Office of Aging & Disability Services

Biennial Report for:

Autism Spectrum Disorder

Pursuant to MRS Title 34-B §6004

2021

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Abbreviations

ASD	Autism Spectrum Disorder
ASM	Autism Society of Maine
CCIDS	Center for Community Inclusion and Disability Studies
CDC	US Centers for Disease Control and Prevention
CDS	Child Development Services
DOE	Department of Education
DOL	Department of Labor
DVR	Division of Vocational Rehabilitation
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
HCBS	Home and Community-Based Services
HCT	Home and Community Based Treatment
ICF-IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan

OADS	Office of Aging and Disability Services
OCFS	Office of Child and Family Services
Maine-LEND	Maine Leadership Education in Neurodevelopmental and Related Disabilities
MAIER	Maine Autism Institute for Education and Research
MDDC	Maine Developmental Disabilities Council
MFP	Maine Family Partnership
MPF	Maine Parent Federation
MRTQ PDN	Maine Roads to Quality Professional Development
NH-ME-LEND	New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities
PCP	Primary Care Provider
PNMI	Private Non-Medical Institution
RCS	Rehabilitative and Community Services

Executive Summary

Like everyone, people with autism spectrum disorder (ASD) have different needs for support throughout their lives, from birth through childhood, adolescence, and adulthood. Public agencies and programs provide services to people with ASD as part of their larger missions to serve Mainers with intellectual and developmental disabilities and other needs. Over the years, the Maine Departments of Health and Human Services (DHHS), Education (DOE), and Labor (DOL) have provided medical, behavioral, and long-term services and supports, special education, and vocational services to Mainers with intellectual and developmental disabilities, including people with ASD. These multiple departments have built a system of care and support spanning the lifetime. Collaboration between the departments is often necessary, particularly as children transition to adult services.

This report fulfills the requirement pursuant to 34-B M.R.S.A. §6004 of the Autism Act and describes the efforts of the Maine Department of Health and Human Services in conjunction with the Department of Education and other agencies to provide services to Mainers with ASD.

Perspectives of Individuals with ASD and their Families

The Department of Health and Human Services contracted with the Maine Developmental Disabilities Council (MDDC) and Autism Society of Maine (ASM) to conduct surveys and focus groups of individuals with ASD and their families to gather their perspectives on the service system. Although survey respondents and focus group participants described being satisfied with the services they and their family members receive, they also described areas needing improvement, including the transition process from children's to adult services.

Children's Services

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services help identify young children with ASD. Once identified, the Office of Child and Family Services (OCFS) Child Development and Behavioral Health Services Team supports children with ASD and their families to access high-quality early childhood education and MaineCare behavioral health services in their homes, schools, and communities. OCFS is in the process of implementing short-term and long-term reform strategies to improve the behavioral health services they provide to children with intellectual and developmental disabilities, including ASD. The strategies are intended to improve access to and proximity of care; appropriateness of the

services, quality of care; and coordination with other agencies to improve the transition to adult services.

The Department of Education, through the Individuals with Disabilities Education Act (IDEA), provides Early Intervention services for young children through Child Development Services (CDS) and Free and Appropriate Public Education for school-age students until age 22. The Department of Education is dedicated to increasing training, professional development and technical assistance to support high quality programming for individuals with ASD in Maine, especially in rural areas of the state.

Transition-age Services

OCFS works with the Office of Aging and Disability Services (OADS) to help children with developmental disabilities transition from school to adulthood, and from developmental services provided through OCFS to adult services provided through OADS. There are several significant structural challenges for parents and their children navigating this transition including a mismatch between the types of services available to children and those available to adults and different eligibility criteria for those services.

In preparation for moving from children's services to adult services, transition planning services are required to be initiated by a student's school, no later than ninth grade. The transition planning process is intended to identify: the student's strengths, interests, and needs; their vision of where they want to live and what kind of work they would like to do; measurable goals to achieve their vision; and sources of support in their adult lives. The Division of Vocational Rehabilitation in the Department of Labor assists in transition planning and in the development of each eligible student's Individualized Plan for Employment and provides Vocational Rehabilitation (VR) services to assist students to get and keep a job.

Adult Services

The Department of Labor provides VR services to adults with physical, emotional, or mental impairment including intellectual or developmental disabilities and ASD. The VR program provides guidance in establishing employment goals, understanding job training requirements, job coaching, obtaining assistive technology, tools, and uniforms, and assisting the individual to seek employment. Adults with disabilities including ASD may also be eligible for Independent Living Services through the Department of Labor.

For adults with ASD (age 18 and older), OADS administers the MaineCare Home and Community-Based Services (HCBS) waiver programs for adults with intellectual disabilities or ASD. HCBS waivers are Medicaid-funded service packages designed specifically for helping older adults and people with disabilities who would otherwise require institutional services to live as independently as possible in the community. These waivers are the primary pathway for accessing services that support the pursuit of one's own goals, employment, and engagement in the community. Other services that may be available for adults with ASD include residential services in Private Non-Medical Institutions or intermediate care facilities for individuals with intellectual disabilities, Targeted Case Management, Person Centered Planning, public guardianship and conservatorship, Adult Protective Services, and statewide crisis prevention and intervention services.

OADS has a two-year plan for improving the design and quality of its programs in order to strengthen OADS' ability to assure that individual goals and preferences are met. Through a process of stakeholder engagement, OADS has identified key areas for improvement in the service system for adults with intellectual disabilities or ASD: community membership to promote full inclusion; innovation in service design and delivery; quality assurance; system capacity and access to services; and interagency coordination to improve outcomes.

Community-Based Organizations and Public-Private Partnerships

Maine is fortunate to have many community-based organizations and public-private partnerships that serve children and adults with ASD and their families. Some of these organizations provide services and learning opportunities directly to individuals with ASD and their families while others focus on advocacy, policy and system change, and professional education and serve a broader population of people with disabilities. These organizations continue to work to enhance system competency to meet the needs of individuals with ASD.

Introduction

In response to the growing awareness of autism spectrum disorder as a developmental disability, the Maine Legislature, through the Autism Act of 1984, directed the Department of Health and Human Services to develop and plan for social and habilitative services for persons diagnosed with ASD or other pervasive developmental disorders, to the extent permitted by resources.

Over the years, the Maine Departments of Health and Human Services, Education, and Labor have provided medical, behavioral, and long-term services and supports, special education, and vocational services to Mainers with intellectual and developmental disabilities, including people with ASD. These multiple departments have built a system of care and support spanning the lifetime. Collaboration between the departments is often necessary, particularly as children transition to adult services.

Although some public agency services are limited to specific ages and may have functional and financial eligibility criteria, they are not limited to a diagnosis of a particular intellectual or developmental disability such as ASD. With a few exceptions, s**ervices available to people with ASD are the same as those available to people with other types of intellectual or developmental disabilities.**

This report fulfills the requirement pursuant to 34-B M.R.S.A. §6004 of the Autism Act that the Commissioner of Health and Human Services submit a report in coordination with the Commissioner of Education every two years on the efforts of the Department of Health and Human Services to the Governor and the joint standing committees of the Legislature having jurisdiction over health and institutional services matters and educational and cultural affairs. The report describes the current prevalence estimates of ASD in Maine; the results of surveys and focus groups of people with ASD and their families; the various public agencies and programs serving people with ASD; and the agency planning efforts to improve how they provide services to meet the needs of people with intellectual or developmental disabilities and ASD. In addition, the report presents descriptions of community-based organization and public-private partnership efforts to enhance system competence for people with intellectual or developmental disabilities and ASD.

DEFINITION & DSM-V DIAGNOSTIC CRITERIA FOR

Autism Spectrum Disorder

Autism spectrum disorder is a neurodevelopmental disorder. Symptoms are present before the age of three, and significantly impact how well the person with ASD functions in day to day life, and the range and severity of symptoms can vary widely. People with ASD have "persistent deficits in social communication and social interaction across multiple contexts." They also have "restricted, repetitive patterns of behavior, interests, or activities."[1] If the symptoms do not impact the person's life in a clinically significant way, the person is not considered to have ASD.

Persistent deficits in social communication and social interaction across multiple contexts.

- Deficits in social-emotional reciprocity.
- Deficits in nonverbal communicative behaviors used for social interaction.
- Deficits in developing, maintaining, and understanding relationships.

Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following:

- Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal/nonverbal behavior.
- Highly restricted, fixated interests that are abnormal in intensity or focus.
- Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.

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).

Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

These disturbances are **not better explained by intellectual disability** (intellectual developmental disorder) or global developmental delay.

1 American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

Prevalence of ASD in Maine and Demographic Characteristics

Figure A. **Children 3-17 with ASD**

According to the CDC, nationally, about 1 in 54 children has been diagnosed with ASD; it occurs across all racial, ethnic, and socioeconomic groups, and is four times more common among boys than girls. The National Survey of Children's Health estimates that 3.9 percent of Maine children age 3-17 has been diagnosed with ASD. The tables below show how Maine compares to the nation.

	Maine	Nationwide
Estimated **total number**	**8,286**	**1,806,976**
Percent of **all children**	3.9%	2.9%
Percent of **boys**	7.0%	4.5%
Percent of **girls**	0.9%*	1.3%

* *Due to small sample size, this statistic may not be reliable.*

Source: *https://www.childhealthdata.org/browse/survey/results?q=7819&r=21&r2=1&g=790&a=13492 and https://www.childhealthdata.org/browse/survey/results?q=7819&r=21&r2=1&a=13492&g=793 accessed January 13, 2021.*

Figure B. **Adults 18-84 with ASD**

In 2020, the CDC released its first study to estimate the prevalence of autism among adults aged 18-84. Using prevalence rates among children and projecting them on to the adult population, the study estimated, nationally, one in forty-five adults has ASD.

	Maine	Nationwide
Estimated **total number**	**23,910**	**5,437,988**
Number of **women**	4,685	1,080,322
Number of **men**	19,225	4,357,667

Source: *Dietz, P.M., Rose, C.E., McArthur, D. et al. National and State Estimates of Adults with Autism Spectrum Disorder. J Autism Dev Disord 50, 4258–4266 (2020). https://doi.org/10.1007/s10803-020-04494-4*

Autism Spectrum Disorder Surveys and Focus Groups

In December 2020, the Department of Health and Human Services contracted with the Maine Developmental Disabilities Council to work with Autism Society of Maine to conduct two surveys and three focus groups to assess how children and youth with ASD experience(d) the service system, including: whether there are services and supports that families of children and youth with ASD are struggling to access; the transition to adult services; and what types of services could be created to make for the best supports possible (see *Appendix A, Survey and Focus Group Questions*).

ASD Service Survey Respondents:

Forty-four family members of children or youth with ASD completed the ASD survey. The majority (thirty-five) of respondents represented children between the age of 5 and 18. More than half (twenty-seven) of the respondents indicated their child was diagnosed after the age of 3, and seventeen reported their child was diagnosed between 13 and 24 months of age (see Figures C and D).

Figure C. **The majority of respondents represented children 5-18 years old**

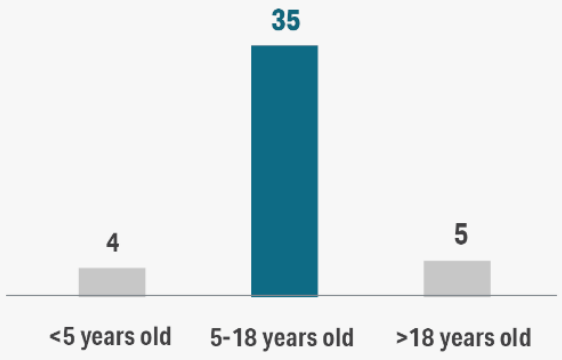
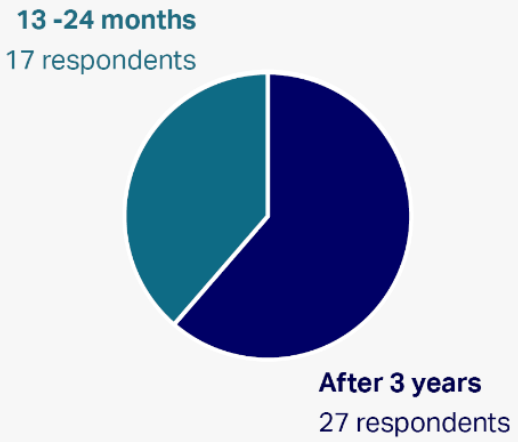


Figure D. **Age of child when diagnosed with ASD**



Results

Planning and arranging for services can take varying amounts of time. Over half of the families reported attending two to five meetings per year, with some families attending ten or more meetings per year for their child.

Survey respondents reported their children and youth access a variety of services, as shown in Figure E:

Figure E. Survey repondent use of children's services

Service	#
Case Management Services	24
Child Developmental Services	10
In-School Services with Individual Education Plan	32
In-School Services with 504 Plan	4
In-Home Supports – §28	9
In-Home Supports – §65	2
Speech Therapy	24
Occupational Therapy	20
Physical Therapy	8

**Includes counseling, psychiatry, assistance with medical management, Applied Behavioral Analysis through private insurance, social skills group and residential hospitalization.*

Access to Services

Over half (twenty-five) of the forty-four respondents agreed or strongly agreed that they could access all the services they needed for their child. When asked if they needed help accessing particular services, ten agreed or strongly agreed they needed help with childcare; fifteen agreed or strongly agreed they needed help with respite services; and four agreed or strongly agreed they needed help accessing dental services for their child.

Twenty-one respondents identified other resources that would be helpful to families (Figure F):

Figure F. **Other resources that would be helpful to families**

Type of Service	Number of respondents
Access to medical/dental/mental health services that understand ASD	5
Access to MaineCare Home and Community-based types of services	4
Access to social/recreational/support groups	4
Education/training/technical assistance for educators	4
Access to educational services	3
Stable workforce	3
No waitlists for the adult system	3
Access to assistive technology	2
Early identification	2
Better coordination/communication between home and school	2
Respite (a few hours)	1
General awareness of ASD	1
More funding	1

Eight families reported that they are still waiting to access MaineCare §28 Children's Services. Other services that respondents reported waiting for include: occupational therapy; speech therapy; case management; counseling services; MaineCare §21 waiver services; psychiatry; U.S. Housing and Urban Development Section 8 Housing; MaineCare §65 Home and Community Treatment Services; and Children's Developmental Services through the Department of Education

A few families described difficulties accessing services due to their child having compromised health or fear of the COVID-19 pandemic. For more perspectives on how the COVID-19 pandemic has impacted people with intellectual disabilities and ASD and their families, please see the section on *Community-based Organization and Public-Private Partnership Perspectives and Efforts to Enhance System Competency*.

Satisfaction with Services

Respondents provided feedback on the services their children received, describing a high level of satisfaction. The number of respondents providing feedback varied by service type.

Case management
Twenty-seven out of thirty respondents agreed or strongly agreed that their case manager responds to their concerns.

Primary care providers
Thirty-seven out of forty-four respondents agreed or strongly agreed that their child's primary care provider/doctor knows about the services their child receives.

Communication between providers
Thirty-three out of thirty-seven respondents agreed or strongly agreed that providers coordinate and communicate about service needs.

In-home supports
Fifteen out of nineteen respondents either agreed or strongly agreed that their child's in-home support met their needs.

Transition Survey and Focus Group:

Services for children and adults can differ in type and eligibility criteria, and navigating the shift from one system to another can present challenges. The purpose of the transition survey and focus group was to gather people's perspectives as they go through or have gone through the transition process from children's services to those available for adults. Eighteen individuals with ASD and/or their family members completed the transition survey. Seventeen of the respondents were family members of individuals with ASD and the remaining respondent was an individual with ASD. Six of the eighteen respondents were currently going through the transition process to adult services. Four guardians of youth with ASD participated in the transition focus group. They were asked to respond to a series of questions related to their experiences navigating the process of moving from children services to the adult service system.

Results

Seventeen of the survey respondents had gone or were going through the transition process. Eight of the seventeen agreed or strongly agreed that they had a transition plan, and nine disagreed or strongly disagreed that they had one. When asked if the transition plan assisted the person in moving to adult services, eight people responded and were split down the middle, either agreeing or disagreeing. The four individuals who agreed indicated that the plan assisted with transitioning to adult services and supports and in particular post-secondary school, employment, waiver services or waitlist placement. Respondents agreed that it is important to start the process early in order to incorporate those goals into the transition plan. One respondent mentioned that their young adult had a transition specialist who focused on identifying goals as they related to transitioning into adulthood. Many of the respondents reported still needing information about the transition process, independent living, employment, post-secondary school and accessing adult medical providers. Finally, nine respondents provided the following thoughts on how the transition process could be improved: start the process early, communicate high expectations, and ensure school transition support staff have up to date information about the complexities of moving from the children's system to the adult system.

Future Services Focus Group

Two focus groups were conducted to assess types of services that are needed but may not currently exist. The first focus group included five mothers of adults with ASD who are eligible for waiver services and considered to have high service needs. The second focus group included six individuals five of whom have ASD. Most of these participants are considered "high" functioning and receive services either through the waiver, the mental health system, or are not eligible for any services.

Results

One of the topics of conversation for the focus group that included mothers of adults with high services needs was the need for the service system to focus on continued skill development as the individual with ASD ages. It was suggested that skill development could continue through employment, secondary education, and building relationships with others that provide opportunities for personal growth. For example, learning skills to increase independence while also having the opportunity to practice those skills.

Adults with ASD who are considered "high functioning" expressed their need to have opportunities to socialize with others so they can practice skills, particularly when it comes to

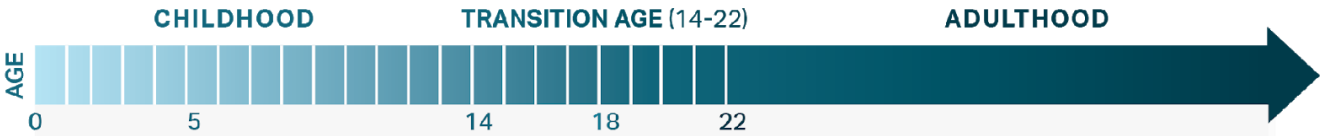
communication. People who communicate in a literal way can struggle to navigate life in the world socially and may need practice to understand social cues, generalizations, and words with multiple meanings. Mentorship was also mentioned as desirable so individuals with ASD could receive help with either social interpretation or executive functioning. Respondents also stressed the importance for service providers to include parents/family members and individuals with ASD to hear their perspectives.

Increasing the opportunity to self-direct services would also increase skill development. Using telemedicine during the COVID pandemic allowed some adults with ASD to be engaged with the health system. A challenge faced by “high functioning adults” is filling out forms at doctor’s offices; it was suggested from one respondent that having an interpreter or other individual to assist them in completing those forms would be helpful.

OVERVIEW

Maine's Public Services and Support Systems

Like everyone, people with ASD have different needs for support throughout their lives, from birth through childhood, adolescence, and adulthood. Public agencies and programs provide services for people with ASD as part of their larger missions to serve Mainers with developmental and intellectual disabilities and other needs. Eligibility for some public agency disability services is determined by level of impairment and/or financial need.



Office of Child and Family Services (OCFS)

MaineCare

- **Ages 0-21:** Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), Children's Behavioral Health, Family Support, Children's Private Non-Medical Institution (PNMI)

Department of Education (DOE)

Child Development Services

- **Ages 0-2:** Developmental Services
- **Ages 3-5:** Inividuals with Disabilities Education Act (IDEA) Part B

Local schools/special purpose private schools

- **Ages 5-22:** Inividuals with Disabilities Education Act (IDEA) Part B

Department of Labor (DOL)

Bureau of Rehabilitation Services

- **Ages 14+**: Vocational Rehabilitation
- **Ages 18+**: Independent Living Services

Office of Aging and Disabilities (OADS)

MaineCare

- **Ages 18+**: Targeted Case Management (TCM), Person-Centered Planning, §29, §21, Private Non-Medical Institution (PNMI), Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID)

Figure G. Number of people with ASD served by MaineCare by Age Group

SFY2019 and SFY2020

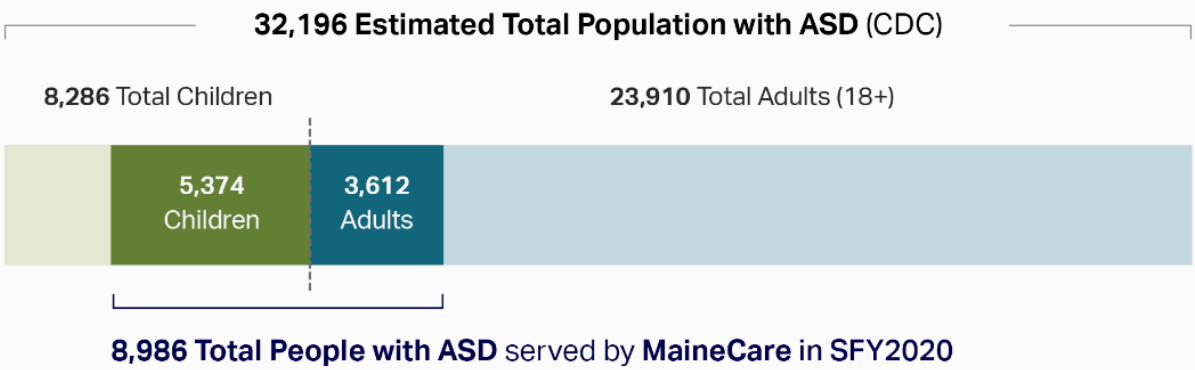
	Age Group	2019	2020
Children 0-17	0-2	293	80
	3-5	1,089	931
	6-13	2,870	2,840
	14-17	1,266	1,523
	Subtotal 0-17	**5,558**	**5,374**
Adults 18+	18-20	834	894
	21-34	1,704	1,926
	35-44	347	378
	45-54	185	206
	55-64	134	134
	65-74	51	57
	75+	13	17
	Subtotal 18+	**3,268**	**3,612**
	TOTAL	**8,786**	**8,986**

Source: *Office of Aging and Disability Services; MaineCare claims data*

While Mainers with ASD access services from different agencies depending on age and type of service needed, MaineCare is a common thread, covering medical, behavioral, developmental, and long-term services and supports for many children and some adults with ASD. Based on diagnostic codes within the MaineCare claims system, in SFY2019 and SFY2020, MaineCare served 8,786 and 8,986 people with ASD, respectively (Figure G).

Using the CDC estimates of the total population of people with ASD, approximately sixty-three percent of children (3-17) and fifteen percent of adults (18+) with ASD access MaineCare services. Note that the MaineCare data for adults with ASD may reflect fewer people with ASD than are actually covered by MaineCare. For example, it is possible that the claims information has the diagnosis code of intellectual disability rather than the specific ASD diagnostic code. In that instance, the adult would not be included in the table below, but they would still be covered by MaineCare and receive adult developmental services (Figure H).

Figure H. **People with ASD and MaineCare coverage,** SFY2020



Services for Children, Ages 0-22

Office of Child and Family Services

Beginning at the youngest ages, birth through age 2, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services are designed to identify ASD and other conditions during well-child visits and to start interventions as soon as possible. EPSDT services are a federally required benefit for any child under the age of 21 covered by Medicaid (§94 of the MaineCare Benefits Manual). According to CMS, the EPSDT benefit "is designed to assure that children receive early detection and preventive care, in addition to medically necessary treatment services, so that health problems are averted or diagnosed and treated as early as possible. All children, including

children with ASD, must receive EPSDT screenings designed to identify health and developmental issues, including ASD, as early as possible." [1]

The American Academy of Pediatrics recommends EPSDT screening for ASD at the 18 and 24-month well-child visits as well as additional screenings if the child has a sibling with ASD.

OCFS Vision

All Maine children and their families receive the services and supports they need to live safe, healthy, and productive lives in their home, school and community.

Once children with ASD are identified, the Office of Child and Family Services (OCFS) Child Development and Behavioral Health Services Team supports them and their families to access high-quality early childhood education and behavioral health services in their homes, schools, and communities. Figure I shows the MaineCare services available to children with behavioral health needs, including children with ASD.[2] Children must be eligible for MaineCare to receive these services. There are additional state and federally funded behavioral health services administered by OCFS including crisis stabilization, family and peer support, and respite care.

[1] Medicaid.gov. https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf accessed January 18, 2021.

[2] MaineCare services and programs are often referred to by their section numbers (§#) in the MaineCare Benefits Manual found at 10-144 C.M.R. ch.1: https://www.maine.gov/sos/cec/rules/10/ch101.htm.

Figure I. **OCFS Services Available to Children with Behavioral Health Needs including Children with Autism Spectrum Disorder**

MaineCare Funded (Requires MaineCare eligibility)

§28 Rehabilitative and Community Services (RCS)	▸ Skill building in areas of daily living and behavioral management to support child's functioning in the home and community, including the use of Applied Behavior Analysis
§13 Case Management	▸ Help to identify, locate, and access natural and community resources and appropriate treatment services to meet the needs of the child and family
§65 Behavioral Health Services	▸ Outpatient behavioral health services, medication management, administration, and/or monitoring ▸ Home and Community Based Treatment (HCT) offers strategies to help the child and family manage mental health symptoms, function better in home, school and community, and prevent hospitalization ▸ Assertive Community Treatment (ACT) provides intense 24/7 symptom management and supports in home, school and community to prevent hospitalization ▸ Therapies including Functional Family Therapy, Multi-Systemic Therapy, and and Multi-Systemic Therapy for youth with Problem Sexual Behavior ▸ Crisis Stabilization
§97 Residential Treatment (Private Non-Medical Institution or PNMI)	▸ Residential treatment is a short term treatment (1 to 4 months) to teach youth/parents skills to manage behaviors safely at home

In both SFY2019 and SFY2020, OCFS administered MaineCare billable children's behavioral health services for over 3,500 children with ASD. Figure J shows the number of children with ASD who used the different types of behavioral health services.

Figure J. **Children with ASD who used MaineCare Children's Behavioral Health Services** SFY2019 and SFY2020

Service	2019	2020
Rehabilitative and Community Services	1,751	1,762
Crisis Stabilization	44	33
Targeted Case Management	1,223	1,117
Children's Private Non-Medical Institution	159	170
Home and Community Based Treatment	315	258
Outpatient	1,678	1,550
Totals	**3,565**	**3,516**

Source: *Maine Office of Child and Family Services*

OCFS System Improvement and Reform Strategies

In 2018, Maine DHHS contracted with an independent consultant to conduct an assessment of the OCFS Children's Behavioral Health Services with the goal of identifying strengths and weaknesses, quality of outcomes, service array, capacity, funding structure, and program operations.[3] The assessment identified five areas impacting children and families seeking and receiving children's behavioral health services:

1. **Access**: Children's behavioral health services are not available immediately (or at all).
2. **Proximity**: Behavioral health services are not always available close to the community where children live.
3. **Appropriateness**: When children do get services, it's not always the right service.

[3] The final report can be found here: https://www.maine.gov/dhhs/ocfs/cbhs/documents/ME-OCFS-CBHS-Assessment-Final-Report.pdf

4. **Quality**: The quality of behavioral health services is not consistent.
5. **Coordination**: Coordination with other child-serving agencies and transition to adult services is inadequate

Since the 2018 assessment was published, OCFS has been working in a collaborative process with Department leadership, OCFS staff, families, providers, and other stakeholders to improve children's behavioral health services by focusing on thirteen prioritized strategies:

SHORT TERM (2019 – 2022)

- Hire a full-time, on-site OCFS Medical Director
- Facilitate access to parent support services
- Explore options to amend current service definitions for MaineCare §28
- Clarify children's behavioral health services roles, responsibilities, procedures, policies, and practices
- Establish one or more Psychiatric Residential Treatment Facilities (PRTF)

LONG TERM (2019 – 2025)

- Address shortages in the behavioral health care workforce
- Align residential services to best practices and federal quality standards
- Improve children's behavioral health crisis services
- Expand the use of evidence-based models and evidence-informed interventions
- Enhance skills of early childhood workforce to address challenging behaviors
- Explore a statewide or regional "single point of access"
- Revise the waitlist process
- Improve coordination for transition-age youth behavioral health services

Although these strategies are not specific to autism, children with ASD and their families would benefit from their success, especially that of amending the service definitions of MaineCare §28. Amending MaineCare §28 to focus on children with intellectual or developmental disability or ASD could make these services more available to the children who could benefit most from skill-building interventions and Applied Behavioral Analysis.

As of December 2020, OCFS has made the most progress on the strategies of hiring a full-time, on-site Medical Director and establishing a Medicaid Rule for a Psychiatric Residential Treatment Facility (PRTF, MaineCare §107). Over half of the tasks required to implement the reform strategies of amending MaineCare §28, clarifying CBHS roles and responsibilities, addressing workforce shortages, and aligning residential services with best practices and federal guidelines have been completed. There has been less progress in revising the waitlist process, improving crisis services, improving coordination for transition-age youth, and expanding evidence-based models, but OCFS continues to move forward. For more information on OCFS's progress in implementing the strategies, see Children's Behavioral Health: An Update on System Improvement Efforts.

Department of Education

The Department of Education administers several different services for children with developmental disabilities, including ASD. The Department of Education is dedicated to increasing training, professional development and technical assistance to support high quality programming for individuals with ASD in Maine, especially in rural areas of the state. Under the Individuals with Disabilities Education Act (IDEA), children with ASD have access to Early Intervention (IDEA Part C) services (birth through age 2) and Free Appropriate Public Education (IDEA Part B) services (ages 3 through 21).

DOE Vision

The people of Maine are lifelong learners served by an innovative, equitable, and learner-centered public education system that supports students – early childhood throughout adulthood - in achieving healthy, successful, and fulfilling lives that allow them to shape the future.

CDS, ages 0 through 5 years

The Child Development Services system is an Intermediate Educational Unit that provides both Early Intervention (birth through age 2) and Free Appropriate Public Education (for ages three through five years). The CDS system ensures the provision of special education rules, federal and state regulations statewide, through a network of regional sites. Regional CDS sites provide case management and direct instruction for families with children from birth through age five. Each site conducts Child Find, which is the systematic process of identifying children with disabilities. Screenings and evaluations are provided in order to identify children who are eligible for services. Regional CDS sites arrange for locally-based services that include early intervention

and special education and related services for eligible children from birth to age five and their families.[4]

The number of children ages 0-2 identified as having developmental delays who used Part C services increased from 698 in 2017 to 1,232 in 2020; **not all children with developmental delay are later diagnosed with ASD.** The number of children ages 3-5 identified as having ASD has fluctuated over the same time period with a high of 1,202 in 2017 to a low of 776 in 2018 (see Figure K).

Figure K. **Number of children using CDS services by Age**
SFY2017-2020

Service	2017	2018	2019	2020
Number of children 0-2 with developmental delay*	698	709	1,087	1,232
Number of children 3-5 with ASD	1,202	776	862	958

** May include children 0-2 with autism spectrum disorder.*

Source: *Child Development Services, Maine Department of Education.*

School-based Special Education, ages 5-21

School-age children (ages 5 through 21) receive special education services in the least restrictive environment under the IDEA through their local school districts or special purpose private schools as needed. Special purpose private schools are specialized schools that provide educational programming and crisis stabilization for students who are unable to access their education in a less restrictive setting within their school district. These schools operate Day Treatment programs; provide coordinated and integrated behavioral, clinical, educational, emotional, medical, and social treatment in order to address the concerns that prevented each student from accessing their education in a less restrictive setting.[5]

Students with ASD have access to the same services available to other students with special education needs. Students with special education needs have Individualized Education Plans to ensure they received specialized instruction and related services. An ongoing initiative of the

[4] Maine Dept. of Education. Child Development Services. Available at https://www.maine.gov/doe/learning/cds

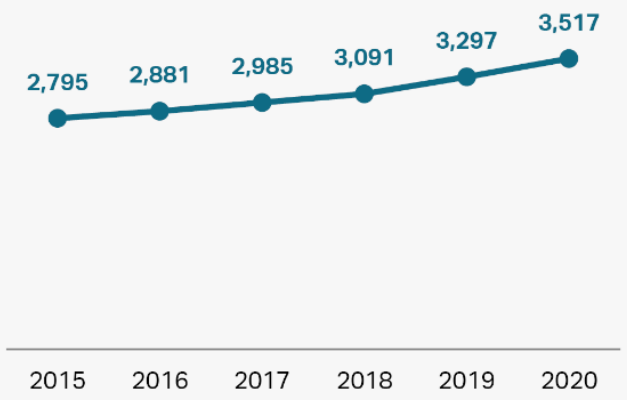
[5] Maine Dept. of Education. Special Purpose Private Schools. Available at https://www.maine.gov/doe/learning/specialed/specialpurposeprivateschools

Department of Education that might have particular impact on students with ASD is Positive Behavioral Intervention and Supports (PBIS). Developed by national experts, PBIS provides a multi-tiered approach to supporting the social, emotional and behavioral development of students in K-12 settings with the goal of improving the social, emotional and academic outcomes for all students, including students with disabilities and students from underrepresented groups. The framework consists of three tiers of intervention—school wide; targeted interventions for groups of students; and individualized interventions. The Department of Education has collaborated with the University of Maine to support districts, schools, and community-based organizations to implement the PBIS framework through providing professional development and technical assistance, access to evidence based practices, and evaluation of outcomes of positive behavior supports.[6]

School districts throughout the state can collaborate with each other on special education initiatives. An example of one such collaboration which specifically targets students with ASD is the Western Maine Regional Program for Children with Exceptionalities. Three school districts in western Maine plus the Oxford Hills Technical School share a space and resources to provide services including experiential learning opportunities to students in sixth through twelfth grade with autism and/or emotional disabilities and other behaviorally challenged students who would otherwise be placed in special purpose private schools outside the participating districts.

The number of school-age students in special education with ASD ages five through twenty has also increased (Figure L).

Figure L. **The number of special education students with ASD ages 5-20 has increased** between 2015 and 2020



Source: *Maine Department of Education*

[6] Positive Behavioral Intervention & Supports. Available at https://www.mainepbis.org/

In 2015, students with ASD made up 9.3 percent of the students receiving special education services. This increased to 10.8 percent in 2020 (Figure M).

Figure M. **Children age 5-20 in Special Education,** 2015-2020

	Total Special Education Students	Special Education Students with ASD	Percent of Special Education Students with ASD
2015	29,967	2,795	9.3%
2016	30,366	2,881	9.5%
2017	31,126	2,985	9.6%
2018	31,791	3,091	9.7%
2019	32,228	3,297	10.2%
2020	32,657	3,517	10.8%

Source: *Maine Department of Education*

As of January 2021, students can receive special education services through age 21, though many students with ASD transition out of special education services after age 17 or 18. Data from 2015-2020 shows this transition has been consistent over time (Figure N).

Figure N. **Special Education Students with ASD by Age,** 2015-2020

Age	2015	2016	2017	2018	2019	2020
5	159	169	159	187	196	243
6	202	207	219	223	262	278
7	222	209	221	240	243	276
8	214	227	231	232	268	247
9	215	231	249	242	251	275
10	247	215	249	244	247	242
11	213	238	224	247	259	256
12	236	218	234	230	264	283
13	208	242	227	243	237	289
14	197	213	245	224	258	236
15	202	207	217	238	234	271
16	191	205	199	214	248	233
17	154	189	193	189	210	240
18	96	73	83	94	84	106
19	33	33	*	*	*	33
20	6	5	*	*	*	9
TOTAL	**2,795**	**2,881**	**2,985**	**3,091**	**3,297**	**3,517**

Most students with ASD leave special education when they are 17-18 years old.

Source: *Maine Department of Education*

Transition-Age Services, ages 14-21

Office of Child and Family Services and Office of Aging and Disability Services

While eligibility for adult developmental services begins at age 18, individuals can continue receiving Children's Behavioral Health up to their 21st birthday. However, individuals cannot receive both children's and adult services at the same time, and the transition from one system to the other is not seamless. The 2018 OCFS Final Assessment report identified the transition process from children's to adult services as an area needing improvement. OCFS has developed an internal road map and begun receiving internal and external stakeholder input on improving the transition process. Though not specifically identified in this goal, children with intellectual and developmental disabilities, including ASD, who are transitioning to adult services will benefit from improvements in this area.

In general, OCFS works with the Office of Aging and Disability Services (OADS) to help children with developmental disabilities transition from school to adulthood, and from developmental services provided through OCFS to adult services provided through OADS. There are several significant structural challenges for parents and their children navigating this transition. First, there is mismatch between the services available to children and those available to adults. Access to adult services is limited to those with an intellectual disability or autism, while eligibility criteria for children's developmental services is more broadly defined. Further, children benefit from Maine's EPSDT program, which requires MaineCare to cover medically necessary services identified through Maine's Bright Futures program, including rehabilitative services, which could be paid for by MaineCare but are not currently covered under the Medicaid state plan. Access to EPSDT services ends after age 20. As families look to the future, they are now faced with the challenge of learning about the different service options, finding out which they might be eligible for and learning about how the level and type of support might be different in adult programs.

For those who are eligible for adult developmental services, the waitlist for the two adult Home and Community-based (HCBS) waiver programs is another structural challenge.[7] Although some people may continue to receive children's services while on the waitlist for one of the adult

[7] OADS reserves up to four openings on §21 for individuals aged 18 to 21 transitioning to adult services who are receiving out-of-home services out of state.

waiver programs, not all people are able to transition directly from children's services to the adult HCBS waiver services. While alternative services may be provided in the interim, some needed services may be unavailable, potentially resulting in negative consequences and setbacks. For example, for parents who work or are otherwise unable to provide the level of support during this interim period, a gap in needed services and supports may lead to a health and safety risk. In addition, starting no later than ninth grade, schools begin preparing children for the transition to adulthood, helping them set goals for what comes after school. For those with educational, employment and other community-based goals, a gap in access to needed supports may stall or even reverse progress.

Another significant challenge is the limited access to case management services from the adult services system while still receiving case management services in the children's services. Individuals transitioning from children's services to adult services may be eligible for up to 30 days of overlapping case management services from both the child and adult systems. While 30 days of overlapping services may be sufficient to effectuate transition once plans are in place, planning for the transition itself takes much longer than 30 days. Without the help of a case manager in the adult system, it is difficult to learn about what adult services options are available, what services an individual is eligible for, what alternative services might be available while on a waitlist for services, and all of the other details that must be addressed to ensure a successful transition.

OADS is committed to working with OCFS to improve transitions on a case-by-case basis. In addition, OADS would welcome the opportunity to participate in system-level conversations about how to address the structural challenges that make transition so difficult for so many.

Department of Education

The Individuals with Disabilities Education Act (IDEA) requires schools to provide services to promote successful transition to employment and independent living for all students with disabilities. The IDEA defines Transition Services as: "a coordinated set of activities for a child with a disability that is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation." OCFS collaborated with the Department of Education, OADS, the Department of Labor, and other

stakeholder organizations to develop a handbook to guide students and families through the transition process.[8]

On January 21, 2021, the Commissioner of the Department of Education issued an administrative letter changing the cut-off age of eligibility for special education from age 20 to age 22, to be consistent with the IDEA as interpreted by the First Circuit in *K.L. v. Rhode Island Board of Education*, 907 F.3d 639 (2018). The administrative letter also specified that all school administrative units must notify adult students who would have previously "aged out" of special education on June 30, 2021 of their right to receive a free, public education until either they receive a regular high school diploma or their 22nd birthday, whichever comes first. This change effectively extends the period for students transitioning to adult services.

Transition planning services are required to be initiated by a student's school, no later than ninth grade, although parents may request transition services to begin earlier. The school maintains a record of the transition plan in the student's Individualized Education Plan, and it must be discussed annually for all transition-age students, more often if possible. Key steps in the plan development include:

- Assessing the student to determine strengths, interests, and needs.
- Identifying the student's vision for where they want to live, what post-secondary education they want to pursue, and what kind of work they would like to do.
- Setting specific, measurable goals around education, employment, and independent living
- Choosing transition services that will enable the student to reach their goals
- Finding support, both natural community support and paid supports.

The transition handbook describes the transition planning process as a team effort by the student, family members, and school, with all members supporting the student to steer the process. The school plays the most significant role as it is responsible for ensuring that an appropriate transition plan is created and services provided. The school is also responsible for creating alternative solutions if other agencies or team members fail to provide a required service.

[8] A Guide to Transition Services in Maine. Available at https://content.govdelivery.com/attachments/MEHHS/2016/06/30/file_attachments/578674/MSK.HDBK-update%25286.23.16%2529.pdf

Department of Labor

The Division of Vocational Rehabilitation (DVR) and Division for the Blind and Visually Impaired, within the Bureau of Rehabilitation Services, Maine Department of Labor, assist transition-age students and young adults (aged 14-24) with disabilities – including those receiving services through an Individual Education Program or a Section 504 Plan[9] as well as adults with physical, emotional, or mental impairment including intellectual or developmental disabilities and ASD – to access vocational rehabilitation services to help them get and keep a job. Students aged 14-21 also have access to "Pre Employment Transition Services" which include:

- Job exploration counseling
- Work-based learning experiences, which may include in-school or after school opportunities, experiences outside of the traditional school setting, and/or internships
- Counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs
- Workplace readiness training to develop social skills and independent living
- Instruction in self-advocacy

Vocational rehabilitation (VR) can assist students with disabilities in coordinating information and resources as they transition from high school to adult life. While VR is a time-limited program—and in general, once an individual is employed for at least 90 days in a job agreed upon by the individual and the VR counselor, services are ended—VR is also committed to creating opportunities for access to career pathways with individuals.

The DVR has collaborated extensively with the Department of Education in supporting Employment First legislation, data sharing, joint training and technical assistance and the launch of interagency efforts, such as the Cross-Agency Council for Transition. A Department of Education staff member serves on the State Rehabilitation Council and the DVR Director serves on the IDEA Part B State Advisory Panel.

The DVR assists in transition planning and in the development of each eligible student's Individualized Plan for Employment. The VR program provides guidance in establishing employment goals, understanding job training requirements, job coaching, obtaining assistive

[9] Section 504 of the 1973 Rehabilitation Act ensures students with disabilities receive accommodations and access to education. For more information, see https://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.pdf

technology, tools, and uniforms, and assisting the individual to seek employment. VR counselors work with students to understand post-secondary education opportunities and ensure that needed supports are in place. For students eligible for services who have an agreed upon vocational goal, VR counselors develop an Individualized Plan for Employment before the student leaves the school setting.

Every Maine high school and private special purpose school has an assigned VR counselor. However, the 2019 State Rehabilitation Council Needs Assessment indicated that VR counselors in some areas of the state such as Cumberland and York counties may have higher caseloads than other areas.[10] More information on the collaborative efforts between the Department of Education and the DVR to improve the transition process for students into employment is available in the DVR's State Plan for 2020, Bureau of Rehabilitation Services: Vocational Rehabilitation State Plan.

The Step-Up program, developed by the DVR in collaboration with the University of Maine's Center for Community Inclusion and Disability Studies, is for students on the Autism Spectrum who wish to go on to post-secondary education. It is a five-week summer program providing social skill instruction to aid with communication, along with a 3-credit college course, college prep seminars and work experience. Students in the program get a taste of what college life is like before going off to college full-time. In 2019, the program served five high school students with ASD. In 2020, the Step-Up program was conducted virtually due to the COVID-19 pandemic; nine students were able to complete the program online. Planning is underway for Step Up for summer 2021.

The DVR is currently undertaking a research project with Dr. Sarah Howorth at the University of Maine to examine the effectiveness of delivering the PEERS® evidence-based social skill curriculum for teens with ASD diagnoses. The PEERS® curriculum is offered via telehealth and is co-facilitated by Dr. Howorth and trained VR staff. The research is being expanded to include young adults ages 20-24 in spring 2021.

In response to the COVID-19 pandemic, VR staff implemented remote intakes, assessments, and Individualized Plan for Employment development. Other services were conducted virtually as well such as career exploration workshops and job shadow experiences. Early in the pandemic, the Divisions kept stakeholders informed through weekly meetings. Throughout the pandemic, the Divisions were responsive to individual client need when providing services.

[10] Department of Labor. State Plans and Needs Assessment. Available at https://www.maine.gov/rehab/dvr/stateplan/index.shtml

Transitioning to Guardianship or Supported Decision-Making

Maine's Probate Code includes a guardianship statute allowing for the appointment of a guardian for individuals who are unable to receive and evaluate information or make or communicate informed decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety or self-care. In 2019, the Maine Legislature updated Maine's Probate Code to specifically require less restrictive alternatives be attempted before a probate court will consider appointing a guardian. Less restrictive alternatives include having supportive services in place, technological assistance, and supported decision-making activities.

Supported decision-making is a strategy to increase self-determination where an individual receives assistance from a supportive team of the individual's choosing that helps the individual understand the nature and consequences of potential personal and financial decisions. This assistance enables the individual to make and communicate their own informed decisions. Transition-age children with intellectual or developmental disabilities, including ASD, and their families can learn about supported decision-making alternatives during the planning activities as they transition from children's to adult services.

Services for Adults, ages 18+

Department of Labor

As described in the previous section on Transition-Age Services, the DVR administers VR services for adults and transition-age students ages 14 and older. In addition to VR, adults with ASD, may also be eligible for Independent Living Services. The four core services that every Independent Living Center provide are:

- Information and Referral
- Individual Independent Living Skills Training
- Peer Counseling
- Individual and Systems Advocacy

In addition, the Independent Living Services program can purchase a variety of products and services to help individuals be more independent in their homes and/or communities. Some examples of products and services available through this program include:

- Home modifications
- Hand controls and lifts for vehicles
- Augmentative Communication Devices
- Telecommunication Devices for the Deaf (TTYs)
- Counseling Services
- Mobility Training

The Independent Living Services Program cannot pay for services that are traditionally provided by other state, federal or private agencies. There is a maximum lifetime expenditure of $5,000 allowed for each eligible individual served by the Independent Living Services Program.

Office of Aging and Disability Services

For adults with ASD (age 18 and older), OADS administers the MaineCare HCBS waiver programs for adults with intellectual disabilities or autism. HCBS waivers are Medicaid-funded service packages designed specifically for helping older adults and people with disabilities who would otherwise require institutional services to live as independently as possible in the community. These waivers are the primary pathway for accessing services that support the pursuit of one's own goals, employment, and engagement in the community. Maine's HCBS waivers are often referred to by their section number (§#) in the MaineCare Benefits Manual.[11] The §21 waiver, sometimes referred to as the "Comprehensive Waiver" provides a broader array of services than available under §29, sometimes referred to as the "Support Waiver."

OADS Vision

To promote individual dignity through respect, choice, and support for all adults.

Both §21 and §29 offer Home Supports,[12] Work Supports, and Community Supports, which are direct support services,[13] and assistive technology designed to support people in their homes, at work, and in the broader community. Both waivers provide services and supports in a privately-

[11] The MaineCare Benefits Manual. 10-144 C.M.R. ch.1. Available at https://www.maine.gov/sos/cec/rules/10/ch101.htm.

[12] Home Support includes several categories of services, including "Home Support – Agency" (group home services), Home Support – Quarter Hour, Home Support – Remote, and Home Support – Family Centered Support.

[13] "Direct support" includes assistance with personal care and other tasks, exercising safe and responsible judgment, and promoting personal development and health and well-being.

owned or rented home or apartment, or in a shared living arrangement. Enrollees under §21 have access to services in a provider-owned or controlled group home. In addition, under §21 enrollees also have access to therapies (*e.g.*, physical, occupational and speech therapy), as well as communication aids and other devices and services designed to overcome physical, sensory, or other barriers to mobility, communication, participation in the community, and other activities. A side-by-side comparison of services covered under each waiver is provided in *Appendix B*.

Maine continues to expand access to good jobs for individuals with a disability. As discussed earlier, Maine is an Employment First state. Under Employment First Maine Act[14] providers are required to offer employment services before offering other services, such as Community Supports. In June 2020, Maine repealed the subminimum wage provision, making Maine one of only three states that ensure that all employees are paid at least minimum wage, regardless of disability. This year OADS is conducting several training events aimed at increasing the knowledge and skills of case managers and direct support professionals to successfully support individuals in obtaining and maintaining employment. Additionally, OADS coordinates with the Office of Behavioral Health and the Bureau of Rehabilitation Services within the Department of Labor to help individuals with disabilities obtain and maintain employment through the Vocational Rehabilitation or the Independent Living Services program that assists adults who have significant disabilities to live more independently in their homes and communities.

Individuals who are not accessing HCBS waiver services may be receiving residential services financed under MaineCare as Private Non-Medical Institution (PNMI) services (§97 in the MaineCare Benefits Manual), or services provided in an intermediate care facility for individuals with intellectual disability (ICF-IID) (§50 in the MaineCare Benefits Manual). Intermediate care facilities are designed to meet the intensive, active treatment needs of persons with intellectual disabilities. PNMIs are funded to provide clinical and personal care services[15] and vary in size; they may serve up to 16 people.

Other services available to adults with ASD who are not accessing either waiver or facility-based services include Targeted Case Management (funded primarily through MaineCare §13), Person Centered Planning, public guardianship and conservatorship, Adult Protective Services, and statewide crisis prevention and intervention services. Person Centered Planning (PCP) is the

[14] 26 M.R.S.A. §§ 3401-3403

[15] "Personal care services" are a subset of "direct support services," typically focusing on helping a person with activities of daily living (ADLs) such as mobility, bathing, toileting, etc.

required annual planning process for adults receiving developmental services in Maine. PCP involves identifying and describing the person's needs and goals as well as the paid and unpaid supports and services the person requires to live in a meaningful and self-directed life.

Figure O. **Number of Adults with ASD Who Used MaineCare Developmental Services** SFY2019 and SFY2020

MaineCare Service	SFY2019	SFY2020
§13 Targeted Case Management	2,318	2,148
§21 Comprehensive Waiver	367	348
§29 Supports Waiver	279	259
§97 Private Non-Medical Institution	209	205
Unduplicated Total Served	**3,565**	**3,516**

Source: *Maine Office of Aging and Disability Services*

Figure O shows the number of adults with ASD who used developmental services in SFY2019 and 2020. The columns will not add up to the total number of people served as individuals could have accessed more than one service within the same year.

OADS Reform Initiatives

OADS has a two-year plan for improving the design and quality of its programs in order to strengthen OADS' ability to assure that individual goals and preferences are met.

OADS recognizes that ambitious change can only move forward with the trust of those receiving and delivering services, and the confidence of the Legislature and public who provide the funding for services. To ensure that services meet the needs of those they serve, program and system improvements must include the input of people with firsthand experience receiving or delivering services. In the past two years, OADS has worked hard to increase transparency and access to information, and engage stakeholders directly in systemic reform. In the summer of 2019, the OADS Director, in partnership with the Maine Developmental Services Oversight and Advisory Board, engaged in a series of listening sessions in Portland, Bangor, and Lewiston, to hear from people receiving services, their families, guardians, providers, and other interested community members. These sessions provided OADS with vital feedback regarding systemic issues, concerns, and successes, which, in turn, have shaped OADS reform initiatives described in the Biennial Plan.

To move forward with these reform initiatives, OADS is taking on an ambitious stakeholder process involving ten stakeholder groups to guide changes in policy and practice, as well as important structural reforms. Some of these efforts were suspended in the wake of the COVID-19 public health emergency, while others have continued virtually. However, OADS has restarted some of these efforts and anticipates that all stakeholder activities will be underway again in 2021. Workgroups include self-advocates, family members, guardians, advocates and providers. Additionally, as noted earlier in this report OADS contracted with the Maine Developmental Disabilities Council to conduct focus groups and surveys to gather input from families, guardians, and individuals with ASD.

2021-2022

OADS Priorities for Improving Services

OADS has a two-year plan for improving the design and quality of its programs in order to strengthen OADS' ability to assure that individual goals and preferences are met. OADS is committed to improving the lines of communication with stakeholders, and stakeholders will be guiding much of the work described in this section. Although not discussed in detail, a separate reform work group will be formed to develop recommendations for improving the accessibility of information (e.g., by using plain language); developing an ongoing stakeholder feedback loop, and other efforts aimed at improving transparency and communication.

In addition to these efforts, OADS' priorities for the 2021-2022 include:

Community Membership

OADS has convened a Community Membership Reform Work Group, to identify strategies to promote full inclusion of people with disabilities into communities. The work group will address enhanced person-centered planning, self-advocacy, family support, community support, and implementation of Maine's Employment First statute. In addition, this group will identify strategies for ensuring compliance with the HCBS settings rule following complete implementation of the HCBS transition plan.

Innovation

In partnership with the Innovation Work Group, OADS will explore new strategies for enhancing self-direction, developing innovative housing options, redesigning the delivery and operation of Maine's HCBS waivers to better ensure that people have the services they need when they need them, explore new options for expanding access through technology, and improving crisis services.

Quality Assurance

In partnership with the Quality Work Group and informed by a consultant's recommendations, OADS will continue to strengthen quality assurance and quality improvement capacity.

System Capacity and Access to Services

OADS will continue to address longstanding challenges in the service delivery system, including waitlists, workforce shortages, and limited access to transportation, and limited access to dental services.

Interagency Coordination to Improve Outcomes

OADS will continue ongoing efforts to improve coordination of services for individuals served by multiple agencies, or people transitioning from one service system to another.

For more details on OADS' planning efforts to meet the needs of adults with intellectual disabilities or autism, please see the most recent Biennial Plan.

Community-based Organization and Public-Private Partnership Perspectives and Efforts to Enhance System Competency

Maine is fortunate to have many community-based organizations and public-private partnerships that serve children and adults with ASD and their families. Some of these organizations provide services and learning opportunities directly to individuals with ASD and their families while others focus on advocacy, policy and system change, and professional education and serve the broader population of people with developmental disabilities. Below is information from some of the key partners highlighting their recent efforts impacting people with ASD and families as well as how the COVID-19 pandemic impacted their programs and the people they serve.

COVID-19

The COVID-19 pandemic has impacted every Mainer, with distinct impacts for people with intellectual disabilities or ASD, particularly those residing in congregate settings. Some people receiving in-home services also experienced hardship, choosing to forgo in-home services to reduce exposure or interruptions in services because of provider shortages exacerbated by the pandemic. For more information on the Department of Health and Human Services response to the pandemic with regard to services for people with intellectual disabilities and ASD, please see the Biennial Plan.

Autism Society of Maine

Advocacy, Education for Families and Professionals, Information, Social Opportunities

The Autism Society of Maine (ASM) is a nonprofit organization providing education and resources to support people with ASD and their families. ASM advocates for the general welfare of individuals with autism through promoting family and community support; advancing ameliorative and preventive study, research, therapy, and care of individuals with autism; promoting the education, training, and vocational opportunities of individuals with autism and

fostering the development of integrated care on their behalf; and furthering the education and training of parents and professional personnel working with, educating, and caring for individuals with autism, among other activities.

In 2020, ASM provided services and resources to 419 children with ASD and 2,586 families. Informational trainings geared toward different audiences included sessions for children, the general public, and law enforcement to broaden understanding of autism. Other training efforts focused on behavioral, social, and communication strategies, navigating the transition from school to adult life, and safety in the community.

ASM also provides a family retreat program, summer camp, teen social groups, and an Autism Information Specialist Program that provides one on one assistance for families, guardians, and individuals in navigating children's or adult services. Autism Information Specialists can participate in educational, transitional, and vocational planning meetings, and they conduct presentations and workshops for agencies and community organizations across the state.

Both the family retreat and summer camp programs were cancelled in 2020 due to the COVID-19 pandemic. In response to the pandemic, the teen social groups converted to an online platform. Workshops that had been set up at the beginning of the pandemic had to be cancelled, and ASM is working to set them up online. ASM's Autism Information Specialist staff decreased as they needed to be at home and care for their own family members, affecting the number of individuals and families ASM could assist. In addition, ASM's fundraising efforts were cancelled due to the pandemic and the organization is struggling to meet its financial obligations, which in turn, affects the services it can provide.

An ASM representative described the impact of the COVID-19 pandemic on people with ASD: "For individuals with autism and receiving services through Zoom, this has been very difficult and they have taken steps backwards for sure. For those that are high functioning individuals, they seem to be maintaining, but for all others are suffering with the current situation-- it will take years for them to regain what they lost."

For more information, please visit ASM at https://www.asmonline.org/

Maine Developmental Disabilities Council

Advocacy, Education for Families and Professionals, Information

The Maine Developmental Disabilities Council (MDDC) is a federally funded partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self-determination, and independence. MDDC works to support system change for all people with developmental disabilities, including people with ASD of all functional levels.

Several MDDC programs directly impact people with ASD including the ongoing "Learn the Signs. Act Early" campaign which, annually, delivers materials and information directly to hundreds of early childhood professionals and parents, health care providers, nutrition program directors and staff, and members of the general public, in order to increase awareness and understanding of developmental milestones so that children with developmental disabilities including ASD can be identified early and access appropriate services. In federal fiscal year 2020 MDDC supported projects, among other things, to; include a self-direction waiver for individuals with developmental disabilities, reduce restraint and seclusion, and increase individuals with developmental disabilities ability to access community through technology.

Like many agencies, MDDC shifted priorities to respond to the COVID-19 pandemic. By the end of April 2020 there were clear indications that people with developmental disabilities were unduly impacted by both the coronavirus itself as well as the societal repercussions of "stay at home" orders and social distancing mandates. Congregate settings were becoming hotspots of transmission, and the services that people with developmental disabilities depend on were being shut down or moved to virtual settings. People with developmental disabilities often lack access to the tools that allow for online and virtual connection, due to the costs of hardware, the learning curve to understand how to use devices, and connectivity issues across the state, among other factors. Faced with a pandemic crisis that was changing the idea of "business as usual," the Council decided that this issue had become a priority. After shifting funding to this nascent project, MDDC purchased 147 new iPads, built a simple website to collect applications, and reached out to parent and self-advocate organizations, service providers and case managers across the state to solicit applications to receive an iPad, with a focus on the level of need, current access to wifi, and desire to use the device to receive services, connect with family and friends, and better advocate for themselves. In one week, MDDC received over 450 requests for an iPad – over 3 times the number of iPads available for this project. The number of applications indicates a clear and pressing need for access to this kind of technology. MDDC is assessing the

results of this project with an eye towards how to support broadening access to technology for people with developmental disabilities in the future.

For more information, please visit the MDDC at https://www.maineddc.org/

Maine Parent Federation

Family Support and Training, Information

The Maine Parent Federation (MPF) is the federally funded Parent Training and Information Center as well as the Family to Family Health Information Center, charged with providing information, resources, and referrals to all families of children with disabilities or special healthcare needs. Its Family Support Navigator program provides direct peer to peer support to families in order to assist them in navigating all systems of care and increase access to services. In the last year MPF has contracted with the New Mainer's Public Health Initiative to make the navigator program more accessible to immigrant families in the Lewiston/Auburn communities. MPF plans to expand the initiative statewide, especially into the Portland area, where there is a large immigrant population.

When the Maine Legislature updated the probate code to require less restrictive options be tried and provide an explanation as to why they may or may not work for an individual before a guardian is appointed, MPF developed and provided trainings and materials for parents, providers, and youth themselves.

Finally, the MPF is working with the Partnership for Children's Oral Health to provide oral health information and trainings to families of children with special healthcare needs and disabilities. The MPF is also working with this partnership to increase oral health accessibility in schools and to make changes at the legislative level to promote better access.

A representative from the MPF reported that the COVID-19 pandemic has made it incredibly difficult for children with special healthcare needs and disabilities to access their education. Parents have had to play the roles of school teacher, parent, and service provider, and despite their best efforts, they are seeing their children regress. The pandemic has also caused healthcare appointments to be postponed or only accessible virtually, causing challenges for children receiving their healthcare services including well child visits, specialty appointments, and therapies.

The MPF identified the many waitlists for services across all systems of care for children with disabilities and special health care needs as an obstacle to obtaining services. There are waitlists

for early intervention services, and children in K-12 schools have experienced reductions in services due to staffing shortages. There are waitlists for targeted case management, in-home and behavioral supports, waivers for adult services, and respite care. At every intersection of care, families find themselves waiting, sometimes for years, to get the interventions that are needed to move the needle on more positive academic, community, behavioral, education, and employment outcomes.

For more information, please visit MPF at http://mpf.org/

Maine Center for Community Inclusion and Disability Studies

Advocacy, Education for Families, Professional Development

The Maine Center for Community Inclusion and Disability Studies (CCIDS) at the University of Maine, Orono, provides interdisciplinary education, research and evaluation, community engagement, and information that promotes inclusion, diversity, universal design and access, and social justice. While not solely focused on ASD, the CCIDS provides resources for individuals with ASD and their families on advocacy, assistive technology, early childhood, education, employment, guardianship and alternatives to guardianship, health, housing, recreation, respite, siblings, Social Security, spirituality/spiritual supports, and transition.

The CCIDS partners with the University of New Hampshire Institute on Disability and Dartmouth-Hitchcock Medical Center in the New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities (NH-ME LEND) Program to provide graduate level interdisciplinary training for 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. Program activities include leadership development, clinical training, continuing education/technical assistance, research, and cultural competency field work. University of Maine trainees participate remotely in the weekly NH-ME LEND seminar through the use of eLearning and videoconferencing technology.

During the COVID-19 pandemic, CCIDS has partnered with Maine Developmental Disabilities Council in a 'social undistancing project.' Although not specifically targeted to them, people with ASD participated in this project that uses technology to support virtual connections during this time of social isolation.

For more information, please visit the CCIDS at https://ccids.umaine.edu/

Maine-LEND

Education for Families, Professional Development

The University of New England Maine Leadership Education in Neurodevelopmental and Related Disabilities (Maine-LEND) program collaborates with several community partners including Maine Medical Center, Maine General Hospital and Northeast Hearing and Speech in its effort to train healthcare providers, parents, educators, and others to improve the health of children and others with ASD. It focuses on timely diagnosis, effective services, and transition to the workforce and social integration at all ages. The Maine LEND Program training includes classroom and experiential learning, parent and provider conferences, and visiting key agencies throughout the state. Each year, trainees from up to ten different disciplines (including family members) receive 300 hours of training over the course of nine months, involving mentored experiences in clinical settings, classrooms, and the community to learn best practices, inter-professional teamwork, leadership development, and advocacy activities to prepare them to take on leadership roles in their respective fields.

For more information, please visit UNE at https://www.une.edu/LEND

Maine Autism Institute for Educational Research

Education for Individuals and Families, Information, Professional Development

The Maine Autism Institute for Education and Research (MAIER) is dedicated to improving outcomes for individuals with ASD across the spectrum and life cycle. MAIER works to build statewide capacity in support of its mission through leadership, training, professional development, technical assistance, collaborative consultation, technology, and research. MAIER is located at the University of Maine in Orono.

MAIER is a unique partnership between the Maine Department of Education, Office of Special Services and the University of Maine, College of Education and Human Development, Special Education program. Established in 2014 with significant financial support from the Maine Department of Education, these two organizations joined forces to promote evidence-based strategies and effective practices for educators and professionals working with individuals with ASD and for supporting families impacted by ASD.

The Institute serves as the primary source for education and training concerning evidence-based practices for professionals working with children and families impacted by autism spectrum disorders, and for undergraduate and graduate students aspiring to serve children, families,

schools, and community service providers. MAIER also provides professional development through the Maine Autism Leader Team (MALT) training and associated coaching support. MALT teams receive training to implement evidence-based practices to support individuals with autism spectrum disorder in their schools and agencies. MAIER in partnership with the University of Maine College of Education and Human Development, offers a 4-course certificate that prepares experienced educators, administrators, and related service providers to assume leadership roles in the development and implementation of educational programs for students with autism in school settings.

Due to the COVID-19 pandemic, MAIER offered all of its professional development opportunities as pre-recorded webinars, allowing a wider audience than professionals and para-professionals to access them at their own convenience. Without the associated cost of venues and travel, MAIER was able to increase the number of professional development offerings during the pandemic. This format has proven to be very successful, and training and resources were used in high numbers by stakeholders, including family members.

In addition to new online video resources to support literacy development for individuals with ASD, MAIER produced a, "Sexuality Education Resource" that was added to the MAIER website. MAIER also created several web pages to support stakeholders, including Family Resources during COVID-19, PreK-12 Resources, and Visiting from Home.

MAIER's 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 identify issues of concern for Maine families and collaborate on projects to promote greater awareness and acceptance, develop print and online resources, address access to services, and support research efforts. Individuals and families involved in the MFP have been integrally involved in the development and revision of the Maine Parent Guide to ASD, the Places and Spaces Project, and all MFP events.

For more information, please visit MAIER at https://umaine.edu/autisminstitute/

Maine Roads to Quality Professional Development Network

Professional Development

The Maine Roads to Quality Professional Development Network (MRTQ PDN) is a partnership between the Cutler Institute at the University of Southern Maine, the University of Maine Center for Community Inclusion and Disability Studies, and the Maine Afterschool Network. The

MRTQ PDN works to promote and support professionalism in the field of early childhood education and to improve quality through the provision of a statewide system of professional development. The MRTQ PDN is the state's Early Childhood and Out of School Time professional development system. Although not specific to ASD, the network's registry, technical assistance consultants, and trainings are available to early childhood educators who serve individuals with autism. The MRTQ PDN is in the recruitment stage of its 3rd year of offering an Inclusion Initiative to support public schools with developmentally appropriate and inclusive early childhood practices to best support children and families.

In response to the COVID-19 pandemic, all MRTQ PDN work went completely virtual. The program experienced a significant increase in on-demand trainings and Communities of Practice. For the latter, the program provided information on self-care, wellness, and health and safety of practitioners, children and families.

For more information, please visit MRTQ PDN https://mrtq.org/

Conclusion

People with ASD are served by multiple agencies with different funding, goals, and policies. No single agency serves this particular population alone, and services available are generally the same as for people with other types of intellectual or developmental disabilities. The reform efforts already underway at OCFS and OADS will benefit people with ASD, and the two offices are continuing to collaborate with the Department of Education and the Department of Labor on developing and implementing plans to ease the transition process from childhood to adult and enhance system capacity.

Appendix

Appendix A

Survey and Focus Group Questions

Families with Children ASD Survey Needs

- How old is your child now?
- How old was your child when first diagnosed with ASD?
- What services does your child receive? (check all that apply)
    - Case Management
    - Child Development Services
    - School with IEP
    - School with 504
    - In-Home Supports: Section 28 Services (HCBS)
    - In- Home Supports: Section 65 Services (HCT)
    - Speech therapy
    - Occupational Therapy
    - Physical Therapy
    - Other (please specify)
- Is your child waiting for one of these services? (Check all that apply)
    - Case Management
    - Child Development Services
    - School with IEP
    - School with 504
    - In-Home Supports: Section 28 Services (HCBS)
    - In- Home Supports: Section 65 Services (HCT)
    - Speech therapy
    - Occupational Therapy
    - Physical Therapy
    - Other (please specify)
- How many meetings a year do you attend for your child's services?

- The below questions were all scaled responses (Strongly Agree, Agree, Disagree, Strongly Disagree, Neither Agree nor Disagree with comments available)
    - My Case Manager listens and responds to my concerns, questions and ideas
    - My child's in-home support/community support meets my child's needs.
    - My child's service providers coordinate and communicate the services to meet my child's needs.
    - My child's Primary Care Provider/Doctor knows about the services my child receives
    - I still need help accessing childcare
    - I still need help accessing respite care.
    - I am able to access all the services my child needs.
    - I still need assistance accessing a dentist who will see my child.
- Please list and other topics where you feel more resources would be helpful.

Transition Survey

- Who is filling out this survey? (family member of an adult/youth with ASD, an Adult with ASD over 18)
- If you are over the age of 18 years old do you:
- If you are under the age of 18 years old, or your youth is under the age of 18, where do you/they live?
- If you are over the age of 18 years old do you:
    - Own your own home
    - Live independent with financial support
    - Live in a waiver run single home
    - Live in a shared living home with a relative
    - Live in a shared living home with someone who is not a relative?
    - Live in your family's home
    - Live in a waiver group home
    - Live in a relative's home
    - Other (Please Specify)
- If you are under the age of 18 years old, or your youth is under the age of 18, where do you/they live? (Above list)

- If you are over the age of 18 years old do you have:
    - Full guardian
    - Limited guardian
    - Power of Attorney
    - Supportive Decision Making Agreement
- The below questions were all scaled responses (Strongly Agree, Agree, Disagree, Strongly Disagree, Neither Agree nor Disagree with comments available)
    - I had/have an IEP that includes a transition plan to adult services
    - The transition plan helped me transition to independent living
    - The transition plan helped me transition to college
    - The transition plan helped me transition to employment
    - The transition plan helped me transition to section 21 waiver or section 29 waiver services
    - I have all the information on the transition process
    - I have all the information on independent living
    - I have all the information on locating as adult medical provider
    - I have all the information on finding a job or employment
    - I have all the information on going to college
- What could have been more helpful?
- Please fill in the blank. The biggest challenge I faced during the transition process was...

Focus Groups

January 20 at 9:30 am

Focus Group – children/adults with autism and significant health needs

What was/is a barrier to your adult/child getting services? Be specific.
If you could change one or two things around receiving services at this moment what would it be?

If you had to pick one phrase/word to describe the future system what would it be
If you could tell one thing to the "Governor" and "Legislature" – what would it be?
Let's dream a little, if there was a service out there (that doesn't exist today) what would it be? What would you want?

January 21 at 2 pm

Focus Group – Transition

1) Did/do you know what transition services mean?
2) Did/do you have a plan in place for transition to adulthood
3) Did/has your school worked with you and your child determining which area's of transition your youth needed to accomplish prior to graduation? How much input did your youth have?
4) Did you work with Vocational Rehabilitation prior to graduation? After graduation? Were they helpful?
5) If you had to change the way this service is offered what would you change and why?

January 21 at 4 pm

Focus Group – adult with autism

1) Looking back at services you received was there something that really worked well?
2) Looking back at services you received was there something that didn't work at all?
3) Do you feel that you could have had a better outcome if something was done differently?
4) If you could tell one thing to the "Governor" and "Legislature" – what would it be?
5) Let's dream a little, if there was a service out there (that doesn't exist today) what would it be? What would you want?

Appendix B

MaineCare Adult Developmental Services Under §21 and §29

Covered Services under §21 and §29

Although both waivers cover a core set of services, §21 covers other services, including communication services, therapies, and crisis.

COVERED SERVICES	§ 21	§ 29
Home Support Agency – Per Diem	x	
Home Support – Family Centered Support	x	
Home Support-Quarter Hour	x	x
Home Support-Remote Support	x	x
Shared Living (Foster Care, Adult)	x	x
Home Accessibility	x	x
Respite Services		x
Consultation Services	x	
Counseling	x	
Crisis Assessment	x	
Crisis Intervention Services	x	
Occupational therapy (maintenance)	x	
Physical therapy (maintenance)	x	
Speech therapy (maintenance)	x	
Career Planning	x	x
Employment Specialist Services	x	x
Work Support-Group	x	x
Work Support-Individual	x	x
Community Support	x	x
Assistive Technology	x	x
Communication Aids	x	
Non-traditional communication assessments	x	
Non-traditional communication consultation	x	
Specialized Medical Equipment and Supplies	x	
Transportation Service	x	x