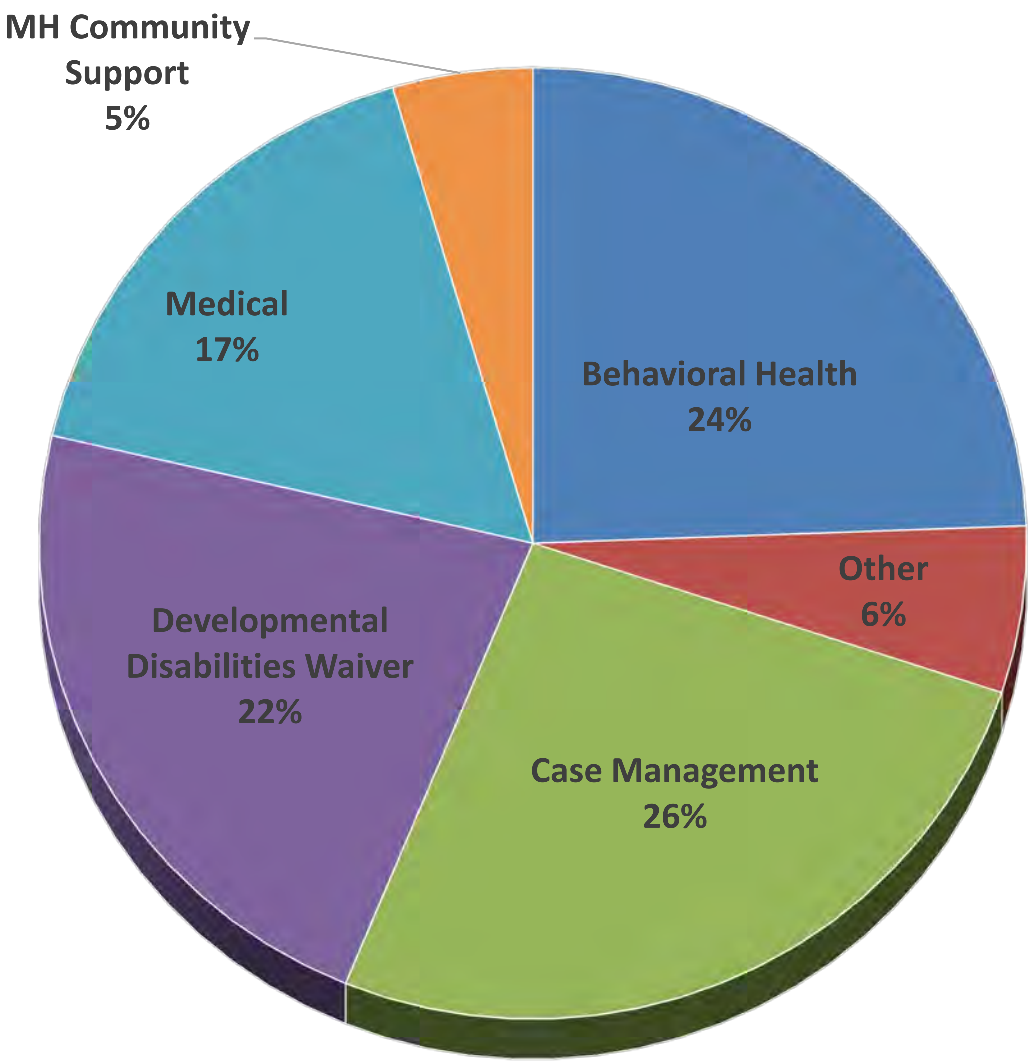
Targeted Case Management Services

Each person eligible for adult Developmental Services is entitled to receive case management services. Case managers are either OADS employees or 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 FY16 for over 1,560 adults with ASD.** While that is a significant increase from FY 4 Case Management service numbers (where over 360 adults with ASD received the service), a significant shift in data collection occurred in FY15. In FY15 the State shifted from using ICD 9 codes to ICD 10 and providers of care for adults with Intellectual Disability and/or ASD received further guidance on how to code for services. **The appearance of an increase may be explained as a better indicator of members utilizing the service as opposed to an actual increase in members.**

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. As of As of April 9, 2017 there were 1496 people on the Section 21 wait list: Priority 2 = 510 and Priority 3 = 986. All members that have been found to be at a need for Priority 1 (to be in need of adult protective services) have received a funded offer.

Primary Service Usage for Adults with ASD over 20 years old.



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. As of July 2015, this waiver does not have a waitlist and applications are maintained in a queue according to the date received. Offers are made by the Developmental Services Waiver Manager based on the queue of applications.

In FY2015 and FY2016, OADS authorized the following amount and types of service for both the Comprehensive and Supports Waivers:

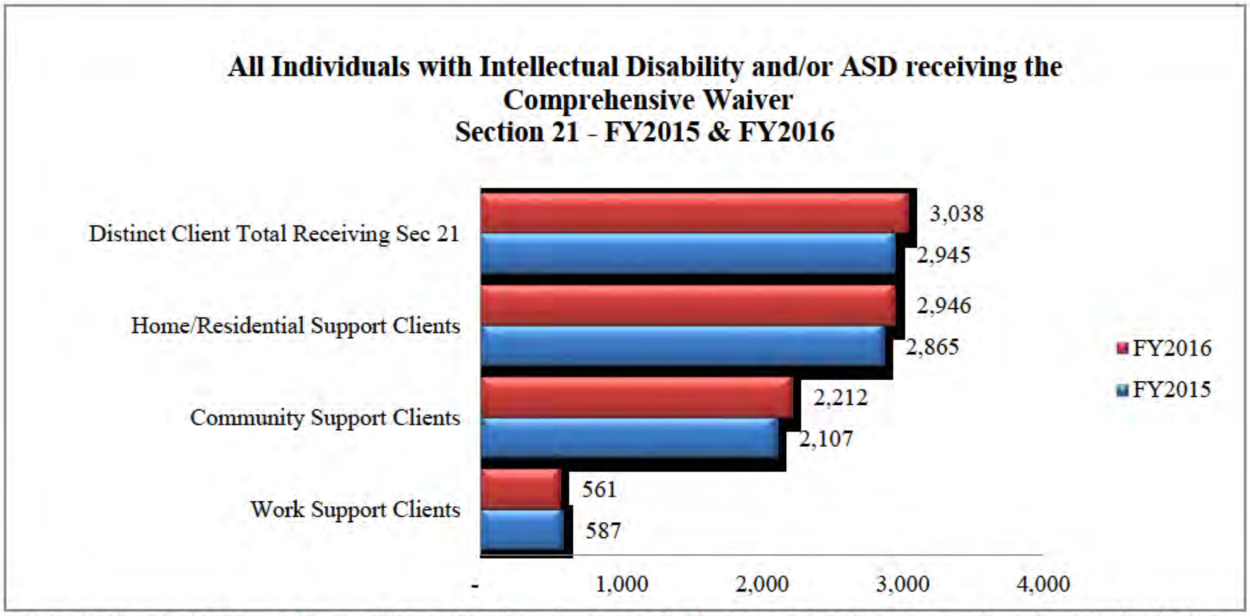


Figure 2—Section 21 Comprehensive Waiver: Number of unique individuals receiving the waiver and number of individuals accessing specific services

Adults with ASD (Cont.)

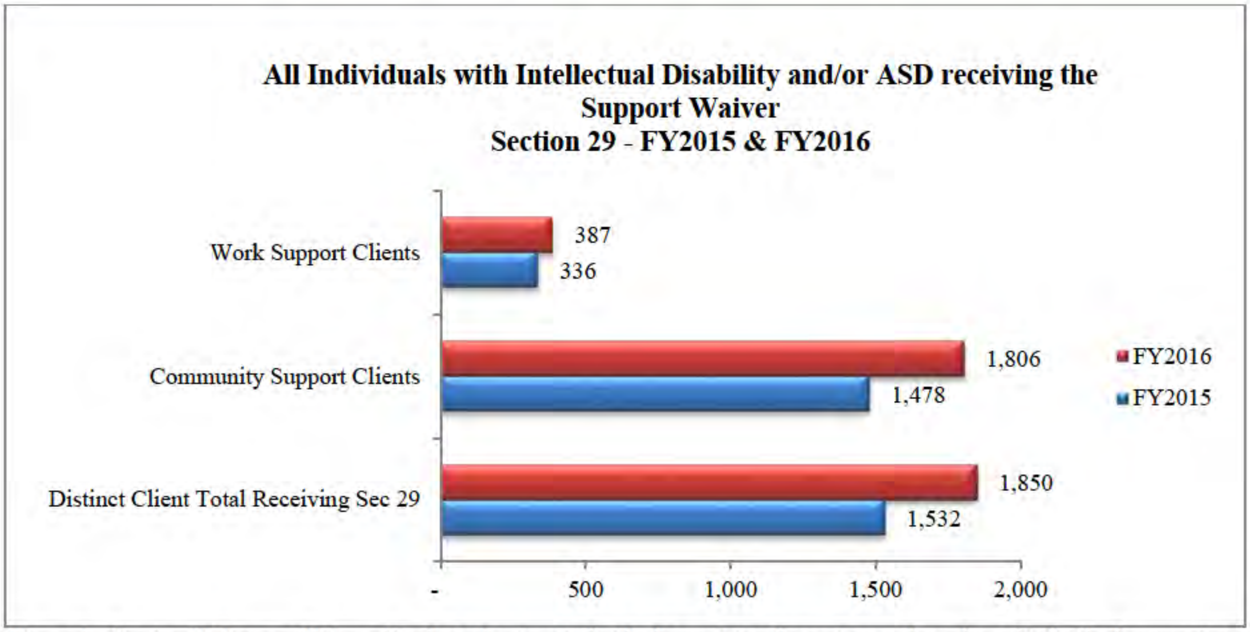
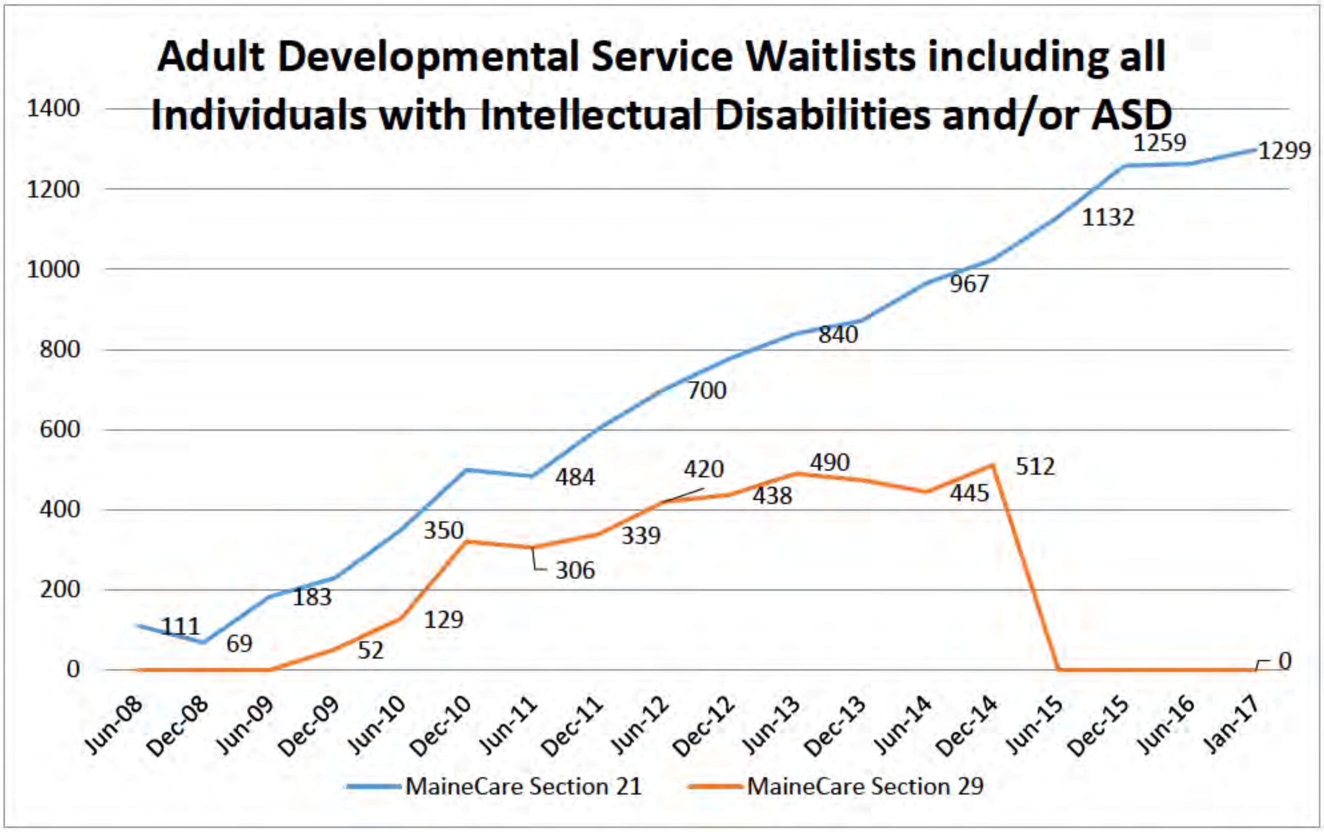


Figure 3—Section 29 Support Waiver: Number of unique individuals receiving the waiver and number of individuals accessing specific services



Other Services

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

In March of 2016, DHHS ceased the implementation of the Supports Intensity Scale (SIS) as a standardized assessment within the Comprehensive Waiver Service (Section 21). DHHS continues to be committed to establishing a standardized assessment process to inform the Person Centered Planning process and to establish appropriate funding and service array for members. DHHS will continue to evaluate and review assessment options in coordination with stakeholders, members, and other interested parties for future use.

Emerging Challenges

OADS faces several challenges in supporting people with ASD. The number of people who are being referred is increasing and national statistics and state level education data suggest that this will continue. The Comprehensive Waiver Program continues to maintain a waiting list. The Supports Waiver has also seen an increase in applications. The vision of OADS includes:

- Be centered on the person and focus on strengths and abilities
- Support each person to make their own informed choices
- Promote respect of adults and their valued roles within their community
- Provide opportunities for quality employment that pays a fair wage and benefits
- Maximize opportunities for independence and self-sufficiency
- Provide quality case management services including conflict free person centered planning
- Support and encourage family, friends and neighbors to help meet an individual's needs
- Ensure health and safety while promoting choices for new growth and development
- Build a coordinated, streamlined service and support system using resources wisely

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.

Employment

Department of Labor (DOL)

Part of the mission of the Maine DOL is providing workers with the skills they need to be competitive in the economy; assisting individuals when jobs are lost; and ensuring safe and fair workplaces for people on the job. Maine DOL services such as Career Centers, are available to people with ASD as members of the general public. However, DOL recognizes that many people with ASD require specialized supports to obtain and retain employment. These supports are provided through the Division of Vocational Rehabilitation (VR).

Division of Vocational Rehabilitation (VR)

VR is working closely with partners in the Departments of Education and Health and Human Services to prepare for meeting the workforce needs of this population. In 2012, Maine VR partnered with the University of Maine's Center for Community Inclusion's Family Centered Transition Project to increase education, outreach and services to transition-age youth and their families with the goal of improving post-secondary outcomes, including employment.

The Division of Vocational Rehabilitation provides assistance to eligible individuals who have disabilities, including Autism, to prepare for, get, and keep a job. VR works with adults as well as with eligible students to coordinate information and resources as they transition to the world of work.

To be eligible for VR Services an individual completes an application and must:

- Have a documented disability that prevents the person from getting or keeping a job
- Need VR services to keep a job

Individuals who receive SSI or SSDI are presumed to be eligible for VR services.

Eligibility is determined within 60 days. An assigned VR Counselor then works with the person to understand their unique employment goals, strengths, and needs and works with them to develop an Individualized Plan for Employment (IPE). The IPE details the VR services that are needed to reach the person's employment goal. Every plan is different. VR can assist with tools, uniforms, or basic equipment needed to start a job. Sometimes VR can assist with some medical/psychological services. If a job coach is needed, VR will provide one. Generally, services end 90 days after the person is working unless long-term support is needed for the person to maintain a job.

Employment (cont.)

Long- Term Support

Some individuals with Autism may need Long-Term Support services to assist them to maintain employment. The Department of Labor's Vocational Rehabilitation (VR) program and the Department of Health and Human Services' Office of Aging and Disability Services (OADS) have a strong and mutual commitment to work together toward the goal of supporting and encouraging individuals with disabilities, including Autism, to obtain and maintain competitive employment in their communities. VR and OADS are actively working together to maintain and improve this cooperation between the two departments in order to increase the employment of individuals with disabilities in Maine. Joint procedural guidance to staff of both agencies details when and how individuals should be referred for Long-Term Support.

Career Planning/Discovering Personal Genius™ (DPG)

Career Planning is a MaineCare waiver-funded service, available to individuals that qualify, which may include individuals with Autism. It is a comprehensive, direct support provided to individuals to assist in maintaining or advancing in competitive employment or self-employment. Career Planning assists with identifying a career direction and developing a plan for achieving competitive, integrated, individual employment or self-employment. Services assist in identifying skills, priorities, and capabilities determined through an individualized discovery process. It may include a referral to benefits planning, referral of assessment for use of assistive technology to increase independence in the workplace, development of experiential learning opportunities and career options consistent with an individual's skills and interests. Career Planning may be used in preparation to gather information to be used as part of a referral for vocational services through VR. Career Planning services are provided one-on-one, between the DPG provider and client and are not conducted in group settings. It can be provided within a variety of community settings such as a CareerCenter, the community, and local businesses.

SUCCESS STORY

A young man on the autism spectrum worked with a job developer of his choice to participate in job tours and job shadows. His High School staff and administration collaborated with his VR counselor to enhance his Individual Plan for Employment. This allowed him to have exposure to employment opportunities within the school. He was hired to assist coaches with sports field preparation and cleaning and detailing of school department vehicles. He worked with a Community Rehabilitation Provider which resulted in a job shadow and a situational assessment at a car dealership. His school staff assisted with transportation to the site. Upon completion of the assessment, the VR counselor arranged on the job training with the employer whereby the first few weeks following hire were paid for by VR. The employer expressed a high level of satisfaction with his new employee, VR set up transportation, while waiting for long term support funds to be implemented through his 29 waiver. The young man has been working successfully for 6 months.

The timeline instituted by the Office of Aging and Disability Service (OADS) for clients receiving Career Planning services include a referral to Vocational Rehabilitation (VR) two weeks after DPG has begun. The Career Planning services offered by OADS are limited to 60 hours and are to be delivered within a six-month period. Therefore, a referral to VR two weeks into the process, will allow the client time to access VR services including orientation, application and determination of eligibility. Ideally, these two processes, DPG and eligibility determination, occur concurrently. When these processes do occur as described, the client, who is engaged in the DPG process can transition smoothly and seamlessly into VR services and the momentum a client has achieved through their participation will not be lost.

Waiver-funded clients are encouraged to participate in the Career Planning process prior to their referral to VR, if deemed appropriate. A discussion with the case manager, client and/or guardian is appropriate, in order to explain the expectations and benefits of using the information received from DPG and how it may expedite the VR process.

Progressive Employment

VR is currently piloting *Progressive Employment* with transition-age youth (14-24) in its Portland and Lewiston offices. Progressive Employment is a dual-customer (business and jobseeker) model that was developed in Vermont where it has been extremely successful. Starting with the belief that everyone is ready for something, Progressive Employment brings together VR Counselors and Community Rehabilitation Providers in regularly scheduled "Jobsville" meetings where client referrals, updates, and labor market information is exchanged in a team environment. Young people referred to Progressive Employment participate in job tours, shadows, mock interviews, and paid work experiences in career fields of their interest. The focus is on engagement and career exploration, however some activities may lead to a job offer. The response from employers has been very positive as they appreciate the opportunity to get to know a young person at little to no risk or cost to their business. Young people with Autism are included in Progressive Employment and have been successful because the pace and activities are directed by their own interests and needs. One young man with Autism has recently

SUCCESS STORIES

An individual with autism started working with VR while in High School as a 5th year student, referred by his Life Skills teacher. Upon completion of High School, he enrolled in a day program and continued to work with VR. He participated in a job tour and a situational assessment for a few months. The employer was pleased with his performance but was unable to financially support his hire. VR set up another job shadow and a situational assessment with an alternative employer; a restaurant business. The individual was officially hired there. His schedule works well with his day care program which he also wanted to stay involved with. Currently, he requires 100% coaching. As he demonstrated difficulty with change, VR arranged to fund a coach at the site for two shifts along with the waiver funded long term support coach to do a warm hand-off. The employer and employee report mutual satisfaction with the outcome.

completed two employer tours while also completing a paid work experience in e-commerce. Another young man with Autism who has an interest in jewelry making recently did a work experience with a bead and crafting shop.

AlphaOne Independent Living Skills

AlphaOne, Maine's Center for Independent Living, is currently piloting efforts in selected southern Maine schools to provide work readiness and independent living skills training to complement other VR efforts to prepare youth for competitive integrated employment. AlphaOne's curriculum is delivered by trained Peer Mentors and includes basic money management, workplace etiquette/ professionalism, writing resumes, job applications, cover letters, communication skills, health and hygiene, conflict resolution, stress management, and time management skills, disability disclosure, basic rights, and related resources. The Peer Mentors also help students clarify their interests, needs, and learning styles.

Summer Work Experience

Research has shown that paid work experience while students are in high school is the best predictor of post-school employment. Many students with disabilities unfortunately do not have the opportunity to build these employment skills with summer employment as their same-age peers do. Across the state, VR is significantly increasing the number of transition-age clients who participate with VR support in summer employment. This support can come in the form of wages, transportation, job coaching, or assistive technology, etc.

Success Stories:

> *A young man expressed an interest in attending college for graphic design and enrolled in a specialized program. He came to the conclusion that college was not a good fit for him despite support provided. The job developer and the Vocational Rehabilitation Counselor identified that he needed more social skill development and support to build upon his self-efficacy and confidence. He was assisted with several work experiences in fields of interest to him. He decided he enjoyed working in the food service industry, working with people, and did not want a fast paced position. Shortly after completing a community based work assessment, he applied, interviewed for, and secured a job as a food demonstrator.*

> *A man with Asperger's syndrome has had many obstacles to overcome; he continues to learn about himself and his challenges so that they can be eradicated as handicaps in order for him to achieve his goals. He has a self-employment plan with VR and is very talented in his craft. He has begun making a new product which has been well received and successfully selling. He has developed a team which includes a VR Counselor, Case*

Manager, and Small Business Development Center representative. Our next step will be to help him hire a bookkeeper so that he can manage his income and understand profits and losses. As of today, there is a strong indication that he is moving toward greater and greater independence with necessary business support in place.

<u>Additional VR and DHHS (OADS) Collaboration:</u>

Currently, 120 people in the State of Maine are reported to be earning sub-minimum wage with certificates allowing them to do so. This is a reduction from 800 individuals and VR continues to make these applicants a priority to serve, in order for them to be able to earn minimum wage or higher in jobs that match their interests and abilities. VR is also considering rule changes which would open the gate to hiring up to 150 qualified coaches through the state of Maine, providing needed support for maximizing success.

OADS - Employment

Research and experience demonstrate 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, national employment rates of persons with developmental disabilities continue to be low. Issues such as access to transportation, understanding benefits and work, and access to supportive services are identified and require individualized solutions.

Maine has a history of a strong employment system to provide efficient and effective supports for individuals with disabilities. Every person served by the Office of Aging and Disability Services is offered the opportunity to work in community-based, integrated, competitive employment. Employment has become a required component of the Person Centered Planning process and assistance to identify and overcome barriers is captured in planning and waiver services. Furthermore, the new waiver service of Career Planning was added in 2015 allowing members to explore employment options before being referred to Vocational Rehabilitation Services for job development. Once employed, people can access long-term job supports funded through the waivers to maintain their employment.

Maine has implemented several new employment-focused endeavors to reduce barriers and increase employment outcomes. A comprehensive Workforce Development System for employment services staff was developed and recently expanded in conjunction with the Department of Labor. The Workforce System provides staff certification, advanced training, and technical assistance focused on employment professionals. The Maine Business Leadership Network, an affiliate of the United States Business Leadership Network, continues to be housed within the Maine State Chamber and provides the business to business platform to promote diverse workforces in Maine businesses. OADS continues to gather 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. A new Work and Benefit Navigator Training has been developed along with Benefit Counseling Services to provide people with accurate information and tools to assist individuals to enter a pathway to employment.

Continued work with the Department of Labor, Bureau of Rehabilitation and other DHHS offices is essential to providing effective employment services to individuals during assessment, evaluation, career development, and on-going support to maintain and advance in employment. Employment First Maine statute promotes the use of state funding to support employment services and supports as *the first and preferred* service or support. The Employment First Coalition has produced a report and recommendations that will assist in the next steps for systems improvement. Maine supports Employment First and will continue to implement new and individualized supports to increase the employment of people with disabilities.

Conclusion

Maine continues to demonstrate its commitment to people with ASD as illustrated in its 2014-2017 efforts to address the goals and objectives identified in the 2013 Maine Autism Strategic Plan, in accordance with the Autism Act of 1984, 34-B M.R.S.A. §6001-6004. The work outlined in this report illustrates the significant strides Maine has taken to improve the multi-agency systems of care utilized by individuals with ASD and their families. Several challenges have been identified to the realization of the full potential of Maine's residents with ASD, including

- The challenge of meeting the needs of the growing population of individuals diagnosed with ASD, especially the very large number of youth with ASD who are transitioning into adulthood.
- That many of Maine's services, 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.
- Developing and adapting flexible, innovative, evidence based, cost effective supports.
- Developing a sustainable workforce to assist persons with ASD to live and work in their communities.

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

In March of 2016, at the request of the DHHS Commissioner, the Maine Developmental Disability Council coordinated and facilitated an ASD Summit to look at the current ASD Strategic Plan and develop the next iteration of that plan. A broad group of stakeholders including parents, self-advocates with ASD, representatives from DHHS, DOE, and DOL, and advocates joined together for a full day meeting to; review progress of the 2014 ASD Strategic Plan, identify the gaps between the plan's projections, and the current landscape, and make provisions for determining the ways to assist with the 2017 Maine Strategic Plan. At the end of the day, the stakeholders agreed that a steering committee of State agency staff should convene to draft the 2017 plan. That occurred over a series of four meetings where the below Strategic Plan was developed. Once the plan was drafted, the original stakeholders had an opportunity to submit comments to the committee. Below is the FY17 ASD Strategic Plan

Early Intervention

Need to be addressed

- Some regions lack resources for comprehensive early intervention.
- Can results of Early Start Denver Model (ESDM) be replicated in Maine?

Response to Need

- DOE will be focusing on expanding the availability of comprehensive early intervention.
- DOE has replicated Early Start Denver Model and is developing methods to sustain the evidence based methodology.

Transition

Need to be addressed

- Need to coordinate and streamline the number of groups working on transition process/results.
- Continue to look for opportunities to strengthen the partnership between VR and Education in an effort to enhance post-secondary transition planning and opportunities.
- Youth and families are unprepared for post-secondary education, employment, and life after high school. There is a gap in parent understanding and transition planning.
- Schools need to continue improvement in the development of IEP post-secondary transition plans that are compliant with IDEA regulations.
- Special educators need to continue training on the requirements of the IEP transition process to ensure that students receive high-quality post-secondary transition services.
- Need broader outreach to rural counties such as Aroostook and Washington.

Transition (cont.)

Response to Need

- DHHS, DOE, and DOL have recently created a cross-departmental coalition that, among other goals, is aimed at aligning efforts and increasing coordination, understanding, and efficiency among different organizations across the state working on similar goals. Over the next two years they hope to have standardized and improved processes of communication and developed a plan for improvement across systems for seamless transitions.
- Under the Workforce Investment Opportunities Act (WIOA), VR is required to spend 15% of its total budget on pre-employment transition services to prepare students with disabilities for post-secondary education and employment. This will present considerable opportunities for collaboration and partnerships.
- A specific plan to address parent understanding of post-secondary transition, employment, and life after high school will be developed by DOE in partnership with other organizations and agencies serving youth and families. The plan should focus on family engagement given a limited response to previous informational initiatives.
- DOE is providing incentives, such as funded training opportunities, to educators aimed at improving the post-secondary transition plans with good results, the 2015-16 results are 89% compliant plans. The training needs to continue
- OCFS will implement policy to support early referral meetings between children's services and adult services.
- DOL, DVR is committed to spend 15% of its total VR budget on pre-employment transition services to prepare students with disabilities for post-secondary education and employment.
- The U.S. Dept. Of Education has awarded the Division of Vocational Rehabilitation Services a $9 million grant to help students with disabilities prepare for post-secondary education and competitive integrated employment above minimum wage. Our goal is to have 90% of study participants in post-secondary education or competitive employment within one year of their high school graduation. We will be collaborating with the Maine Depts. of Education, Health and Human Services, and others. DVR will also use the progressive employment model to expand business and community relationships in conjunction with partnering with Jobs for Maine Graduates.

Children's Services

Need to be addressed

- There is no Person Centered Plan for children's services.
- Need broader outreach to rural counties such as Aroostook and Washington.

Children's Services (cont.)

Response to Need

- DHHS, OCFS is in the process of designing a conflict-of-interest-free planning process based on the Person Centered Plan model for all children. This process will be fully shaped and testing will begin over the next two years.
- OCFS Regional and Program Coordinators will convene workgroups with regional families, community collaboratives, providers, and other stakeholders to increase service availability.

Employment, Post-secondary Education & Training Programs

Need to be addressed

- Individual Education Plans and Person Centered Plans should read reflecting person's actual desires for employment.
- Need for systems to communicate/coordinate more effectively with each other and with families in order for successful employment to occur.
- Continue to strengthen partnership between vocational rehabilitation and education.
- Need broader outreach to rural counties such as Aroostook and Washington.

Response to Need

- OCFS is updating its questionnaire for transitioning youth in the case management database to focus on public and private resources that promote post-secondary education and employment.
- DOL, DVR will continue to work with the Maine Department of Health and Human Services to ensure that all individuals who have the waiver, but have not taken advantage of employment services, are aware of employment supports open to them through coordination between the two Departments.
- DOL, DVR will continue implementing Memorandums of Understanding (MOUs) with partners including; DOE, Corrections, OADS, and Veterans Administration, regarding referral, application, collaborative engagement toward successful outcomes, and long term support services.
- DOL, DVR will continue to provide access and training to the BRIDGE – Career Exploration Workshop, appropriate for individuals with intellectual disabilities. Maine DVR will further undertake efforts to continue to embrace and implement an "Employment First" philosophy during the next year as documented by a decrease of 5% in the statewide unemployment rate of people with intellectual disabilities.
- DHHS, DOE, and DOL will continue to participate in the work of Employment First Maine's coalition, which includes targeted goals to improve employment outcomes for individuals with significant disabilities.
- DOL, DVR will implement a change in Community Rehabilitation Provider (CRP), also known as Employment Specialists billing reimbursement rates to foster an increase in CPR to serve individuals in underserved geographical locations as well as populations that are determined to be underserved (culturally Deaf/individuals who speak a language other than English).

Health

Need to be addressed

- Expanded resource need for more psychiatrists, psychologists, and Board Certified Behavioral Analysis professionals who have expertise in ASD.
- Need for better awareness about issues related to aging and I/DD.
- Need better transition from child to adult healthcare.

Response to Need

- OCFS is working to enhance the use of Applied Behavior Analysis (ABA) throughout the State. One way the methodology is being promoted is that improvements are being made to MaineCare regulations to make ABA/BCBA billing more clearly.
- MaineCare will publish a guidance letter to pediatricians outlining best practice methods to transition youth into adult health care.

Adult Services and Community Inclusion

Need to be addressed

- How to help communities learn to build inclusive communities?
- Community members, individuals, families, and professionals need more education on assistive technology.
- Need better focus on using Assistive Technology for communication support.
- Need ways for individuals with ASD to be able to select the type of services that they need in a dynamic way so as to prevent being forced into systems of care that were developed for other populations.
- Need access to comprehensive, family-centered, continuous, coordinated, compassionate, and culturally effective medical homes.

Response to Need

- DHHS/OADS will investigate new waiver options that include cash-follows-the-person philosophy. This philosophy provides a budget to the individual and guidelines to utilize the moneys then supports the individual and family in selection of appropriate services that may be unique to that individual's needs.
- DHHS will investigate the expansion of health services by developing pilots or expanding existing health home services specific to individuals with developmental disabilities. A piece of the health home will be to provide comprehensive care coordination. Care coordinators will provide a key connection between the medical plans, service plans, and life in the community with non-paid friends and family.

Overarching

Need to be addressed

- There is a lack of recognition of impact of trauma on ASD and DD.
- Maine rules/regulations/policies need updating from DSM-IV to DSM-V to reflect newest research and medical community, services system need information/understanding on how to apply the new diagnostic regulations.

Response to Need

- Maine rules/regulations/policies are in the process of being updated from DSM-IV to DSM-V.
- There is a commitment across age range and systems to improve services to be trauma informed, one example of this is that DHHS, OCFS utilizes the Child and Adolescent Needs and Strengths (CANS), a multi-purpose tool developed for children’s services to support decision making. CANS is building a specific module to address adverse childhood effects.

Appendix B

Acronym Glossary

Acronym	**Definition**
AAP:	American Academy of Pediatrics
ABA:	Applied Behavioral Analysis
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

Acronym Glossary (cont.)

Acronym	**Definition**
FFY	Federal Fiscal Year
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
IFSP	Individual Family Service Plan
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.)

Acronym	Definition
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
UVM:	University of Vermont
WIOA	Workforce Investment Opportunities Act