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Office of Aging & Disability Services

BIENNIAL REPORT FOR

Autism Spectrum Disorder

Pursuant to 34-B MRS Section 6004

April 2025



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This report was prepared for the Maine Department of Health and Human Services by the Catherine Cutler Institute, Muskie School of Public Service, University of Southern Maine, under agreement #ADS-25-9813.

Abbreviations

CAHPS	Consumer Assessment of Healthcare Providers and Systems
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	Person-Centered Plan
PNMI	Private Non-Medical Institution
RCS	Rehabilitative and Community Services
SAU	School Administrative Unit

Executive Summary

Like everyone, people with autism spectrum disorder (autism) have different needs for support throughout their lives, from birth through childhood, adolescence, and adulthood. Public agencies and programs provide services to people with autism 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 autism. 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 MRS Section 6004 of the Autism Act. It 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 autism.

Perspectives of Individuals with Autism and their Families

To inform this report, the Department of Health and Human Services (the Department) contracted with the Catherine Cutler Institute, Muskie School of Public Service at the University of Southern Maine to survey individuals with autism and their families to understand their satisfaction with current services and gather feedback about what kinds of services could improve their quality of life. Overarching findings from the survey include the need for more social opportunities, transportation, behavioral health, and employment services, as well as challenges with specialty providers who do not understand the needs of people with autism and case managers with high caseloads.

Children's Services

Administered through the Office of MaineCare Services, Maine's state Medicaid agency, the Medicaid Early and Periodic Screening, Diagnostic, and Treatment benefit¹ provides

¹ Medicaid EPSDT Services

comprehensive coverage, including assessment, preventative services, and treatment services designed to help identify children with conditions, including autism, early, and supports access to medically necessary services designed to correct or ameliorate conditions discovered, including evidence-based models such as Applied Behavior Analysis. To aid in early identification and support for families, the Office of Child and Family Services established [Help Me Grow Maine](#) to link families and professionals to information on child development and community resources for children up to age 8. A key goal of this effort is to make developmental screening universally available throughout the state.

Once children with autism are identified, the Office of Behavioral Health Children's Behavioral Health Services (CBHS) team supports providing behavioral health services, including providing access to services through developing provider resources and ensuring the quality of care. CBHS also has a lead family coordinator supporting families with questions about their child's diagnosis, services designed to meet their child's needs, and available resources in their communities. CBHS continues to refine its strategies and implement new initiatives to increase accessibility, availability, quality, and consistency of behavioral health services for children, including those with intellectual and developmental disabilities and autism.

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 autism in Maine, especially in rural areas of the state.

Adult Services

The Department of Labor provides [Vocational Rehabilitation \(VR\)](#) services to students 14+ and adults with physical, emotional, or mental impairment, including intellectual or developmental disabilities and autism. 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 in seeking employment. Adults with disabilities, including autism, may also be eligible for Independent Living Services through a Department of Labor contract with a private agency.

For adults with autism (ages 18 and older), the Office of Aging and Disability Services administers the MaineCare Home and Community-Based Services (HCBS) waiver programs for adults with intellectual disabilities or autism. HCBS waivers are Medicaid-funded service packages designed specifically to help 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 autism include Targeted Case Management, Person-Centered Planning, residential services in Private Non-Medical Institutions or intermediate care facilities for individuals with intellectual disabilities, public guardianship and conservatorship, Adult Protective Services, and statewide behavioral health and support services.

Reforming Transitions across the Lifespan

The Departments of Health and Human Services, Education, and Labor have undertaken several initiatives to improve long-standing problems with the transition process from child to adult services. The Department anticipates that the development and implementation of a new comprehensive Lifespan HCBS waiver will help Maine comply with federal HCBS rules and address key areas needing improvement in the system of care for adults with intellectual disabilities and autism:

- ▶ Community Inclusion
- ▶ Competitive Integrated Employment
- ▶ Control over Personal Resources
- ▶ Prioritizing the Person-Centered Plan/Person-Centered Service Plan reflecting
 - member needs, desires, and goals
 - preferences for living arrangements
 - what covered services they wish to receive
 - who they want to provide such services.

With the implementation of the Lifespan waiver and other ongoing initiatives, the Department will continue engaging with individuals, families, the Department of Education, the Department of Labor, providers, advocates, and other community partners to ensure services for people with autism are provided efficiently and meet their needs.

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 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 autism. 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 developmental 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 autism. With a few exceptions, services available to people with autism 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 MRS Section 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 autism in Maine, the results of a survey of people with autism and their families, the current public agencies and programs serving children and adults with autism, and the agency planning efforts to improve transitions across the lifespan.

Definition & DSM-V-TR Diagnostic Criteria

AUTISM SPECTRUM DISORDER

Autism spectrum disorder refers to any one of a group of disorders with an onset typically occurring during the preschool years and characterized by difficulties with social communication and social interaction along with restricted and repetitive patterns in behaviors, interests, and activities. Autism, Asperger's syndrome, and childhood disintegrative disorder are no longer considered distinct diagnoses, and medical or genetic disorders that may be associated with autism, such as Rett's syndrome, are identified only as specifiers of the disorder.

Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history (examples are not exhaustive)

- 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. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Source: American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders (5th ed., text rev.)*.

Figure 1. Prevalence of autism in Maine



Public Engagement Informing the Biennial Report

In fall of 2024, the Department of Health and Human Services (the Department) contracted with the Catherine Cutler Institute, Muskie School of Public Service at the University of Southern Maine to conduct an online survey to gather information from individuals with autism and their families about what is working well and what could be improved in Maine system of care for individuals with autism.

Biennial Survey of Individuals with Autism and their Families

The University's Institutional Review Board reviewed the survey protocol and data-gathering activities for the report. It determined that they did not meet the definition of Human Subjects Research under CFR 46.102(I) (Protocol #IRB-2024-147). Cutler staff conducted the online survey using the Qualtrics XM Platform.² An anonymous link to the survey was distributed by the Office of Aging and Disability Services (OADS) and partner organizations. The survey was conducted from September 19 – October 11, 2024, and measured individuals' and families' satisfaction with specific services as well as aspects of care delivery, such as whether they felt their providers respected their cultural values and preferences, listened to them, and discussed individuals' goals and dreams (Appendix A: Autism Services Satisfaction Survey).

The survey also asked about their quality of life and what they felt could be improved in broad topic areas such as school, employment, social opportunities, and housing. It also allowed respondents to give open-ended feedback to the Department on the service system for people with autism. The survey was targeted toward individuals with autism and their families who receive services from the Departments of Health and Human Services, Education, and Labor.

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.](#)

RESPONDENTS

Nine individuals with autism and fifty-seven family members responded to the survey (total n=66). Table 1 presents demographic information of all respondents as a group. One-third of respondents (22) represented individuals with autism under 18, and 63% (42) represented individuals with autism 18 and older.

Table 1. Autism services satisfaction survey respondent demographics

	NUMBER of respondents	PERCENT of respondents
Age of individual with autism		
Under 18	22	33%
18 or older	42	63%
Missing data	2	2%
Age at diagnosis		
Under 3	22	33%
Between 3 and 5	14	21%
Older than 5	24	36%
Not sure/missing data	3	5%
Race		
White	48	73%
Race other than White*	1	2%
Did not answer	17	12%
Ethnicity		
Hispanic or Latino	2	3%
Not Hispanic or Latino	48	73%
Did not answer/missing data	16	24%

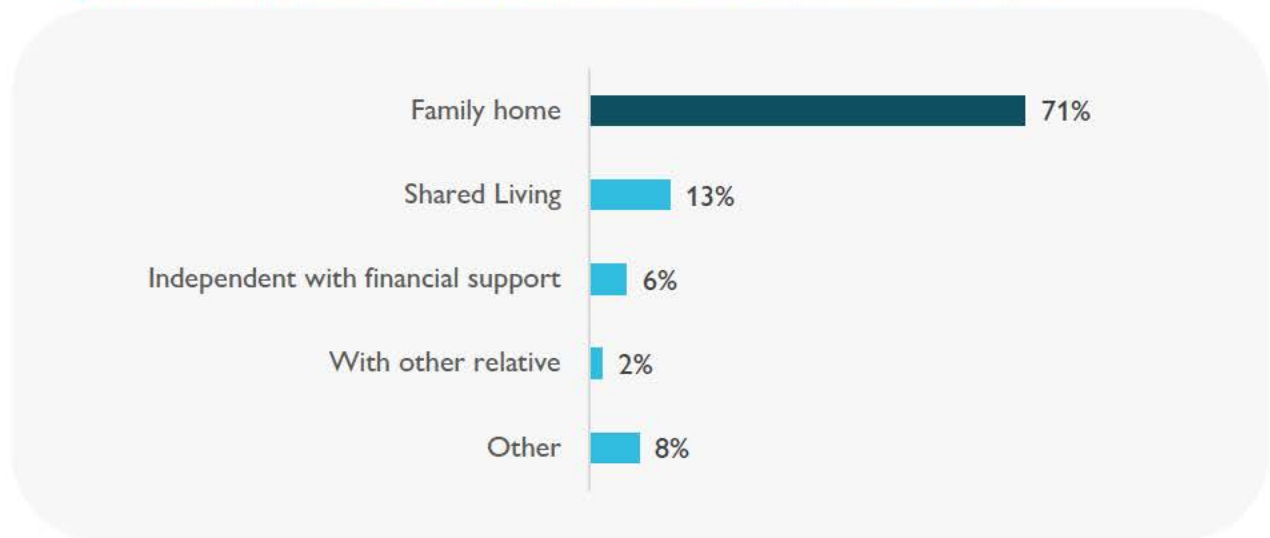
	NUMBER of respondents	PERCENT of respondents
Gender identity		
Female	12	18%
Male	37	56%
Nonbinary	1	2%
Did not answer/did not know	15	23%
Sexual orientation		
Bisexual	1	2%
Gay or Lesbian	0	-
Straight	35	53%
Did not answer/did not know	20	30%

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

Across all respondents, most people with autism live in their family home (71%) (Figure 2). Although not shown in Figure 2, the reliance on living with family members continues into adulthood, with seventy-four percent³ of adults with autism living in their family home or with other relatives.

³ Includes three respondents who noted the Shared Living provider is the parent in the family home

Figure 2. Most respondents said the person with autism lived in their family's home.



SATISFACTION AND EXPERIENCE WITH SERVICES

Respondents were asked to identify which services they used and rank their satisfaction with them on a scale of 1 to 5:

- 1) Extremely dissatisfied
- 2) Somewhat dissatisfied
- 3) Neither satisfied nor dissatisfied
- 4) Somewhat satisfied
- 5) Extremely satisfied

To better understand individuals' care 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 1 to 5:

- 1) Never
- 2) Sometimes
- 3) About half of the time
- 4) Most of the time
- 5) Always

As the Department is committed to providing person-centered services and planning for the people it serves, respondents were asked how strongly they agreed with the

statement, “Your providers talk with you about your goals and dreams,” on a scale of 1 to 5:

- 1) Strongly disagree
- 2) Somewhat disagree
- 3) Neither disagree nor agree
- 4) Somewhat agree
- 5) Strongly agree

RESULTS

Table 2 shows the number of respondents using different types of services. Case management was used by most respondents (50), followed by School with an Individualized Education Plan (IEP) (25) and Section 29 (24). Seven respondents specified other types of services, including job support, medication management, and therapy.

Table 2. Number of respondents using different types of services

Service Type	N
Case Management	50
Child Development Services	8
Occupational Therapy	19
Other	7
Physical Therapy	8
School with a 504 plan	6
School with an IEP	25
Section 21 Comprehensive Waiver Services	14
Section 28 Children’s Rehabilitative and Community Services (RCS)	9
Section 29 Supports Waiver Services	24

Service Type	N
Section 65 Children's Behavioral Health Services	5
Speech Therapy	15

Table 3 shows an average score (1 to 5) for services used by at least ten people. Individuals with autism tended to be more satisfied with their Case Management services than family members, with an average score of 4.3 compared to 3.2.

Table 3. Satisfaction with services by service type

Service Type	Average score Individuals with Autism Responses	Average score Family Member Responses
Case Management	4.3	3.2
Occupational Therapy	5	4.1
Physical Therapy	-	3.9
School with an IEP	-	3.3
Section 21 Comprehensive Waiver Services	4.3	4.1
Section 29 Supports Waiver Services	4.5	4
Speech Therapy	-	3.1

Satisfaction with Case Management varied by the age of the person with autism. Adults with autism and their family members were more satisfied with Case Management than family members of children with autism.

Table 4. Satisfaction with case management services by age

Service Type	Average score (1 to 5)
18 and older <i>n=39</i>	4.1
Under 18 <i>n=7</i>	3.0

For the responses about 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 about how often providers use unkind or hurtful words, the ideal score is 1, or “never.” All services scored well in providing culturally sensitive services and listening to people with autism. Overall, most providers never or only sometimes use hurtful or unkind words (Table 5).

Table 5. Survey responses about provider respect for the individual by type of service

<i>How often do your providers...</i>	Respect cultural values and preferences (5 is ideal)	Listen (5 is ideal)	Use hurtful or unkind words (1 is ideal)
Case Management	4.9	4.4	1.1
Speech Therapy	4.4	4.2	1.3
Occupational Therapy	4.6	4.5	1.1
Section 21 Comprehensive Waiver Services	4.9	4.3	1.6
Section 28 Children’s RCS	4.9	4.2	1.0
School with an IEP	4.2	3.8	1.5
Section 29 Supports Waiver Services	4.9	4.4	1.7
Child Development Services	4.6	3.9	1.0

Fifty-six people responded to the person-centered planning statement, “Your (your family member’s) providers talk with you (them) about your (their) goals and dreams.” Table 6 shows the distribution of responses, with over three-quarters (77%) either somewhat agreeing or strongly agreeing that their providers talk about goals and dreams.

Table 6. Survey responses about providers discussing individuals’ goals and dreams

Providers talk about goals and dreams	Percent of responses (n=56)
Strongly agree	50%
Somewhat agree	27%
Neither agree nor disagree	13%
Somewhat disagree	5%
Strongly disagree	5%

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 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 Section 21 had the largest number of respondents on a waitlist (9 individuals). Case management had the largest number of people waiting for an available provider (9). Respondents also described being on waitlists or waiting for available providers, including psychiatry and other behavioral health care, oral surgeons, and one-to-one school aides.

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.

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

	Number on a waitlist for services	Number waiting for an available provider
Case Management	8	9
Child Development Services	0	1
Occupational Therapy	2	4
Other (please specify)	8	9
Physical Therapy	2	2
School with a 504 plan	0	1
School with an IEP	1	1
Section 21 Comprehensive Waiver services	9	5
Section 28 Children's RCS	6	6
Section 29 Supports Waiver services	3	2
Section 65 Behavioral Health Services	4	5
Speech therapy	3	4
Not sure	10	1

Note: Other includes assistive technology, counseling, day programs, one-to-one school aide, oral surgeon, psychological evaluation, and psychiatric services.

Quality of Life⁵

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

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

Across individuals (n=5) and family members (n=50), seventy-eight percent identified **social opportunities** as a priority area that could improve the quality of life for people with autism. Over half (58%) identified **behavioral and emotional health**, one-third (34%) identified **housing**, and over one-quarter (26%) identified **employment** as priority areas. Several respondents identified other priority areas, including dental care, crisis services, home and community support, occupational therapy services, and alternative school settings that are equipped to handle significant behavioral needs.

Respondents were then asked what services are currently available or that they would like to see made available that could help address the priority areas they identified. Thirty-four respondents gave a variety of suggestions. The services most suggested were **behavioral health care**, including psychiatrists and therapists, and **transportation** such as taxis or alternatives to MaineCare transportation services. Other suggested services were social opportunities, employment assistance, and more and better-trained providers – especially specialists like **dentists**.

A final question asked if there was anything respondents would like to tell the Department. Twenty-three family members and two individuals with autism responded with comments and suggestions. A common theme in the open-ended responses was a lack of understanding of autism among medical providers, including emergency departments and dentists, therapists, law enforcement, teachers, employers, and the

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

public. This results in a constant need to educate people about autism and how it manifests in different ways.

“We don't need more awareness--everyone's aware of it--we need understanding and education. The burden of education about autism and effective communication rests with the autistic individual and their families, who are already struggling with a lack of understanding and support from everyone around them.”

Families described the consequences of the lack of providers trained in the communication and behavioral needs of people with autism – dental needs may not be attended to until they are in crisis, and individuals may have poor experiences in the emergency department. When teachers do not have training or experience with students with unique communication and behavioral needs, the student may experience bullying by the teacher and fellow students.

“The professionals we desperately need are either underpaid or are not qualified, especially for the more severe behaviors.

Several family members specifically noted a need for more and better-trained case managers. There was concern that current case managers are overwhelmed. These sentiments may explain the relatively low satisfaction with case management among family members compared to other services (3.2 out of 5).

“Case managers need more training.”

“Case managers today are overwhelmed and unable to really support families.”

“We really need more case managers. Ours is overwhelmed with their caseload.”

Reflecting the need for person-centered services, several respondents suggested that day programs could be better tailored to individual needs and offer more activities than shopping trips, coloring, and puzzles. One respondent suggested that a peer-led program could help their child want to participate. More options for day programs at times later than 9 am to 2 pm could help individuals who are not “morning people.” Some respondents expressed concern that day programs and group home settings are focused on getting individuals out into the community to socialize, yet it can be stressful for an individual with autism. Others wanted more social opportunities outside of school for children and adults after graduation – especially when the adult with autism cannot independently schedule and plan activities.

Two respondents appreciated having the opportunity to provide feedback to the department, and two said they were pleased with their services, including Shared Living and Self-direction.

“We are using the Self-directed services, and that is working very well. We can hire our own staff and are no longer on the wait list for services like we were before because there were no professionals available to hire.”

Overall, while most respondents are somewhat or extremely satisfied with the services they and their family members receive, there are distinct areas that could be improved to help individuals with autism live, work, and socialize in the communities of their choice.

ADDITIONAL SATISFACTION FINDINGS FROM HCBS CAHPS

The findings from the online survey conducted for this report mirror those of the recent Consumer Assessment of Healthcare Providers and Systems for Home and Community-Based Services (HCBS CAHPS) survey in 2023 conducted on behalf of the Office of Aging and Disability Services by Knowledge Services, Inc.

HCBS CAHPS, developed by CMS, is an in-person or telephonic survey to gather feedback about waiver services and ask individuals about their experiences with:

- Getting needed services

- ▶ Communication with providers
- ▶ Case managers
- ▶ Choice of services
- ▶ Medical transportation
- ▶ Personal safety
- ▶ Community inclusion and empowerment
- ▶ Employment

CAHPS survey data is collected anonymously and included in CMS's HCBS quality measure set and may be used to evaluate quality assurances associated with all HCBS waiver programs OADS administers. OADS conducted a two-year pilot to administer the survey for the first time in Maine. The results presented here are from the first year. Participants in waiver services were randomly selected to complete this survey from 10/16/2023-12/29/2023.

Out of 7,760 members sampled, 1,991 completed this survey, resulting in a response rate of 26%. Section 21 and Section 29 participants comprised many of those who responded to the study. Of the 1,991 respondents, 528 (27%) received Section 21 services, and 578 (29%) received Section 29 services. Section 29 members were further divided into those without self-direction and those with self-direction. Section 29 self-direction participants comprised less than 1% of the total survey respondents and were overall more satisfied than other participants. For this report, Section 29 survey results discussed below focus solely on those without self-direction.

Although not all HCBS CAHPS respondents receiving Section 21 and Section 29 services have autism, overall findings from 2023 indicated that people felt good about their safety and respect and that staff were reliable and helpful. Eighty-five percent of Section 21 and 93% of Section 29 survey respondents said that staff mostly or always treated them how they wanted to be treated, and 96% stated they could contact their case manager when needed (in Section 29 self-direction, this was 100%).

Challenges were related to transportation and accessing the community. Thirty-seven percent of Section 21 and 31% of Section 29 members reported they sometimes did not have a way to get places. For those who used transportation services, 29% from Section 21 and 47% from Section 29 said their ride sometimes did not arrive on time. Forty-four percent of Section 21 and 39% of Section 29 respondents also reported they could sometimes not do things they liked within their community. Thirty percent of respondents

for both Section 21 and 29 also stated their services did not include some of the things they thought were important.

Year two of the HCBS CAHPS survey began in June 2024. All surveys were completed by September 20, 2024, and survey findings were presented to OADS in November 2024. The HCBS CAHPS two-year pilot project survey results will help inform future HCBS-related quality improvement efforts in Maine and will be used as part of Maine's quality measurement system for all HCBS programs. All HCBS CAHPS survey results can be found [here](#).⁶

⁶ HCBS CAHPS Initiative on OADS website.

Maine's Public System of Support

People with autism have different needs for support throughout their lives, from birth through childhood, adolescence, and adulthood. Public agencies and programs provide services for people with autism 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 the level of impairment and/or financial need.

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

Childhood		Transition Age (14-22)		Adulthood	
Age					
0	5	14	18	22	
Office of Behavioral Health					
<i>MaineCare</i>					
Ages 0-21: Early and Periodic Screening, Diagnostic, and Treatment, Family Support, Children's Behavioral Health Services, Children's Private Non-Medical Institution (PNMI)					
Department of Education					
<i>Child Development Services</i>					
Ages 0-2: Developmental Services					
Ages 3-5: Individuals with Disability Education Act (IDEA) Part B					
<i>Local Schools/Special Purpose Private Schools</i>					
Ages 5-22: IDEA Part B					
Department of Labor					
<i>Bureau of Rehabilitation Services</i>					
Ages 14+: Vocational Rehabilitation					
Ages 18+: Independent Living Services					
Office of Aging and Disability Services					
<i>MaineCare</i>					
Ages 18+: Targeted Case Management, Person-Centered Planning, Home and Community-Based Waiver Services, PNMI, Intermediate Care Facility for Individuals with Intellectual Disabilities					

Individuals with autism 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 autism. Based on diagnostic codes within the MaineCare claims system, in FY2022 and FY2023, MaineCare served 13,948 and 15,133 people with autism, respectively Table 8.

Table 8. Number of people with autism served by MaineCare by age group 2022-2023

	Age Group	2022	2023
Children 0-17	0-2	219	211
	3-5	1,666	1,847
	6-13	4,095	4,450
	14-17	1,858	1,908
	Subtotal 0-17	7,838	8,416
Adults 18+	18-20	1,347	1,375
	21-34	3,520	3,888
	35-44	669	789
	45-54	285	319
	55-64	176	219
	65-74	89	97
	75+	24	30
	Subtotal 18+	6,110	6,717
ALL AGES TOTAL		13,948	15,133

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

Services for Children Ages 0-22

OFFICE OF BEHAVIORAL HEALTH

ABOUT THE OFFICE OF BEHAVIORAL HEALTH

OBH is committed to supporting a complete and coordinated behavioral health continuum of care that serves the whole person, the whole community.

Beginning at the youngest ages, birth through age 21, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services are designed to identify autism 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 21 covered by Medicaid (Section 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 autism, must receive EPSDT screenings designed to identify health and developmental issues, including autism, as early as possible.”⁷

The American Academy of Pediatrics recommends EPSDT screening for autism at the 18- and 24-month well-child visits, as well as additional screenings if the child has a sibling with autism. Maine has adopted the Bright Futures⁸ recommendations for preventive pediatric health care from the American Academy of Pediatrics to ensure screening occurs routinely at all ages of development. To aid in early identification and support for families, the Office of Child and Family Services (OCFS) Early Care and Education team established [Help Me Grow Maine](#), a free information link that links families and professionals to information on child development and community resources for youth up to age 8. A key goal of Help Me Grow Maine is to make developmental screening universally available across the state.

⁷ Clarification of Medicaid Coverage of Services to Children with Autism, accessed October 24, 2024.

⁸ See [Bright Futures](#) for more information.

The Office of Behavioral Health (OBH) Children’s Behavioral Health Services (CBHS) team supports providing behavioral health services, including providing access to services through developing provider resources and ensuring quality of care. CBHS also has a lead family coordinator supporting families with questions about their child’s diagnosis, services designed to meet their child’s needs, and available resources in their communities. Table 9 shows the MaineCare services available to children with behavioral health needs, including children with autism.⁹ Children must be eligible for MaineCare to receive these services. Additional state and federally funded behavioral health services are administered by OBH and CBHS, including crisis stabilization, family and peer support, and respite care.

Table 9. OBH/CBHS MaineCare-funded Services Available to Children with Behavioral Health Needs including Children with Autism

OBH/CBHS Service	Service Description
Section 28 Rehabilitative and Community Services (RCS)	▶ Skill building in areas of daily living and behavioral management to support the child’s functioning in the home and community, including the use of Applied Behavior Analysis
Section 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
Section 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

⁹ 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.

OBH/CBHS Service	Service Description
	<p>better in home, school, and community, and prevent hospitalization</p> <ul style="list-style-type: none"> ▶ Assertive Community Treatment (ACT) provides intense 24/7 symptom management and supports in the home, school, and community to prevent hospitalization ▶ Therapies including Functional Family Therapy, Multi-Systemic Therapy, and Multi-Systemic Therapy for youth with Problem Sexual Behavior ▶ Crisis Response and Stabilization Service ▶ Parent training services using evidence-based models for children with disruptive behavior disorders.
Section 97 Residential Treatment (Private Non-Medical Institution or PNMI)	<ul style="list-style-type: none"> ▶ Residential treatment is a short-term treatment (1 to 4 months) to teach youth/parents skills to manage behaviors safely at home

In FY2022 and FY2023, over 3,000 children with autism received children’s behavioral health services. [Table 10](#) shows the number of children with autism who used the different behavioral health services.

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

Service	2022	2023
Rehabilitative and Community Services	1,532	1,196
Crisis Stabilization	138	204
Targeted Case Management	1,289	1,298
Children's Private Non-Medical Institution	109	55

Service	2022	2023
Home and Community-Based Treatment	225	214
Outpatient	1,240	1,357
Unduplicated Total Served	3,365	3,243

Source: Maine Office of Behavioral Health

CBHS System Improvement and Reform Strategies

In 2018, the Department contracted with an independent consultant to assess the OCFS Children’s Behavioral Health Services to identify strengths and weaknesses, quality of outcomes, service array, capacity, funding structure, and program operations.¹⁰ 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)

¹⁰ The final report is the 2018 Children's Behavioral Health Services Assessment.

- Hire a full-time, on-site OCFS Medical Director (**complete**)
- Facilitate access to parent support services (**complete**)
- Explore options to amend current service definitions for MaineCare Section 28 (in process)
- Clarify children’s behavioral health services roles, responsibilities, procedures, policies, and practices (**complete**)

LONG TERM (2019 – 2025)

- Establish one or more Psychiatric Residential Treatment Facilities (PRTF) (in process)
- Address shortages in the behavioral health care workforce (in process)
- 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 the early childhood workforce to address challenging behaviors (in process)
- Explore a statewide or regional single point of access (in process)
- Revise the waitlist process (in process)
- Improve coordination for transition-age youth behavioral health services (**complete**)
- Facilitate access to services that can help families support children with behavioral health needs (in process)

In 2022, CBHS heard the concerns and suggestions of experts, advocates, the Department of Justice, families, youth, and providers. This input helped CBHS tailor and intensify strategies, initiatives, and investments to ensure it maximizes the potential to improve the CBHS care system. CBHS has refocused its work for the next four years into three main goals, which seek to improve the foundational pillars of the children’s behavioral health system:

- ▶ **Accessibility** to address how youth and families access CBHS
- ▶ **Availability** to address service needs through a variety of training initiatives and working to close identified gaps in the delivery system
- ▶ **Quality and Consistency** to update rules and regulations with a focus on quality, including expanding quality assurance activities by CBHS

One of the most impactful activities affecting CBHS in 2023 was the historic rate reforms for behavioral health services, which invested \$237 million in federal and state funds into revised reimbursement rates for providers of MaineCare reimbursable services. In addition to these reforms, the Department committed to providing annual cost of living adjustments to keep pace with inflation. These reforms update the rate models for services to ensure they are data-driven and reflect provider costs, utilizing value-based payment strategies as applicable. CBHS is excited about these changes and looks forward to seeing their impact on the delivery system in the coming years.

While the true impacts of the investments in reimbursement rates for services are still becoming known, the preliminary data is promising. Section 65 Home and Community-based Treatment has seen a 21.3% reduction in the waitlist from a high of 753 youth in June 2022. Section 28 Rehabilitative and Community Support Services for Children with Cognitive Impairments and Functional Limitations has seen a 21.8% reduction in waitlist from a high of 615 youth in September 2022. CBHS continues to aim to eliminate waitlists for services, and this data is encouraging.

In 2024, the Department moved CBHS from OCFS to the Office of Behavioral Health to better align children's services within the broader continuum of the behavioral health system of care across the lifespan while maintaining a close connection with other OCFS programs. More information about the transition can be found on the Department's [website](#).

CBHS has continued to move forward in meeting several long-term goals, including collaborating with OCFS, the Office of Aging and Disability Services (OADS), OBH, and the Departments of Education and Labor on developing resource documents for transition-age youth; working with OADS to align policies and procedures between the two offices; supporting shared initiatives, such as the Pathways to Partnership¹¹; strengthening Section 28 RCS services by licensing providers; increasing training and

¹¹ Pathways to Partnership Press Release

certification opportunities for evidence-based treatments (e.g. Trauma-Focused Cognitive Behavior Therapy, Triple P, Research Units in Behavioral Intervention); developing a Center of Excellence to be the training and resource hub for High Fidelity Wraparound (an evidence-based intensive care coordination model supporting youth to maintain in their homes and communities); and reviewing assessment and referral pathways for medium to high-intensity behavioral health services. For more information on CBHS's progress in implementing the strategies, [see Children's Behavioral Health | Department of Health and Human Services \(maine.gov\)](#).

DEPARTMENT OF EDUCATION

DEPARTMENT OF EDUCATION MISSION

To promote the best learning opportunities for all Maine students by focusing on a whole student approach; encouraging innovation; respecting educators; providing information, guidance, professional learning, and support to schools and educators; providing adequate and equitable school funding and resources; and inspiring trust in our schools.

The Department of Education (DOE) administers several services for children with developmental disabilities, including autism. The Department of Education is dedicated to increasing training, professional development, and technical assistance to support high-quality programming for individuals with autism in Maine, especially in rural areas of the state. Under the Individuals with Disabilities Education Act (IDEA), children with autism 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 special education rules and 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, 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, including early intervention, special education, and related services for eligible children from birth to age five and their families.¹²

In response to [LD 1528](#) and with partner input from families, advocacy groups, superintendents, school board members, educators, public school service providers, education experts, and others, DOE is conducting a pilot that shifts the responsibility of educational services for preschool-age children with disabilities, including those with autism, from CDS to local school administrative units (SAUs). The pilot, operating in several willing SAUs, is intended to lead toward full inclusion of preschool students with disabilities in the general education setting and is in line with [guidance](#) from the US Department of Education's Office of Special Education Programs to educate children with disabilities in the least restrictive environment, alongside their typically developing peers. Intensive training and technical support in developmentally appropriate practices for working with young children and their families and in inclusive educational practices allowing children to learn together and receive necessary support is provided to the participating SAUs. Maine DOE anticipates all SAUs will assume the responsibility for providing special education to their preschool students with disabilities by fall 2026.

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 cannot access their education in a less restrictive setting within their school district. These schools operate Day Treatment programs and provide coordinated and integrated behavioral, clinical, educational, emotional, medical, and social treatment to address the

¹² See [Child Development Services](#)

concerns that prevented each student from accessing their education in a less restrictive setting.¹³

Students with autism can access the same services available to other students with special education needs. Students with special education needs have Individualized Education Plans to ensure they receive specialized instruction and related services. An ongoing initiative of the Department of Education that might have a particular impact on students with autism is Positive Behavioral Intervention and Support (PBIS). Developed by national experts, PBIS provides a multi-tiered approach to supporting students' social, emotional, and behavioral development in K-12 settings to improve 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 in implementing the PBIS framework by providing professional development and technical assistance, access to evidence-based practices, and evaluation of outcomes of positive behavior supports.¹⁴

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 monitor evidence-based practices with students with autism from age birth to 22 years old.¹⁵

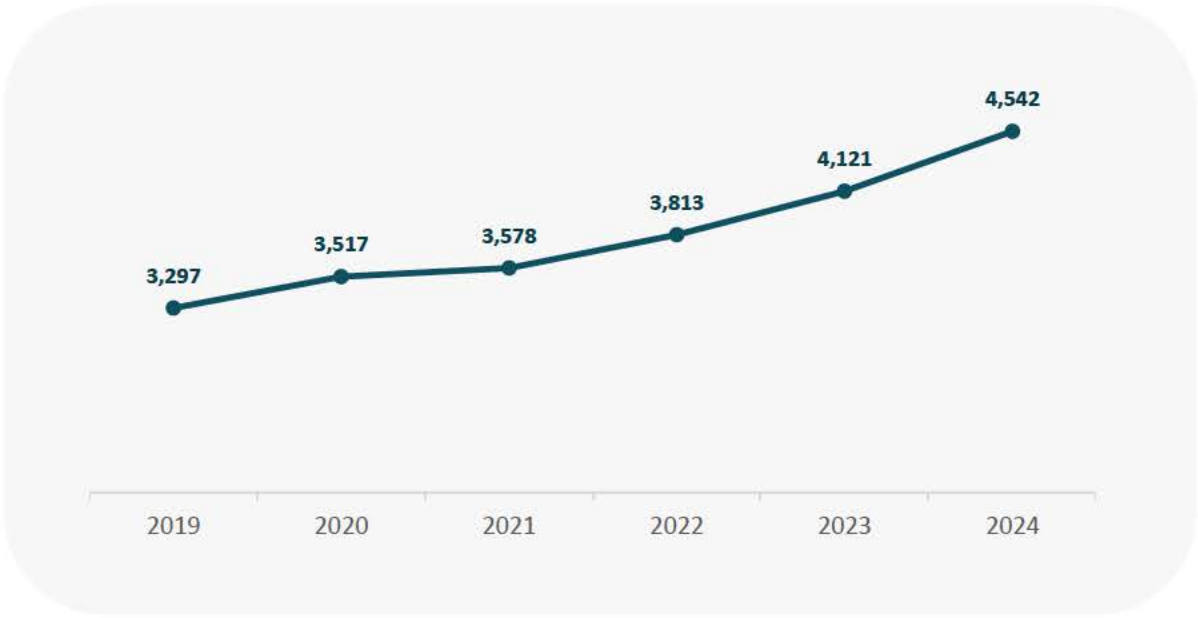
The number of school-age students in special education with autism ages five through twenty increased by over 1,200 students during 2019-2024 ().

¹³ See [Department of Education Special Purpose Private Schools](#)

¹⁴ [Maine Positive Behavioral Intervention & Supports](#)

¹⁵ For more information, see [Professional Learning for Education Technicians](#)

Figure 4. The number of special education students with autism ages 5-20 increased between 2019 and 2024



Source: Maine Department of Education

In 2019, students with autism made up ten percent of the students receiving special education services. This increased to thirteen percent in 2024 (Table 11).

Table 11. Children ages 5-20 in special education, 2019-2024

Year	Special Education Students with Autism	Percent of Special Education Students with Autism
2019	3,297	10.2%
2020	3,517	10.8%
2021	3,578	11.2%
2022	3,813	11.7%
2023	4,121	12.3%
2024	4,542	13.1%

Source: Maine Department of Education

Over the past several years, there has been a concerted effort through initiatives like Help Me Grow Maine to identify children with autism as early as possible. The increase in the number of five-year-olds with autism receiving special education in 2019 - 2024 may reflect progress in this area (Table 12). As of January 2021, students can receive special education services through age 21, though many students with autism transition out of special education services after age 17 or 18. Data from 2019 through 2024 shows that this transition has been consistent.

Table 12. Special Education students with autism by age, 2019-2022

Age	2019	2020	2021	2022	2023	2024
5	196	243	218	270	352	413
6	262	278	314	320	365	449
7	243	276	285	329	358	421
8	268	247	268	309	350	381
9	251	275	246	287	324	358
10	247	242	279	252	296	338
11	259	256	244	289	259	301
12	264	283	258	244	297	271
13	237	289	282	259	252	315
14	258	236	297	276	285	261
15	234	271	241	293	288	288
16	248	233	282	245	287	294
17	210	240	223	260	222	276
18	84	106	101	114	120	103
19	*	33	*	37	46	48
20	*	9	*	25	20	25
TOTAL	3,297	3,517	3,578	3,813	4,121	4,542

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

Source: Maine Department of Education

Services for Adults Ages 18+

DEPARTMENT OF LABOR

The Bureau of Rehabilitation Services (BRS) within the Department of Labor administers Vocational Rehabilitation (VR) through the Division of Vocational Rehabilitation (DVR) for adults and transition-age students ages 14 and older.

BUREAU OF REHABILITATION SERVICES MISSION

BRS works to bring about full access to employment, independence and community integration for people with disabilities.

VR assists people with disabilities in getting and keeping a job by developing an Individualized Plan for Employment that describes realistic goals agreed upon by the individual and the VR Counselor and a plan for achieving those goals. Services may include:

- ▶ Job-seeking skills instruction
- ▶ Job skills training
- ▶ Job development and placement
- ▶ Job coaching- short term
- ▶ Job coaching- Supported Employment (SE)
- ▶ Community-Based Situational Assessment (CBSA)
- ▶ On-the-job-training
- ▶ Business engagement & employer relations

VR services may be provided by Community Rehabilitation Providers (CRPs), vendors who contract with BRS to provide various employment services to individuals with disabilities. BRS has established [Quality Indicators](#) for CRPs to ensure the delivery of high-quality employment services, including consumer choice and participation, qualified employment services staff, and competitive, integrated employment settings.

In addition to VR, adults with autism may also be eligible for Independent Living Services. The four core services that every Independent Living Center provides are:

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

The Independent Living Services program can purchase various 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 traditionally provided by other state, federal, or private agencies. A maximum lifetime expenditure of \$5,000 is allowed for each eligible individual served by the Independent Living Services Program.

OFFICE OF AGING AND DISABILITY SERVICES

For adults with autism (ages 18 and older), the Office of Aging and Disability Services (OADS) administers the MaineCare Home and Community-Based Services (HCBS) waiver programs for adults with intellectual disabilities or autism. HCBS waivers are Medicaid-funded service packages designed to help 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 Section 21 waiver, sometimes called the "Comprehensive Waiver," provides a broader array of services than available under Section 29, sometimes referred to as the "Support Waiver."

OFFICE OF AGING AND DISABILITY SERVICES VISION

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

Both Section 21 and Section 29 offer Home Supports,¹⁶ Work Supports, and Community Supports, which are direct support services,¹⁷ and assistive technology to support people in their homes, at work, and in the broader community. Both waivers provide services and support in a privately owned or rented home or apartment or a Shared Living arrangement. Members of Section 21 have access to services in a provider-owned or controlled group home. In addition, under Section 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.

Self-directed services are available through Section 29. Self-directed services are home and community-based services that help individuals across all types of disabilities maintain their independence and determine what mix of supports and services works best for them. Self-direction provides participants with a flexible budget that enables them to hire their own workers and decide when they will work, how much they get paid, and manage the workers. If an individual wishes to use this option but prefers to have another person manage these responsibilities, they can appoint a representative to act on their behalf. A side-by-side comparison of services covered under each waiver is provided in [Appendix B: MaineCare Adult Developmental Services Under Section 21 and Section 29](#).

Maine continues to expand access to good jobs for individuals with a disability. Maine is an Employment First state, and Employment First Maine Act¹⁸ providers must offer

¹⁶ 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.

¹⁷ “Direct support” includes assistance with personal care and other tasks, exercising safe and responsible judgment, and promoting personal development and health and well-being.

¹⁸ 26 MRS Section 3401-3403.

employment services before offering other services, such as Community Supports. OADS coordinates with the OBH and BRS to help individuals with disabilities obtain and maintain employment. BRS and the Office of Behavioral Health partnered with OADS to form a Workforce Development System that provides basic staff certification, advanced training, and resources for providers of employment services to people with disabilities. Providers assist with Career Planning, Employment Specialist services, and Work Support, meet with employers, and help with applications for unemployment and other work-related needs. Individuals experiencing job loss or unable to work can access accurate information about wages, benefits, and unemployment services through Maine Medical Center’s statewide Benefits Counseling Services.

Individuals who are not accessing HCBS waiver services may be receiving residential services financed under MaineCare as Private Non-Medical Institution (PNMI) services (Section 97 in the MaineCare Benefits Manual) or services provided in an intermediate care facility for individuals with intellectual disability (ICF-IID) (Section 50 in the MaineCare Benefits Manual). Intermediate care facilities are designed to meet the intensive, active treatment needs of persons with intellectual disabilities. PNMIIs are funded to provide clinical and personal care services¹⁹ and vary in size; they may serve up to 16 people.

Other services available to adults with autism who are not accessing either waiver or facility-based services include Targeted Case Management (funded primarily through MaineCare Section 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 a meaningful and self-directed life.

Table 13 shows the number of adults with autism who used developmental services in FY2022 and FY2023. The columns will not add to the total number of people served, as individuals could have accessed more than one service within the same year.

¹⁹ “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.

Table 13. Number of adults with autism who used MaineCare Developmental Services, in 2022 and 2023

MaineCare Service	2022	2023
Section 13 Targeted Case Management	3,632	3,159
Section 21 Comprehensive Waiver	929	1,006
Section 29 Supports Waiver	1,066	1,124
Section 97 Private Non-Medical Institution	222	195
Unduplicated Total Served	3,781	3,289

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

Transitioning from Children to Adult Services

As documented in this report, multiple state agencies play a role in the lives of people with intellectual and developmental disabilities and autism. 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 autism transition from school to adulthood and from developmental services provided through CBHS to adult services provided through OADS. This section describes current transition services and the reform efforts anticipated to be implemented in 2025.

Current Transition Services

DEPARTMENT OF EDUCATION TRANSITION SERVICES

The Individuals with Disabilities Education Act requires schools to provide services to promote a 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.” [A Guide to Transition Services in Maine](#) is available to help students and families navigate the transition process.

A student’s school must initiate transition planning services 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 ensures 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 and Division for the Blind and Visually Impaired, within the BRS, assist transition-age students and young adults (ages 14-24) with disabilities – including those receiving services through an Individual Education Program or a Section 504 Plan²⁰ as well as adults with physical, emotional, or mental impairment including intellectual or developmental disabilities and autism – to access vocational rehabilitation services to help them get and keep a job. Students ages 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

²⁰ 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 \(PDF\)](#).

- Instruction in self-advocacy

Vocational Rehabilitation 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 developing 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. In addition, there are [Career Exploration Workshop](#) materials to help students learn about their strengths and employment interests and understand how person-centered planning can inform their employment goals. More information on the collaborative efforts between the Department of Education, OADS, and the DVR to improve the transition process for students into employment is available in the DVR's [State Plan 2024-2027 Draft](#).

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 autism 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 college life before going to college full-time.

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 autism, and their families can learn about supported decision-making alternatives during the planning activities as they transition from children's to adult services.

Improving Transitions across the Lifespan

There have been several long-standing structural challenges for parents and their children navigating the transition from children to adult services. First, there is a mismatch between the services available to children and adults. Access to adult services is limited to those with an intellectual disability or autism, while eligibility criteria for children's developmental services are more broadly defined. As individuals and families look to the future, they face 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 differ in adult programs.

The waitlist for MaineCare HCBS waivers has been another structural challenge for those eligible for adult developmental services.²¹ While 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 adult HCBS waiver services. Alternative services may be provided in the interim, but some needed services may be unavailable. Another challenge is the limited access to case management services from the adult services system while still receiving children's case management services.

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

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.

The transition from childhood to adulthood is not the only transition people have in their lifetimes. Changing jobs, moving to a new home, and experiencing changes in family structure with aging parents are moments of transition that all people encounter across the lifespan. People with intellectual disabilities or autism may require assistance navigating these transition points and accessing new services to meet their changing needs.

The [2023-2024 Biennial Plan for Adults with Intellectual Disability or Autism](#) described several key areas of planned improvements for the service system: Person-Centered Planning and Community Inclusion, Quality Improvement, System Capacity and Access to Services, Statewide Behavioral Health and Support Services, Transitions across the Lifespan, and Innovation. Much of the Department's work in these areas in 2023-2024 was supported through federal funding available through the 2021 American Rescue Plan Act Section 9817. The results from these initiatives are impacting and informing ongoing work in 2025-2026.

The American Rescue Plan Act Section 9817 Projects to Improve Home and Community-Based Services

The American Rescue Plan (ARP) Act of 2021 was enacted in response to the COVID-19 pandemic. Section 9817 of the ARP provided a temporary 10 percentage point increase to the federal medical assistance percentage (FMAP) for certain Medicaid expenditures for HCBS. Originally scheduled to end on March 31, 2024, this funding was extended through March 31, 2025. States have been able to use Section 9817 funding to initiate improvement projects in HCBS services.

Maine has developed and administered many initiatives to improve the HCBS service system for all its waivers. More information on all Section 9817 projects can be found at [Home and Community-Based Services Improvement Plan](#).

THE LIFESPAN WAIVER

With ongoing engagement with people with intellectual disabilities or autism, their families, providers, advocates, and other partners, OADS has developed a new comprehensive Lifespan HCBS waiver. The planning activities for Lifespan encompassed many key areas of improvement outlined in the 2023-2024 Biennial Plan.

Designed to respond to the needs of individuals as they transition from childhood (age 14) to early adulthood and beyond into older age, the Lifespan waiver further operationalizes the federal policy objectives for all HCBS programs to “provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings.” The Lifespan waiver also provides a framework for reducing or minimizing service waitlists.

In Maine’s [Final Statewide Transition Plan for Implementing the Federal HCBS Settings Rule](#), the Department identified several areas of improvement to align Maine’s policy with the federal HCBS rule that could be addressed through the Lifespan waiver:

- ▶ Community Inclusion
- ▶ Competitive Integrated Employment
- ▶ Control over Personal Resources
- ▶ Prioritizing the Person-Centered Plan/Person-Centered Service Plan (PCP/PCSP) reflecting
 - member needs, desires, and goals
 - preferences for living arrangements
 - what covered services they wish to receive
 - who they want to provide such services.

The proposed Lifespan waiver includes new services designed to enhance these and other service priorities (Figure 5). Additional information and details are available on the [HCBS Lifespan Project website](#).

Figure 5 Proposed new Lifespan waiver services by domain

Domain to improve	Proposed Lifespan waiver services
Community inclusion	Community Connections Assistance Community and Relationship Connecting Community Transportation Services

Domain to improve	Proposed Lifespan waiver services
Competitive integrated employment	Career Planning Co-worker Supports Employment Exploration Job-career Development Plan and Outcome Integrated Employment Path Services Self-employment Start-up Plan and Outcome Individual Job Coaching
Control over personal resources	Expansion of Self-Direction, where many new services can be elected to be managed by the member Individual-Directed Goods and Services for members who self-direct Family Empowerment and Systems Navigator Home-Based Independent Living Skills Training Peer Support, provided by other waiver members who choose to participate and assist with skills and tasks, providing lived experience to other members. The service will also provide support for waiver members with PCP and for defining who they want to attend and support the PCP process.
Prioritizing PCP/PCSP	Housing Counseling to encourage more independent residential options, including housing rental or ownership by waiver participants Community Supported Living where participants can rent or own their own home and have services come to them as needed 24/7 Transition Case Management and Community Resource Coordinator

A specialized case manager called a Community Resource Coordinator will provide the proposed Transition Case Management service. The Community Resource Coordinator (CRC) will address all forms of transition, including youth to adult services, and any other life transition, such as the transition to a less restrictive residential setting, discharge from a hospital, or other significant life change. In the surveys and listening sessions conducted for the [2023 Biennial Plan for Autism](#) and the study conducted for this report, parents expressed deep concerns about what will happen to their adult children with autism when they are no longer able to care for them or pass away. The Lifespan waiver CRC role is designed to address this type of later-life transition.

OADS anticipates the Lifespan waiver will open by July 2026, contingent on federal waiver approval and major substantive rule development following the Maine Administrative Procedures Act process. Before Lifespan opens, OADS expects to have ended the waiting list for Section 29 services, and Sections 21 and 29 will be closed to new enrollment. When Lifespan opens, OADS proposes three priority groups for the first year:

- ▶ Youth in transition, ages 14-17
- ▶ Adults (18+) on the Section 21 waiting list receiving no other waiver services (i.e., they are not receiving Section 29 waiver services).
- ▶ Reserve slots for emergencies, similar to existing waivers' reserve slots.

After these priority groups are enrolled, OADS plans to open enrollment to individuals new to OADS services with other related conditions like cerebral palsy. There will be no required transition from other waiver programs to the Lifespan waiver. However, voluntary transitions will be possible from Sections 21 and 29 and from Section 20 HCBS for Adults with Other Related Conditions in subsequent years.

OADS anticipates that, through the enrollment framework of the Lifespan waiver, within five years, there will be no significant waitlists for the waivers supporting people with intellectual disabilities, autism, or other related conditions. OADS estimates that it will take five years to process those who want a comprehensive waiver but for whom Section 21 is closed to new participants.

In addition to improving person-centered planning and community inclusion, quality, system capacity, and access through innovative service delivery for all people with intellectual disabilities and autism, OADS anticipates that the Lifespan waiver will lead to fewer people experiencing crises in the service system. Currently, priority for an available slot on the Section 21 waiver is reserved for those who are at imminent risk of abuse, neglect, or exploitation. This has resulted in members of Section 29 who want Section 21 services having to wait until they have an urgent need or crisis to access Section 21. With the anticipated wait-list reduction, members will be able to enroll as soon as they apply for services.

Lifespan Quality Assurance, Improvement, and Monitoring Structures

Across all HCBS programs, the Department has focused on improving Quality Assurance using federal funds available through the ARP Section 9817. The Department used this

funding to add contracted positions to the district offices to increase efforts related to monitoring and technical assistance support to agencies regarding reportable events, develop plans of correction as needed, and develop and initiate Maine's ongoing monitoring plan as outlined in the [Statewide Transition Plan](#). This funding has also allowed the Department to hire quality consultants who are helping to define an improved system and a new provider licensing rule. These efforts continue with work on building quality assurance and monitoring into the Lifespan waiver and rules, including:²²

- ▶ Using the new [federal HCBS quality measures set](#) for federal reporting
- ▶ Implementing the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey to assess waiver participant experiences
- ▶ Basing provider certification on state standards, required training in the delivery of services, and defined expectations for delivery and outcomes
- ▶ Using outcomes-based services reimbursement. Payment for several services, notably in the employment domain, will be based on achieving outcomes for the waiver participant, e.g., the successful completion of an employment plan or successful placement in a job.
- ▶ Enhancing behavioral and communication supports for individuals with exceptional needs
- ▶ Including waiver-funded case management, the CRC, so that greater oversight and control of the quality of case management can be sustained. In addition, there will be a formal training program for the CRC, and competency standards will be established focusing on the functions of the role as well as on the PCP and planning process expectations. Regular professional development will be required to remain current with the range of public services available and local community resources and services.
- ▶ Standardizing the assessment of service needs through the Supports Intensity Scale. By using a standard tool delivered by high-quality, conflict-free, certified assessors, with quality assurance processes built into the delivery of the assessment, the case managers will have better quality data to define support options and will provide a fair and level playing field so that all individuals get the supports they need.

²² The federal HCBS quality measure set and CAHPS survey will be implemented for all HCBS waivers OADS administers.

Workforce, Staffing, and Administrative Burden Improvement Strategies under Lifespan

Recruiting and maintaining qualified staff across the human services and healthcare fields has been challenging for some time. Lifespan proposes several strategies to support the hiring and retention of direct care staff, easing administrative burden and increasing efficiency.

- ▶ Establishing Direct Support Professional (DSP) career lattices that enable them to obtain additional certifications for supporting individuals with exceptional behavioral or medical needs and establishing tiered DSP reimbursement rates that reflect these additional skill sets. Better-trained specialists can offer better quality and more effective services.
- ▶ Reducing caseload sizes for CRCs. Because a CRC will require additional time to fully address all the intersections of a person with their community, employment options, other state and federal resources, and housing options, the Department proposes a lower caseload to improve quality and responsiveness in these complex cases and to improve the sustainability of the CRC role.
- ▶ Reducing paperwork by establishing rates of reimbursement for the CRC role in Lifespan that are by day or month instead of fifteen-minute intervals, for example. Increasing the billable unit size will reduce the documentation requirements.
- ▶ Building prioritization for administrative efficiencies in database systems development

Conclusion

Multiple agencies serve people with autism with different funding, goals, and policies. No single agency serves this population alone, and the services available are generally the same as for people with other types of intellectual or developmental disabilities. The reform efforts already underway at OADS and CBHS will benefit people with autism, 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 transitions across the lifespan.

Appendices

Appendix A: Autism Services Satisfaction Survey

The survey was conducted online using the Qualtrics XM Platform.²³ OADS distributed an anonymous link to the survey, and responses were collected September 19 – October 11, 2024.

The online survey worded the questions specifically for individuals and family members, depending on how they answered the first question. The survey questions 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

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

- ☐ In your family's home

²³ 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. <https://www.qualtrics.com>

- ☐ 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: Section 28 Services (Rehabilitative and Community Services (RCS))
 - ☐ In-Home Supports: Section 65 Services (Behavioral Health Services including Home and Community Based Treatment (HCT))
 - ☐ Section 21 Comprehensive Waiver services
 - ☐ Section 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: Section 28 Services (Rehabilitative and Community Services (RCS))
- ☐ In-Home Supports: Section 65 Services (Behavioral Health Services including Home and Community Based Treatment (HCT))
- ☐ Section 21 Comprehensive Waiver services
- ☐ Section 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: Section 28 Services (Rehabilitative and Community Services (RCS))
- ☐ In-Home Supports: Section 65 Services (Behavioral Health Services including Home and Community Based Treatment (HCT))
- ☐ Section 21 Comprehensive Waiver services
- ☐ Section 29 Supports Waiver services
- ☐ Speech therapy
- ☐ Occupational Therapy
- ☐ Physical Therapy
- ☐ Other (please specify)

- ☐ Not sure

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
- ☐ 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)?

Is there anything else you would like to share with the Department?

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

Table 14. Satisfaction with Services by Service Type

Service Type	N	Average score Individuals with Autism Responses	Average score Family Member Responses
Case Management	50	4.25	3.24
Child Development Services	8	-	4.1
Occupational Therapy	19	5	-
Physical Therapy	8	-	3.9

Service Type	N	Average score Individuals with Autism Responses	Average score Family Member Responses
School with an IEP	25	-	3.3
School with a 504 plan	6	-	3.3
Section 21 Comprehensive Waiver Services	14	4.3	4.1
Section 28 Children's RCS	9	-	4.3
Section 29 Supports Waiver Services	24	4.5	4
Section 65 Children's Behavioral Health Services	5	-	2.5
Speech Therapy	15	-	3.1
Other	7	5	4.6

Table 15. Experience with different provider types

<i>How often do your providers...</i>	Respect cultural values and preferences (5 is ideal)	Listen (5 is ideal)	Use hurtful or unkind words (1 is ideal)
Case Management	4.6	4.3	1.2
Child Development Services	3.4	2.6	1.5
School with an IEP	3.8	3.1	1.5
School with a 504 plan	2.5	2.3	1.5
Section 28 Children's RCS	4.0	4.0	1.4

<i>How often do your providers...</i>	Respect cultural values and preferences (5 is ideal)	Listen (5 is ideal)	Use hurtful or unkind words (1 is ideal)
Section 65 Services			
Behavioral Health Services	3.2	3.2	1.2
Section 21			
Comprehensive Waiver Services	4.3	4.1	1.3
Section 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

Open-ended suggestions for services that could meet the priority areas identified by respondents fell into several categories.

Table 16. Service gaps identified by respondents

Service Gaps	Number of respondents
More and better trained providers, especially behavioral health and case managers, but also dental providers and coverage for conscious sedation, medical specialists, day program providers	24
More social opportunities including peer-led services and age-appropriate activities	7
Transportation to social and work opportunities	5
More employment opportunities	4

Service Gaps	Number of respondents
More Special Purpose Private School options and in-person speech therapy in school	3
Housing, especially for those with aging parents	3
Increased oversight of behavioral health providers and protection from abusive providers	2
Respite care	2
Transition improvement	2
Nutrition and hygiene training	1
Paying the parent to care for the child	1

Appendix B: MaineCare Adult Developmental Services Under Section 21 and Section 29

COVERED SERVICES UNDER SECTION 21 AND SECTION 29

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

COVERED SERVICES	Section 21	Section 29
Assistive Technology	x	x
Career Planning	x	x
Communication Aids	x	
Community Support	x	x
Consultation Services	x	
Counseling	x	
Crisis Assessment	x	
Crisis Intervention Services	x	
Employment Specialist Services	x	x
Home Accessibility	x	x
Home Support – Family Centered Support	x	
Home Support Agency – Per Diem	x	
Home Support-Quarter Hour	x	x
Home Support-Remote Support	x	x

COVERED SERVICES	Section 21	Section 29
Non-traditional communication assessments	x	
Non-traditional communication consultation	x	
Occupational therapy (maintenance)	x	
Physical therapy (maintenance)	x	
Respite Services		x
Self-directed Services		x
Shared Living (Foster Care, Adult)	x	x
Specialized Medical Equipment and Supplies	x	
Speech therapy (maintenance)	x	
Transportation Service	x	x
Work Support-Group	x	x
Work Support-Individual	x	x

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