Office of Aging & Disability Services

BIENNIAL REPORT FOR

Autism Spectrum Disorder

Pursuant to 34-B M.R.S. §6004

Department of Health and Human Services

Contents

Abbreviations

ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control
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
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, 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.

This report fulfills the requirement pursuant to 34-B M.R.S. §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 Catherine Cutler Institute at the University of Southern Maine to conduct two surveys of individuals with ASD and their families to understand their satisfaction with current services and gather feedback about what kinds of services could improve their quality of life. The Cutler Institute also conducted two virtual listening sessions, one with providers on October 3, 2022, and one with individuals with ASD and their families on October 13, 2022, to gather their perspectives on what is working well and what can be improved in how Maine’s service system meets the needs of children and adults with ASD. Overarching findings from the surveys and listening sessions include frustrations with waitlists for needed services brought on by workforce shortages, challenges in transitioning from children to adult services, and a need for more social opportunities, transportation, and Shared Living services for people with ASD in Maine.

Children’s Services

Early and Periodic Screening, Diagnostic, and Treatment 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, provides Early Intervention services for young children through Child Development Services 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. The Department of Health and Human Services, Department of Education, and the Department of Labor have undertaken a stakeholder engagement process to explore ways to mitigate the challenges in the transition process.

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 individuals 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 to help assure that individual goals and preferences are met. Two priority areas, Community Inclusion and System Capacity & Access to Services, address many of the issues raised by individuals with ASD, their families, and providers in the surveys and listening sessions conducted for this biennial report.

OADS STRATEGIES

Community Inclusion Strategies

- Person-centered planning, self-determination, and self-advocacy
- Community integration and compliance with the HCBS Settings Rule
- Increase supportive housing options
- Implementation of Employment First statute and practices

System Capacity & Access to Services Strategies

- Address the waitlist for HCBS waiver services
- Strengthen the Direct Support Professional workforce
- Explore more effective delivery of transportations services
- Increase capacity for assistive technology assessment
- Improve the transition process between OCFS children's services and OADS adult services

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 autism spectrum disorder (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 and behavioral health care, 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 services for individuals with development disabilities are limited to specific ages and may have functional and financial eligibility criteria, they are generally not limited to a diagnosis of a particular intellectual or developmental disability such as ASD. With a few exceptions, **services 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. §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 two surveys of people with ASD and their families; findings from listening sessions with people with ASD and their families and providers; the 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.

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."[1] They also have "restricted, repetitive patterns of behavior, interests, or activities." 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.

Figure 1. Prevalence of ASD in Maine

CHILDREN 3-17 WITH ASD

According to the CDC, nationally, about 1 in 44 children have been diagnosed with ASD; it occurs across all racial, ethnic, and socioeconomic groups, and is more common among boys than girls. The 2020-2021 National Survey of Children's Health estimates that 3.3% of Maine children ages 3-17 have been diagnosed with ASD.

	Maine	Nationwide
Estimated **total number**	**8,286**	**1,806,976**
Percent of **all children**	3.3%	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: Data Resource Center for Child and Adolescent Health accessed *November 7, 2022.*

ADULTS 18-24 WITH ASD

In 2020, the CDC released its first study to estimate the prevalence of autism among adults ages 18-84. Using prevalence rates among children and projecting them onto 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 **men**	19,225	4,357,667
Number of **women**	4,685	1,080,322

Source: Dietz, Rose, McArthur, and Maenner, 2020.

Public Engagement Activities Informing the Biennial Report

In October 2022, the Department of Health and Human Services contracted with the Catherine Cutler Institute at the University of Southern Maine to conduct two types of public engagement activities, electronic surveys and virtual listening sessions, to gather information from individuals with autism and their families and providers of services about what is working well and what could be improved in Maine system of care for individuals with autism.

Across both types of engagement activities, individuals, families, and providers consistently identified the inability to access services due to waitlists, lack of providers, or lack of transportation options as significant challenges. Respondents noted a need for more housing options and work opportunities for adults as well as social opportunities for people of all ages with ASD.

Surveys

Two electronic surveys were conducted online using the Qualtrics XM Platform.[2] Anonymous links to the surveys were distributed by OADS. The first survey, conducted from October 6-November 4, 2022, measured individuals' and families' satisfaction with specific services as well as aspects such as whether they felt their providers respected their cultural values and preferences, listened to them, and discussed individuals' goals and dreams (see Appendix A). The second survey, conducted from October 26-November 4, 2022, asked individuals and families about their quality of life and what they felt could be improved in broad topic areas such as school, employment, social opportunities, and housing. This survey also provided an opportunity for respondents to give open-ended feedback to the Department on the service system for people with ASD (see Appendix B). Both surveys were targeted to individuals with autism and their

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[2] Qualtrics software, Version October 2022 of Qualtrics. Copyright © 2022 Qualtrics. Qualtrics and all other Qualtrics product or service names are registered trademarks or trademarks of Qualtrics, Provo, UT, USA. Visit Qualtrics website.

families and who receive services from OADS, the Department of Education, or the Department of Labor.

AUTISM SERVICES SATISFACTION SURVEY

Respondents

Fourteen individuals with ASD and 104 family members responded to the survey (total N=118). Table 1 presents demographic information of all respondents as a group. Twenty-five percent of respondents (29) represented individuals with ASD under 18, and 75% (89) represented individuals with ASD 18 and older.

Table 1. Autism Services Satisfaction Survey Respondent Demographics

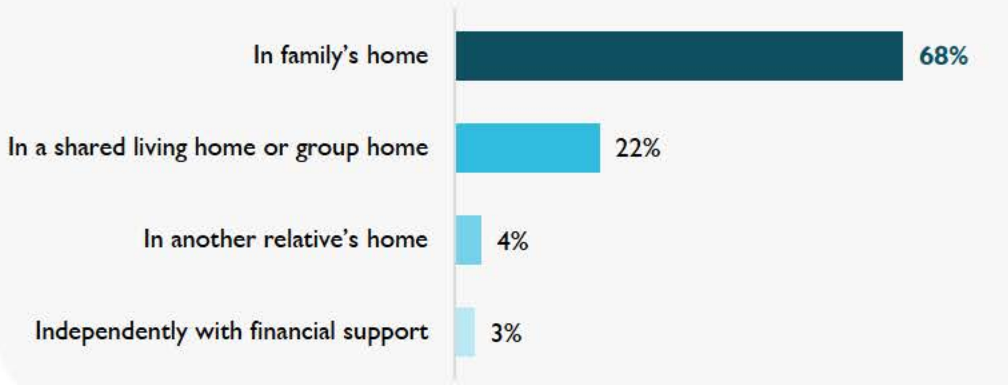
	NUMBER of respondents	**PERCENT** of respondents
Age of individual with ASD		
Under 18	29	25%
18 or older	89	75%
Age at diagnosis		
Under 3	28	24%
Between 3 and 5	41	35%
Older than 5	36	31%
Not sure/missing data	13	10%
Other	7	6%
Race		
White	83	70%
Race other than White*	11	10%
Did not answer	24	20%
Ethnicity		
Hispanic or Latino	8	7%

	NUMBER of respondents	**PERCENT** of respondents
Not Hispanic or Latino	88	75%
Did not answer	22	17%
Gender identity		
Female	26	22%
Male	66	56%
Nonbinary	2	2%
Did not answer/did not know	24	20%
Sexual orientation		
Bisexual	7	6%
Gay or Lesbian	0	-
Straight	55	47%
Other not listed	3	3%
Did not answer/did not know	53	44%

Notes: *Includes Black or African American; American Indian or Alaska Native; Asian; some other race not listed; and multiple races.

Across all respondents, the family home was the most common living arrangement (68%) (Figure 2). Although not shown on Figure 2, the reliance on living with family members continues into adulthood with close to two-thirds (63%)[3] of adults with ASD living in their family home or with other relatives.

Figure 2. The **majority of respondents** (68%) indicated that the **person with ASD lived in their family's home.**



Satisfaction and Experience with Services

Satisfaction and experience with services was measured by asking five different questions. Respondents were asked to identify which of the following services they used and rank their satisfaction with them on a scale of "extremely dissatisfied (1)" to "extremely satisfied (5)."

- Case Management
- Child Development Services
- School with an IEP (Individual Education Plan)
- School with a 504 plan
- In-Home Supports: §28 Services (Rehabilitative and Community Services RCS)
- In-Home Supports: §65 Services (Behavioral Health Services including Home and Community Based Treatment)

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[3] Includes three respondents who noted they are Shared Living providers for their children with ASD.

- §21 Comprehensive Waiver Services
- §29 Supports Waiver Services
- Speech Therapy
- Occupational Therapy
- Physical Therapy
- Other (please specify)

To better understand individuals' experiences with different provider types, respondents were then asked how often providers respected their cultural values and preferences, listened to them, and used hurtful or unkind words with them using a scale of "never (1)" to "always (5)." As the Department is committed to providing person-centered services and planning for the people it serves, a final question asked respondents how strongly they agreed with the statement "Your providers talk with you about your goals and dreams," on a scale of "strongly disagree (1)" to "strongly agree (5)."

Results

Table 2 (following page) shows the number of respondents using different types of services. Case management was used by the most respondents (97) followed by §29 (44), §21 (31), and School with an Individual Education Plan (IEP) (23). Thirteen respondents specified other types of services including vocational rehabilitation and job coaching, psychiatry, psychological services, medication management, §19 Home and Community Based Waiver services, and Private Non-Medical Institution.

Table 2. Number of Respondents Using Different Types of Services

Service Type	N
Case Management	97
§29 Supports Waiver Services	44
§21 Comprehensive Waiver Services	31
School with an IEP (Individual Education Plan)	23
Occupational Therapy	22
Speech Therapy	20

Service Type	N
§28 Services Children's Rehabilitative and Community Services	15
Other	13
Child Development Services	11
Physical Therapy	8
§65 Services Children's Behavioral Health Services including Home and Community Based Treatment)	6
School with a 504 plan	4

The following tables show findings for services that were used by more than 10 individuals responding to the survey. Results for all service types can be found in Appendix A.

Table 3 shows that, overall, there was good satisfaction with case management, §28, §21, §29, and speech, occupation, and physical therapies. Respondents were less satisfied with Child Development Services and School with an IEP.

Table 3. Satisfaction with Services by Service Type

Service Type	Average score (1-5)	*Extremely or Somewhat* DISSATISFIED	*Extremely or Somewhat* SATISFIED
§21 Comprehensive Waiver Services	4.2	13%	81%
Case Management	4	18%	72%
Occupational Therapy	4	14%	77%
Speech Therapy	3.8	25%	70%
§28 Services Children's Rehabilitative and Community Services	3.6	33%	67%
§29 Supports Waiver Services	3.5	34%	59%

Service Type	Average score (1-5)	*Extremely or Somewhat* DISSATISFIED	*Extremely or Somewhat* SATISFIED
School with an IEP (Individual Education Plan)	**2.9**	48%	38%
Child Development Services	**2.7**	46%	46%

Satisfaction with Adult Case Management Services was somewhat higher than Children's Case Management Services.

Table 4. Satisfaction with Case Management Services, by Age

Service Type	Average score (1-5)	*Extremely or Somewhat* DISSATISFIED	*Extremely or Somewhat* SATISFIED
18 and older *n=75*	**4.1**	76	16
Under 18 *n=21*	**3.7**	62	24

For the responses to how often providers respect cultural values and preferences and how often they listen to individuals, the ideal score is 5, or "always." For the responses to how often providers use unkind or hurtful words, the ideal score is 1, or "never." Case management, speech, and occupational therapy, and §21 providers scored well across measures of providing culturally sensitive services, listening to the individuals they care for, and not using hurtful or unkind words. Child Development Services, School with IEP, §28, and §29 providers scored comparatively less well across the measures (Table 5).

Table 5. Survey Responses about Provider Respect for the Individual, by Type of Service

How often do your providers...	Respect cultural values and preferences	Listen	Use hurtful or unkind words
	Ideal score = **5 (always)**		*Ideal score* = **1 (never)**
Case Management	4.6	4.3	1.2
Speech Therapy	4.5	4.1	1.3

How often do your providers…	Respect cultural values and preferences	Listen	Use hurtful or unkind words
	Ideal score = **5 (always)**		*Ideal score =* **1 (never)**
Occupational Therapy	4.4	3.7	1.3
§21 Comprehensive Waiver Services	4.3	4	1.4
§28 Services Rehabilitative and Community Services	4	2.3	1.5
School with an IEP (Individual Education Plan)	3.8	3.1	1.5
§29 Supports Waiver Services	3.8	3.2	1.2
Child Development Services	3.4	2.6	1.5

One hundred eight respondents answered the person-centered planning question, "Your (your family member's) providers talk with you (them) about your (their) goals and dreams," resulting in an average score of 3.82. Table 6 shows the distribution of responses with 67% either somewhat agreeing or strongly agreeing that their providers talk about goals and dreams. The Department continues to engage with providers to fully operationalize the person-centered planning process.

Table 6. Survey Responses about Providers Discussing Individuals' Goals and Dreams

Providers talk about goals and dreams	Percent of responses *(n=108)*
Strongly agree	39%
Somewhat agree	28%
Neither agree nor disagree	18%
Somewhat disagree	8%
Strongly disagree	7%

Note: Not all survey respondents answered this question.

Waitlists and Waiting for Available Providers

Some services have waitlists that are tied to available funding, such as the home and community-based waivers. An individual may qualify for services, but the number of participants may be capped, and the individual must wait until there is an opening.[4] Sometimes, individuals seeking services find there are no providers available in their area or even in the state. Survey respondents were asked whether they or their family members were on a waitlist or waiting for an available provider. Table 7 shows that §21 had the largest number of respondents on a waitlist (26 individuals). Section 29 had the largest number of people who were waiting for an available provider. Respondents also described being on waitlists or waiting for available providers including psychiatry and other behavioral health care, job coaching and vocational rehabilitation, augmentative alternative communication services, childcare for children with serious disabilities, §19 medication management, and day programming.

Table 7. Survey Responses about Waitlists and Waiting for Available Providers

	Number on a waitlist for services	Number waiting for an available provider
§21 Comprehensive Waiver services	**26**	10
Other (please specify)	17	15
§28 Services Rehabilitative and Community Services	14	10
Not sure	12	20
§65 Services Behavioral Health Services including Home and Community Based Treatment	11	7
§29 Supports Waiver services	9	**15**

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[4] The Office of Aging and Disability Services and Office of Child and Family Services maintain data dashboards on their websites showing the number of individuals on waitlists for services.

	Number on a waitlist for services	Number waiting for an available provider
School with an IEP (Individual Education Plan)	6	5
Physical Therapy	6	4
Case Management	5	4
Speech therapy	4	6
Occupational Therapy	4	6
Child Development Services	1	2
School with a 504 plan	1	1

QUALITY OF LIFE FEEDBACK SURVEY

Respondents

Twenty-seven respondents participated in the Quality-of-Life Feedback Survey. Seven were individuals with ASD, all of whom were 18 or older. Twenty respondents were family members of individuals with ASD who represented five children and fifteen adults with ASD. The respondents represented nine females, eleven males, one binary individual, and three respondents preferred not to specify a gender.

Respondents were asked to think about their or their family member's quality of life and identify the top four areas that they would like to see improved. Priority areas listed were:

- School
- Employment
- Housing
- Transportation
- Social Opportunities
- Behavioral and Emotional Health
- Physical Health
- Other (please specify)

Respondents were then asked what services currently available or that they would like to see made available that could help address the priority areas they identified. A final open-ended question elicited feedback respondents wanted to share with the Department.

Results[5]

Across individuals and family members, the need for **social opportunities** was the most common priority area identified that could improve the quality of life for people with ASD. In addition, respondents described a need for more **public transportation** and **job/employment opportunities**. Both individuals and family members expressed frustration with lack of care or service due to lack of staffing.[6]

Priority Areas Among Individuals with Autism

Among the seven individuals with ASD responding to the survey, the top priority was social opportunities (4 responses). Three respondents chose employment (3 responses). Housing, Transportation, and Behavioral and Emotional Health each received 2 responses.

Two individuals with autism suggested that public transportation, adapted housing, and financial and legal representation could help address their priority areas. One individual suggested better training for case managers so they have more knowledge of the array of services a person might be able to access including Medicare, MaineCare, other federal, state, or local programming, and Area Agency on Aging services.

Priority Areas Among Family Members of Individuals with Autism

Among the twenty family members responding to the survey, the top answer was social opportunities (17 responses). In second place was behavioral and emotional health (9 responses), and in third place was Physical Health (7 responses). School and Employment each received 6 responses, and Housing and Transportation each received 4. Several respondents identified other priority areas including dental care, inclusive afterschool opportunities, home and community support, physical activities, and speech therapy services.

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[5] Quotes throughout this section have been lightly edited to ensure anonymity and for clarity.

[6] See OADS Reform Initiatives for a brief description and the 2023-2024 *Biennial Plan for Adults with Intellectual Disabilities or Autism* for more details on how OADS plans to address this issue.

Thirteen family members suggested several types of services they would like to address their priority areas including public transportation/transportation services, Shared Living providers that are near public transportation, job coaching and career services, unified sports teams and teen social/activity groups, more and better access to services, including in rural areas of the state, such as children's behavioral health and community supports, educational resources for adults, and respite care.

> "There are kids with ASD/special needs that have hardly any opportunities up here in northern Maine. There needs to be more available for free (e.g., swimming, gyms, etc.) along with more workers."

Additionally, respondents described frustration with not being able to access the services their family members qualify for due to a lack of available staff, with some noting problems with quality of care and frequent staff turnover. Seven respondents answered the open-ended feedback question to share additional commentary reiterating the frustration with the lack of the services available, waitlists for waiver services, the need to expand the concept of mainstreaming beyond the educational setting and into the community.

Listening Sessions

Two virtual listening sessions were conducted via Zoom, one for autism services providers on October 3, 2022, and one for individuals with ASD and their family members on October 13, 2022. The provider session was designed to gather feedback about what is working well and what could be improved in Maine's service system, including how providers measure their success in implementing person-centered planning and Charting the LifeCourse activities. The individual and family session was designed to gather information on what is working well and what could be improved in the broad topic areas of school and work, social opportunities, transportation, access to care, transition services, and housing.

RESULTS[7]

COMMON THEMES ACROSS BOTH SESSIONS

- Years-long waitlists/Lack of staffing
- Inability to obtain all services in a care plan/Lack of different types of needed services
- Challenges in transitioning from children to adult services
- Transportation to services

Individuals and Families

Family members described difficulties with school-based services relating to their child's autism diagnosis and how it impacts the services they receive including through the child's IEP. Family members feared that psychological evaluations conducted by schools resulting in the removal of the autism diagnosis would result in a decrease of available services when they transition to adulthood.

> "In my son's situation, his behaviors, he's improved greatly. But if that diagnosis was taken away, my head goes right to 'Oh no, what about adult services?'"
>
> FAMILY MEMBER

Some family members expressed frustration with school providers who do not understand autism, especially how their child's behavior can vary day to day and impact their performance in class and school activities. Waitlists for children's behavioral health providers as well as staff turnover were another source of anxiety and frustration for families. Family members also described having to strongly advocate for their children with autism to be able to participate in school activities such as sports.

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[7] Quotes throughout this section have been lightly edited to ensure anonymity and for clarity.

Families expressed some frustrations with their children's school experience, yet there was a common theme relating to the relative richness of the children's service system compared to adult services. Some family members noted their children had access to counseling and other services at school and feared that would change upon graduation and their system of care, including pediatric specialists, would no longer be available. While some families said they had had some very positive experiences with behavioral health providers who really got to know and engage their family members, others described years-long waitlists for behavioral health providers and other specialists. One family member advised people approaching transition age to line up providers to pay out of pocket once the child transitions out of eligibility for children's services to minimize disruptions if there is a waitlist for adult services.[8]

A common theme throughout the listening session was the vital role families play in the lives of people with ASD, providing transportation, supervision, and housing well into their child's adult years. As children transition out of the school system and into adulthood, families said they are not provided adequate opportunities for work and socialization. The behavioral challenges associated with autism compound the problem, and families said they had encountered some providers who refused to work with their family members. Family members felt there is a lack of acceptance of people with autism within the community and therefore a lack of support.

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[8] See Improving Transitions across the Lifespan for information on the Department's efforts to address this issue.

> “I drive him. I think there would be no way I could put him in a car with anyone else. It takes everything just to get him to places myself. To put him in a KVCAP [transportation provider] or anything like that would never work for my situation and with my son.”
>
> FAMILY MEMBER

Family members worried about their own aging and how it will impact their ability to continue to provide for their adult children with ASD. Family members described a second transition process, beyond that from children to adult services, when an adult with ASD must move out of the family home. With few options for living outside the family home for people with ASD who may have significant behavioral and mental health challenges, family members worried that there is no way to plan for the transition before a crisis occurs.[9]

> “We ought to be able to figure out a way that he can safely be able to transition to a different living situation. So that while we are still here, we can see that he can figure out life with other people with supports.”
>
> FAMILY MEMBER

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[9] See OADS Reform Initiatives for a brief description and the 2023-2024 *Biennial Plan for Adults with Intellectual Disabilities or Autism* for more details on how OADS plans to address this issue.

Providers

Service providers noted improvements in screening and identification of ASD have led to faster referrals to services. However, they also described having waitlists for children's and adult services due to inadequate staffing. Children's providers noted that some families delay transitions to other services because there are waitlists for new providers. Case management providers suggested that additional services like Board Certified Behavior Analyst be made available and more publicized to provide resources, tools, and strategies to families while they wait for other programming.

Adult service providers described a mismatch between where services are available and where people want to live. For example, they said Shared Living services are more available in the Portland area, but less so in the Augusta area and along the coast. In addition, while there may be a provider available in an area, they may not be a good fit for the individual needing services. Providers noted a need for a greater variety of providers of Shared Living, group home, and dental services.

Providers of children's and adult services said a lack of transportation providers resulted in people with ASD not being able to utilize the services they are entitled to. The lack of transportation has been a long-standing issue in rural areas, but some providers noted that urban areas like Lewiston are now seeing similar problems.

> "If someone is over 30 minutes away, they just can't find staff to transport them. So, they're excluded from having that connectivity and skill development and looking for different meaningful connections in their life."
>
> SERVICE PROVIDER

A common theme across providers was the complexity of the service system for people with ASD and the difficulties they see families having. A seamless transition from children's services to adult services can be hampered by the inability of an adult case manager to join the transition earlier in the process to ensure that individuals apply for adult services and get on waitlists before they age out of children's services.[11] Siloed providers and state agencies make it challenging for case managers to ensure their clients with ASD can access the appropriate services.

> "There's educational services over here and behavioral health services over here, and medical over here. And I think it can be really challenging for a lot of families, and for providers who have limited capacity because of the issues that we're talking about."
>
> SERVICE PROVIDER

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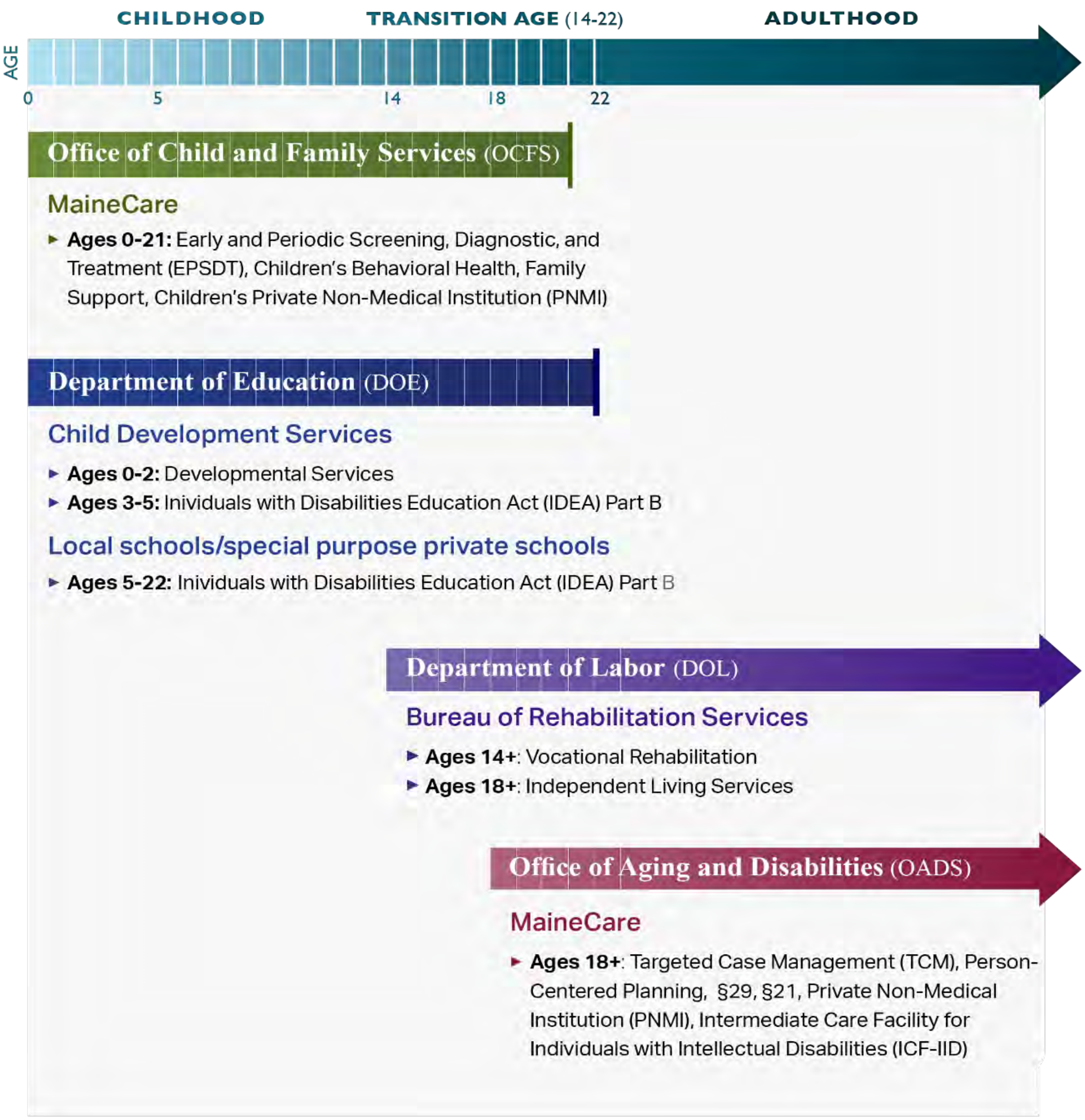
[11] See Improving Transitions across the Lifespan for information on the Department's efforts to address this issue.

Maine's Public System of Support

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 (Figure 3). Eligibility for some public agency disability services is determined by level of impairment and/or financial need.

Figure 3. Overview of Maine's Public Services and Support Systems



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)

Individuals with ASD access services from different agencies depending on age and type of service needed, and 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 SFY2020 and SFY2021, MaineCare served 12,533 and 12,860 people with ASD, respectively (Table 8).[12]

Table 8. Number of people with ASD served by MaineCare by age group

	Age Group	2020	2021
Children 0-17	0-2	123	135
	3-5	1,398	1,443
	6-13	3,851	3,847
	14-17	1,935	1,878
	Subtotal 0-17	**7,307**	**7,303**
Adults 18+	18-20	1,259	1,260
	21-34	2,913	3,202
	35-44	527	570
	45-54	277	270
	55-64	168	166
	65-74	61	69
	75+	21	20
	Subtotal 18+	**5,226**	**5,557**
	ALL AGES TOTAL	**12,533**	**12,860**

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

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[12] The *2021 Biennial Report for Autism Spectrum Disorder* included MaineCare data only with the diagnosis code for Autistic Disorder. The current report also includes diagnosis codes for Asperger's syndrome and pervasive developmental disorders to be consistent with the definition of autism currently used by the Department of Education. Differences in definitions and diagnosis codes can impact how people are counted in different programs year to year.

Services for Children, Ages 0-22

Office of Child and Family Services

ABOUT OCFS

OCFS is dedicated to helping create a future where all Maine children and families are safe, stable, happy, and healthy.

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." [13]

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.

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. Table 9 shows the MaineCare services

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[13] Clarification of Medicaid Coverage of Services to Children with Autism (PDF), accessed November 14, 2022.

available to children with behavioral health needs, including children with ASD.[14] 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.

Table 9. OCFS Services Available to Children with Behavioral Health Needs including Children with Autism Spectrum Disorder, MaineCare Funded (requires MaineCare eligibility)

OCFS Service	Service Description
§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 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,

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[14] 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.

OCFS Service	Service Description
	Multi-Systemic Therapy, 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 SFY2021 and SFY 2022, OCFS administered MaineCare billable children's behavioral health services for over 3,000 children with ASD. Table 10 shows the number of children with ASD who used the different types of behavioral health services.

Table 10. Children with ASD who used MaineCare Children's Behavioral Health Services

Service	2021	2022
Rehabilitative and Community Services	1,708	1,532
Crisis Stabilization	161	138
Targeted Case Management	1,166	1,289
Children's Private Non-Medical Institution	152	109
Home and Community Based Treatment	284	225
Outpatient	1,283	1,240
Unduplicated Total Served	**3,430**	**3,365**

Notes: Data include children with diagnosis codes F840, F845, and F849, autistic disorder, Asperger's syndrome, and pervasive developmental disorder not otherwise specified, respectively. The 2021 Biennial Report on Autism Spectrum Disorder included only F840.

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.[15] The assessment identified five areas impacting children and families seeking and receiving children's behavioral health services:

- **Access:** Children's behavioral health services are not available immediately (or at all).
- **Proximity:** Behavioral health services are not always available close to the community where children live.
- **Appropriateness:** When children do get services, it's not always the right service.
- **Quality:** The quality of behavioral health services is not consistent.
- **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 (complete)
- Facilitate access to parent support services (in process)
- Explore options to amend current service definitions for MaineCare §28 (in process)
- Clarify children's behavioral health services roles, responsibilities, procedures, policies, and practices (in process)

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[15] The final report can be found here: 2018 Children's Behavioral Health Services Assessment.

LONG TERM (2019 – 2025)

- Establish one or more Psychiatric Residential Treatment Facilities (PRTF)
- Address shortages in the behavioral health care workforce (on hold)
- Align residential services to best practices and federal quality standards (complete)
- Improve children's behavioral health crisis services (in process)
- Expand the use of evidence-based models and evidence-informed interventions (in process)
- Enhance skills of early childhood workforce to address challenging behaviors (in process)
- Explore a statewide or regional single point of access (SPOA) (in process)
- Revise the waitlist process (in process)
- Improve coordination for transition-age youth behavioral health services (in process)
- Facilitate access to services that can help families support children with behavioral health needs (in process)

Although these strategies are not specific to autism, children with ASD and their families would benefit from their success. As of December 2021, OCFS had hired a full-time, on-site Medical Director and worked with MaineCare to update §97 PNMI services to align rules and rates with federal Quality Residential Treatment Program standards. Over half of the tasks required to amend MaineCare §28, clarify CBHS roles and responsibilities, address workforce shortages, and improve crisis services have been completed.

Although over half of the tasks required to implement revisions to the waitlist process have been completed, the waitlist for children's behavioral health community-based services have not been reduced. The impact of the COVID-19 pandemic on existing workforce shortages has continued to limit the availability of therapists and other direct care workers throughout the state. Although not all children on the waitlist for services have ASD, the lack of providers and subsequent wait time for services is of great concern to families of children with ASD, as noted in the listening session and survey results. As of September 2022, the average number of days children waited for behavioral health services varied by county from a low of 82 days in Franklin County to a high of 437 days in Sagadahoc County.[16]

OCFS continued to move forward in meeting several long-term goals including collaborating with OADS, OBH, DOE, and DOL on developing a resource document for transition age youth; working with OADS to align policies and procedures between the two offices; increased training and certification opportunities for evidence-based, Trauma-Focused Cognitive Behavior Therapy clinicians; and creating a stakeholder engagement plan to assist in the development of a SPOA. 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

DOE MISSION

To promote the best learning opportunities for all Maine students by providing information, guidance, and support to our schools, educators, and leaders and by providing adequate and equitable school funding and resources.

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).

CHILD DEVELOPMENT SERVICES, AGES 0 THROUGH 5 YEARS

The Child Development Services (CDS) 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

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[16] Source: OCFS Children's Behavioral Health Data Dashboard

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 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.[17]

The most recent data available show that 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 Table 11).

Table 11. Number of children using CDS services by age

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

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[17] Child Development Services

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.[18]

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 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.[19]

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 Department of Education hosts Education Technician professional learning opportunities through its website, including one on Autism Focused Intervention Resources and Modules (AFIRM). AFIRM modules help Ed Techs plan for, use, and

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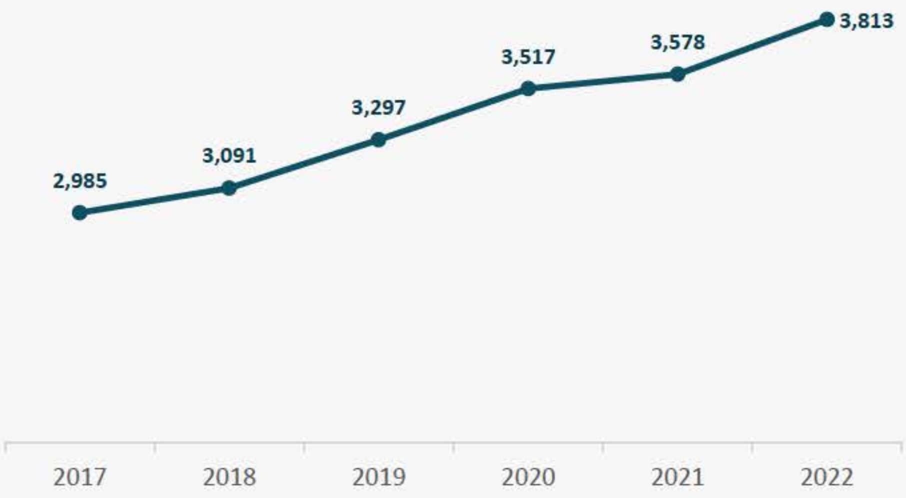
[18] Department of Education Special Purpose Private Schools

[19] Maine Positive Behavioral Intervention & Supports

monitor evidence-based practices with students with ASD from age birth to 22 years old.[20]

The number of school-age students in special education with ASD ages five through twenty increased by nearly 1,000 students during 2017-2022 (Figure 4).

Figure 4. The number of **special education students with ASD ages 5-20 increased** between 2017 and 2022



Source: *Maine Department of Education*

In 2017, students with ASD made up 9.6 percent of the students receiving special education services. This increased to 11.7 percent in 2022 (Table 12).

Table 12. Children Ages 5-20 in Special Education, 2017-2022

Year	Special Education Students with ASD	Percent of Special Education Students with ASD
2017	2,985	9.6%
2018	3,091	9.7%

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[20] For more information, see Professional Leaning for Education Technicians

Year	Special Education Students with ASD	Percent of Special Education Students with ASD
2019	3,297	10.2%
2020	3,517	10.8%
2021	3,578	11.2%
2022	3,813	11.7%

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 (Table 13).

Table 13. Special Education students with ASD by age, 2017-2022

Age	2017	2018	2019	2020	2021	2022
5	159	187	196	243	218	270
6	219	223	262	278	314	320
7	221	240	243	276	285	329
8	231	232	268	247	268	309
9	249	242	251	275	246	287
10	249	244	247	242	279	252
11	224	247	259	256	244	289
12	234	230	264	283	258	244
13	227	243	237	289	282	259
14	245	224	258	236	297	276
15	217	238	234	271	241	293
16	199	214	248	233	282	245
17	193	189	210	240	223	260

Most students with ASD leave Special Education when they are 17-18 years old

Age	2017	2018	2019	2020	2021	2022
18	83	94	84	106	101	114
19	*	*	*	33	*	37
20	*	*	*	9	*	25
TOTAL	2,985	3,091	3,297	3,517	3,578	3,813

Source: *Maine Department of Education*

Improving Transitions across the Lifespan

Reform efforts of the Department of Health and Human Services, Department of Education, and Department of Labor

Multiple state agencies play a role in the lives of people with developmental disabilities and ASD including the Department of Health and Human Services (the Department), Department of Education (DOE), and Department of Labor (DOL). Different constraints in policies, funding, and priorities can make aligning systems and programs across state agencies challenging at times, particularly when children with developmental disabilities and ASD transition from school to adulthood, and from developmental services provided through OCFS to adult services provided through the Office of Aging and Disability Services (OADS).

There are several long-standing 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. As individuals and families look to the future, they are 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.

Although Medicaid allows a 30-day overlap in children's and adult case management services, planning for the transition takes much longer.

For those who are eligible for adult developmental services, the waitlist for HCBS services is another structural challenge.[21] Although some people may continue to receive children's services while on the waitlist for one of the adult waiver programs, not all are able to transition directly from children's services to the adult HCBS waiver services. Alternative services may be provided in the interim, but some needed services may be

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[21] 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.

unavailable. Another 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. 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 other details that must be addressed to ensure a successful transition.

During this past reporting period, several efforts have been underway to address these barriers and improve the transition process. LD 924[22] directed DOE to establish a task force focused on reducing the barriers that inhibit young adults with developmental disabilities from accessing higher education and vocational opportunities. OADS has participated in this work. Building on past efforts, a group of staff from OCFS and OADS have gathered weekly since July 2021 to assess the current state of transition planning and recommend improvements moving forward. This group has also engaged experts from OMS, DOE, and DOL to inform planning.

Along with continued collaboration with DOE, the Department plans to use American Rescue Plan Act (ARPA) funding to implement a pilot program designed to provide regional supports focusing on transition issues and consistent engagement of key stakeholders (e.g., schools, families, and others) to improve communication and collaboration. A lack of training, time, and resources contributes to inconsistent approaches to transition. This pilot will address the lack of specialized case management services available to assist people during transitions and reduce the risk of disruptions and poor outcomes that can occur with a change or loss of services and supports. Plans for 2023-2024 include the following strategies.

- As a pilot, creating four transition liaison positions withing OCFS and OADS that have specific and exclusive focus on transitions. Plans for the Transition Services Pilot Program include establishing a full-time project manager to oversee transition staff and continue to facilitate and coordinate efforts to improve the transition process. These positions will assist in identifying cohorts of transition-age youth, provide transition case management support and implementation, triage cases for family-members/caregivers involving individuals without case

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[22] See PL 2021, Chapter 116, Resolve, To Establish a Task Force To Study the Coordination of Services and Expansion of Educational Programs and Vocational Opportunities for Young Adults with Intellectual or Developmental Disabilities or Acquired Brain Injury

managers, help facilitate access to state systems to ease application processes, provide training and education, and assist with systems-level reporting and monitoring.

NEW TRANSITION SERVICES PILOT PROGRAM KEY GOALS

- Streamlined eligibility process for MaineCare services
- Reduced wait-times for services/case management during transition period
- Improved youth and family/caregiver satisfaction
- Connecting youth to employment and housing to maximize independence
- Ensuring access to supports in the least restrictive and costly setting
- Reducing poor outcomes that may result from gaps in care
- Increased public information and awareness
- Supporting implementation of a lifespan waiver

- The Department has also initiated work on a Lifespan Project, which is exploring stakeholder interest and the feasibility of developing a service program designed to make sure people have the services they need as their needs and circumstances change, particularly as youth age into adults. The Lifespan Project could potentially eliminate the need to changing program based on age and provide more robust supports for youth focused on in-home supports, life skills, and employment services to better prepare people for adulthood.

DEPARTMENT OF EDUCATION TRANSITION SERVICES

The Individuals with Disabilities Education Act 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 DOE, OADS, the Department of Labor, and other stakeholder organizations to develop a handbook to guide students and families through the transition process.[23]

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 are provided. The school is also responsible for creating alternative solutions if other agencies or team members fail to provide a required service.

DEPARTMENT OF LABOR TRANSITION SERVICES

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

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[23] A Guide to Transition Services in Maine.

those receiving services through an Individual Education Program or a §504 Plan[24] 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 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 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.**

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[24] Section 504 of the 1973 Rehabilitation Act ensures students with disabilities receive accommodations and access to education. For more information, see the Office for Civil Rights Section 504 Fact Sheet (PDF).

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 2022 Modifications.

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 with ASD 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 2020 and 2021, the Step-Up program was conducted virtually due to the COVID-19 pandemic.

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.

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. 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

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

Both §21 and §29 offer Home Supports,[25] Work Supports, and Community Supports, which are direct support services,[26] 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-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 D.

Maine continues to expand access to good jobs for individuals with a disability. Maine is an Employment First state, and Employment First Maine Act[27] 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. In 2022 OADS conducted several training events aimed at increasing the knowledge and skills of case managers and direct support professionals to

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[25] 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.

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

[27] 26 M.R.S. §§ 3401-3403.

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[28] 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 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.

Table 14 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.

Table 14. Number of adults with ASD who used MaineCare Developmental Services

MaineCare Service	2020	2021
§13 Targeted Case Managment	2,175	2,281

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[28] "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.

MaineCare Service	2020	2021
§21 Comprehensive Waiver	858	893
§29 Supports Waiver	860	932
§97 Private Non-Medical Institution	91	90
Unduplicated Total Served	**2,574**	**2,498**

Note: Data include adults with diagnosis codes F840, F845, F848, and F849, autistic disorder, Asperger's syndrome, other pervasive developmental disorder, and pervasive developmental disorder not otherwise specified, respectively. The 2021 Biennial Report on Autism Spectrum Disorder included only F840.

Source: *Maine Office of Aging and Disability Services*

OADS REFORM INITIATIVES

OADS has a two-year plan for improving the design and quality of its programs to strengthen OADS' ability to assure that individual goals and preferences are met which can be found in the 2023-2024 *Biennial Plan for Adults with Intellectual Disabilities or Autism (Biennial Plan)*. Beginning in 2019, OADS established three primary Work Groups: Community Membership and Inclusion, Innovation, and Quality Assurance and Quality Improvement. In addition to these work groups, OADS participated in other stakeholder work groups focused on transportation services, housing, and other aspects of the service delivery system.

These work groups were made up of a cross representation of individuals who were invested in improving developmental disability services in Maine including individuals receiving services, agency providers, family members, advocates, and state agency staff at OADS, and their input serves as the cornerstone of the Department's reforms.

KEY OADS STAKEHOLDER GROUPS CONVENED IN 2019-2022

Community Membership

OADS convened a Community Membership Reform Work Group in 2019 to identify strategies to promote full inclusion of people with disabilities into communities. The work group issued a report in January 2022 addressing enhanced person-centered planning, self-advocacy, family support, community support, and implementation of Maine's Employment First statute. In addition, this group identified 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 developed 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. The work group issued its report in January 2022.

Quality Assurance

In partnership with the Quality Work Group and informed by a consultant's recommendations, OADS has developed recommendations to strengthen quality assurance and quality improvement capacity at the individual, provider, and systemic level. These recommendations were finalized in July 2022.

The *Biennial Plan* outlines several key reform priorities, including Person-Centered Planning and Community Inclusion, Quality Improvement, System Capacity and Access to Services, Statewide Behavioral Health and Support Services, Transitions Across the Lifespan (described earlier in this report), and Innovation. These reform efforts address many of the issues raised by individuals with ASD, their families, and providers in the surveys and listening sessions described earlier in this report, especially in the areas of

Community Inclusion and System Capacity & Access to Services. Please see the *Biennial Plan* for a full description of all of OADS' reforms strategies.

Community Membership and Involvement

Strategies and planned activities for 2023-2024 address several key areas consistent with the Department's commitment to ensuring that people have the planning, services and supports they need to live in places they call home, work for good pay and benefits, build relationships, and have opportunities to give back and grow and learn. OADS has adopted Charting a LifeCourse Framework, to inform efforts to ensure that services better conform to the lives of the people served rather than requiring people to sacrifice personal choice and self-determination to get the services they need. Initiatives for 2023-2024 focus in 4 priority areas:

- Person-centered planning, self-determination, and self-advocacy
- Community integration and compliance with the HCBS Settings Rule
- Increase supportive housing options
- Implementation of Employment First statute and practices

Improving System Capacity & Access to Services

Maine continues to experience several ongoing system capacity issues that result in unmet need. A gap in needed services can have a negative impact on the quality of life for the people OADS serves. A shortage of direct support professionals can limit a person's ability to work, maintain relationships, and participate in community activities. In a rural state like Maine, inadequate access to transportation can contribute to social isolation, with negative consequences for physical and emotional health. Initiatives for 2023-2024 focus in 4 priority areas:

- Address the waitlist for HCBS waiver services
- Strengthen the Direct Support Professional workforce
- Explore more effective delivery of transportation services
- Increase capacity for assistive technology assessment

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 enhancing system capacity and implementing plans to ease the transition process from childhood to adulthood.

References

Dietz, P.M., Rose, C.E., McArthur, D. Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, ***50,*** 4258–4266. *https://doi.org/10.1007/s10803-020-04494-4*

Appendix

Appendix A Autism Services Satisfaction Survey

The survey was conducted online using the Qualtrics XM Platform.[29] An anonymous link to the survey was distributed by OADS, and responses were collected October 6-November 4, 2022.

The online survey worded the questions specifically for individuals and family members, depending on how they answered the first question. The survey questions presented below show the questions as they were presented to individuals with autism with the language for family members indicated in parentheses, e.g., (your family member).

Choose what best describes you

○ I have autism and receive services from the Department of Health and Human Services, Department of Education, and/or the Department of Labor

○ I have a family member with autism who receives services from the Department of Health and Human Services, Department of Education, and/or Department of Labor

Are you (your family member) (choose one)

○ Under 18 years old

○ 18 or older

When were you (your family member) first diagnosed with autism?

○ Under age 3

○ Between 3 and 5 years old

○ Older than 5 years old

○ Not sure

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Do you (your family member) live... (choose one)

○ In your family’s home
○ In another relative’s home
○ In a Shared Living home or group home
○ Independently with financial support
○ Other (Please Specify)

____

What types of services do you (your family member) use? (Check all that apply.)

☐ Case Management
☐ Child Development Services
☐ School with an IEP (Individual Education Plan)
☐ School with a 504 plan
☐ In-Home Supports: §28 Services (Rehabilitative and Community Services (RCS))
☐ In-Home Supports: §65 Services (Behavioral Health Services including Home and Community Based Treatment (HCT))
☐ §21 Comprehensive Waiver services
☐ §29 Supports Waiver services
☐ Speech therapy
☐ Occupational Therapy
☐ Physical Therapy
☐ Other (please specify)

____

☐ Not sure

(Each service selected by respondents in the previous question appeared in the following four questions)

How satisfied are you with your (your family member's) services?

- ○ Extremely satisfied
- ○ Somewhat satisfied
- ○ Neither satisfied nor dissatisfied
- ○ Somewhat dissatisfied
- ○ Extremely dissatisfied

How often do the provider(s) of this service respect your (your family member's) cultural values and preferences?

- ○ Always
- ○ Most of the time
- ○ About half the time
- ○ Sometimes
- ○ Never

How often do the provider(s) of this service use hurtful or unkind words with you (your family member)?

- ○ Always
- ○ Most of the time
- ○ About half the time
- ○ Sometimes
- ○ Never

How often do you feel the provider(s) of this service listen to you (your family member)?

- ○ Always
- ○ Most of the time
- ○ About half the time
- ○ Sometimes

○ Never

Your (your family member's) providers talk with you (them) about your (their) goals and dreams

○ Strongly agree
○ Somewhat agree
○ Neither agree nor disagree
○ Somewhat disagree
○ Strongly disagree

Are you (your family member) on a waitlist for any of these services? (Check all that apply.)

☐ Case Management
☐ Child Development Services
☐ School with an IEP (Individual Education Plan)
☐ School with a 504 plan
☐ In-Home Supports: §28 Services (Rehabilitative and Community Services (RCS))
☐ In-Home Supports: §65 Services (Behavioral Health Services including Home and Community Based Treatment (HCT))
☐ §21 Comprehensive Waiver services
☐ §29 Supports Waiver services
☐ Speech therapy
☐ Occupational Therapy
☐ Physical Therapy
☐ Other (please specify)
____
☐ Not sure

Are you (your family member) waiting for an available provider for any of these services? (Check all that apply.)

☐ Case Management

☐ Child Development Services

☐ School with an IEP (Individual Education Plan)

☐ School with a 504 plan

☐ In-Home Supports: §28 Services (Rehabilitative and Community Services (RCS))

☐ In-Home Supports: §65 Services (Behavioral Health Services including Home and Community Based Treatment (HCT))

☐ §21 Comprehensive Waiver services

☐ §29 Supports Waiver services

☐ Speech therapy

☐ Occupational Therapy

☐ Physical Therapy

☐ Other (please specify)

____

☐ Not sure

Your responses to these next questions will help us be sure we're hearing from a diverse group of people.

Please select the racial categories that describe you (your family member). You may select as many as apply:

☐ American Indian or Alaska Native

☐ Asian

☐ Black or African American

☐ Native Hawaiian or Other Pacific Islander

☐ White

☐ Some other race not listed

☐ Prefer not to answer

Are you (your family member) Hispanic or Latino?

○ Yes

○ No

○ Prefer not to answer

What sex were you (your family member) assigned at birth, on your original birth certificate?

○ Female

○ Male

○ Prefer not to answer

What is your (your family member's) gender identity?

○ Female

○ Male

○ Nonbinary

○ Other not listed

○ I don't know

○ Prefer not to answer

What is your (your family member's) sexual orientation?

○ Bisexual

○ Gay or Lesbian

○ Straight

○ Other not listed

○ I don't know

○ Prefer not to answer

SATISFACTION SURVEY RESULTS, ALL SERVICES

How satisfied are you with…	N	Mean score (1-5)	*Extremely or Somewhat* Dissatisfied	*Extremely or Somewhat* Satisfied
§21 Comprehensive Waiver Services	31	4.2	13%	81%
Case Management	97	4	18%	72%
Occupational Therapy	22	4	14%	77%
Speech Therapy	20	3.8	25%	70%
§28 Services Rehabilitative and Community Services	15	3.6	33%	67%
Physical Therapy	8	3.6	25%	63%
§29 Supports Waiver Services	44	3.5	34%	59%
School with an IEP	23	2.9	48%	38%
Child Development Services	11	2.7	46%	46%
§65 Services Behavioral Health Services (including Home and Community Based Treatment)	6	2.7	50%	33%
School with a 504 plan (Individual Education Plan)	4	1.8	75%	25%

How often do your providers…	**Respect cultural values and preferences**	**Listen**	**Use hurtful or unkind words**
	*Ideal score = **5 (always)***		*Ideal score = **1 (never)***
Case Management	4.6	4.3	1.2
Child Development Services	3.4	2.6	1.5
School with an IEP (Individual Education Plan)	3.8	3.1	1.5
School with a 504 plan	2.5	2.3	1.5
§28 Services Rehabilitative and Community Services	4.0	4.0	1.4
§65 Services Behavioral Health Services (including Home and Community Based Treatment)	3.2	3.2	1.2
§21 Comprehensive Waiver Services	4.3	4.1	1.3
§29 Supports Waiver Services	3.8	3.7	1.3
Speech Therapy	4.5	4.3	1.0
Occupational Therapy	4.4	4.2	1.2
Physical Therapy	4.1	3.6	1.3

Appendix B Quality of Life Feedback Survey

The survey was conducted online using the Qualtrics XM Platform.[30] An anonymous link to the survey was distributed by OADS, and responses were collected October 26 - November 4, 2022.

The online survey worded the questions specifically for individuals and family members, depending on how they answered the first question. The survey questions presented below show the questions as they were presented to individuals with autism with the language for family members indicated in parentheses, e.g., (your family member)

Choose what best describes you

- I have autism and receive services from the Department of Health and Human Services, Department of Education, and/or the Department of Labor
- I have a family member with autism who receives services from the Department of Health and Human Services, Department of Education, and/or Department of Labor

Are you (your family member) (choose one)

- Under 18 years old
- 18 or older

When you think about your family member's current quality of life, what are the top areas in their life that you would like to see improved? (Select up to 4 choices or write in your own.)

- School
- Employment
- Housing
- Transportation
- Social opportunities
- Behavioral and emotional health
- Physical health

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- Other (please specify)

What services (currently available or that you might like to see made available) could help address these gaps in the quality of life for you (your family member)?

I**s there anything else you would like to share with the Department?**

What is your (your family member’s) gender identity?

- Female
- Male
- Nonbinary
- Other not listed
- I don’t know
- Prefer not to answer

Appendix C Listening Session Protocols

PROVIDER LISTENING SESSION, HELD VIA ZOOM ON OCTOBER 3, 2022

When thinking about services for children with autism...

1) What is working well?

Probe:

- Screening and identification?
- Access to services?
- What do you do well? What does the larger system do well?

2) Are there areas you feel need to be improved?

Probe:

- Specific children's services that are missing?
- Provider training specific to autism?
- Systems navigation issues?
- Communication between providers—behavioral health, medical, education--especially during transition to adult services?
- Communication between state agencies, especially during transition to adult services?
- Best practices from other states that could be replicated?

How about for services for adults with autism...

3) What is working well in Person-centered Planning/Charting the LifeCourse of adults with autism?

Probe:

- What are the facilitators of that process?

- How do you discover a person’s interests as you go through the charting the lifecourse process with them?
- Are there barriers to communication in exploring a person’s interests and goals? Are you able to overcome those barriers? Or is there something that you know you need that would help?

4) How well have you been able to implement the goals and outcomes that have been developed as part of the person-centered plan?

Probe:

- If not, why not?
- How do you measure your success in implementing the goals and outcomes? How do you know it’s working?
- Are there barriers?
    - Support and training specific to person-centered planning?
    - Specific adult services that are missing?
    - Provider training specific to autism?
    - System navigation issues?
    - Communication between providers—behavioral health, medical, developmental services?
    - Communication between state agencies—OCFS, OADS, DOE, DOL during transition?
- Best practices from other states that could be replicated?

5) What is the one outcome that you have wanted to achieve that you haven’t been able to?

Probe:

- What have been the barriers?

Magic wand question for everyone—

6) If you could re-do how you deliver services now, what three things would you change in how you deliver them?

INDIVIDUALS WITH AUTISM AND THEIR FAMILIES LISTENING SESSION, HELD VIA ZOOM ON OCTOBER 13, 2022

1) First, we are going to talk about school and work.

- For those who are in school, what do you like about school?
    - What is NOT working so well for you? What would you like to see changed?
- For those who are working, what do you like best about your job?
    - What is NOT working so well for you? What would you like to see changed?
- Have you or are you running into problems getting what you need or want?

Probe: Transition, supports, time,

Social Opportunities

2) Next, we'd like to hear from you about how you spend your time outside of school or work, including going to day programs.

- Tell us about what you like to do during the day when you're not at school or at work—can you work on hobbies, social activities?

Probe: Barriers—transportation, staffing, rules, financial, lack of opportunities, etc.

Transportation

3) Next, we want to talk about how you get around. How easy or hard it is to get to the places you need to go and want to go.

- What is working well for you?
- What is NOT working well for you? What is getting in the way? What would make transportation better for you?

Access to Health / Dental / Behavioral Health Care

4) Being healthy and getting the right care you need is important. We want to hear about your experiences getting medical care.

- What is working well for you when you go to the doctor, dentist, or counselor?
- What is NOT working well for you?
- What might make it better for you?

Probe: Transition, communication, decision-making, access issues

Transition to Adult Services and Supports—Information / Planning

5) For those of you who are going through the transition to adult service or who have **recently** gone through it—folks who are 16 to 23:

- How do you feel in control of your services, choices, and life in the person-centered planning process? Do you feel in control? What is working well for you? How do you learn about what's available to you?
- How do people know what your goals are? (tie in the "how do you feel empowered" question—how do you feel listened to?)
- What is NOT working well for you?
- What might make it easier for you to get information you need?

Probe: Timing, information sharing, trusted sources, navigation, decision-making

Housing

6) First, we want to talk about your living situation…...your house or apartment.

- What is working well for you? What do you like about where you are living?
- What is NOT working well for you? What would make things better about where you live?

Probe: Living space, privacy, friends, roommates, isolation, rules, safety

We've talked about a lot of different parts of your life today but now we want to ask a big question.

7) Is there something that you have wanted to do or achieve that you haven’t been able to?

Probe:

- What have been the barriers?
- What would you change?

Wrap-Up

- Anything you would like to share that we haven’t already talked about?

Appendix D 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

COVERED SERVICES	§21	§29
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

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