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# Adults with Intellectual Disability or Autism Spectrum Disorder. Executive Summary

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# C H A R T B O O K

## **Adults with Intellectual Disability or Autism Spectrum Disorder: *Population and Service Use Trends in Maine 2014 Edition***

### **Executive Summary**

**Prepared for:**  
Office of Aging and Disability Services  
Maine Department of Health and Human Services



Paul R. LePage, Governor

Mary C. Mayhew, Commissioner

**Prepared by:**  
Muskie School of Public Service  
University of Southern Maine



Adults with intellectual disability or autism spectrum disorder (ID/ASD) have a variety needs for long term services supports to enable them to live as independently as possible. In Maine, the Office of Aging and Disability Services/Developmental Services provides a wide array of services to adults with ID/ASD, the majority of which are funded through MaineCare.

This chartbook describes Maine’s historical trends in meeting the needs of adults with ID/ASD through institutional and community based services in comparison to other states; a detailed analysis of the population’s utilization of different types of services and their costs in SFY 2010; the implementation of the Supports Intensity Scale (SIS) as a means of identifying the supports needs of the adults with ID/ASD; and the complement of providers serving this population in Maine.

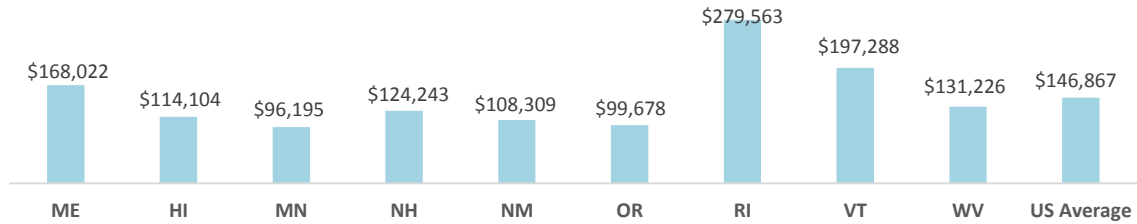
Throughout the chartbook, we refer to the home and community based waiver programs for adults with ID/ASD who are eligible for the institutional intermediate care facility (ICF-IID) level of care. The Section 21 Comprehensive waiver provides a wide array of community based support and residential care services such as group homes. The Section 29 Supports waiver provides community support to adults with ID/ASD who live on their own or with family members; it does not provide coverage for residential services.

To present as much detail as possible on the different aspects of the population and services used, we had to use multiple data sources, sometimes reflecting different years. The most current and reliable data for the national comparisons covered the years 2005 to 2010. The Maine-specific data on institutional and waiver participation covered the years 2005 to 2012. Our detailed claims analysis used a linked dataset showing Medicare and Medicaid claims for 2010. And our analysis of MaineCare expenditures for members on the waiver waitlists reflect 2013 data. Please note that the year and data source used are clearly marked on each chart. Our key findings are listed below.

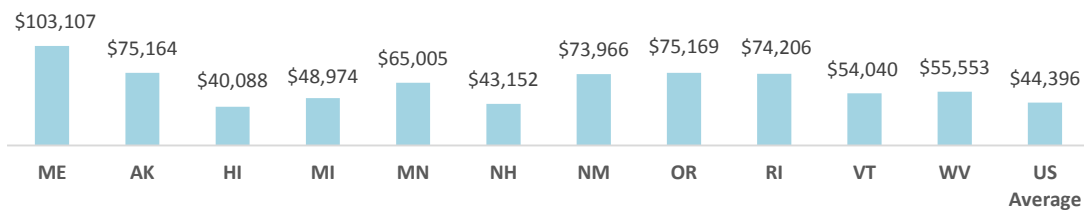
### **Key Findings: Historical Trends**

Using 2005 to 2010 data from the Maine CMS-372 reports and national data from the University of Minnesota’s National Residential Information Systems Project (RISP), we compared Maine to other states that do not have large, state-owned intermediate care facilities for individuals with intellectual disability. These states are similar to Maine in their trend away from using institutional care in favor of home and community based options. Among the comparison states:

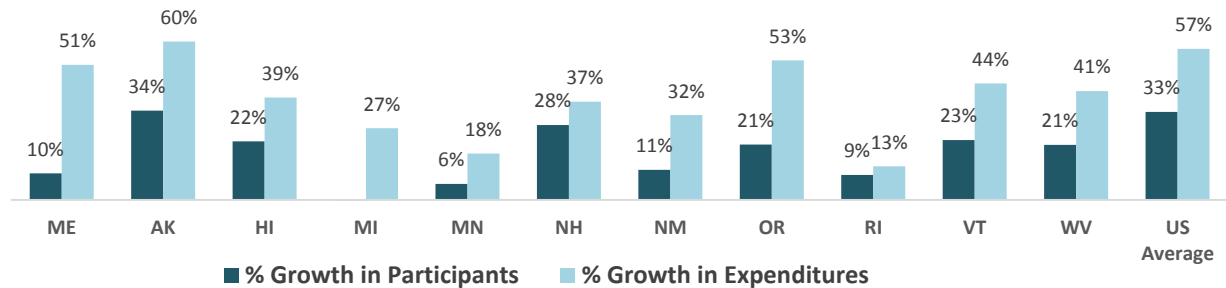
- Maine had the 3<sup>rd</sup> highest annual per person expenditure for ICF-IID services in 2010.<sup>1</sup>



- Maine had the highest annual per person expenditure for comprehensive home and community based waiver services in 2010.<sup>2</sup>



- While participants on the Section 21 Comprehensive waiver grew 10% from 2005 to 2010, expenditures grew by 51% during the same time period, the largest disparity across the comparison states.<sup>3</sup> (Michigan did not experience growth in participants over the time period.)



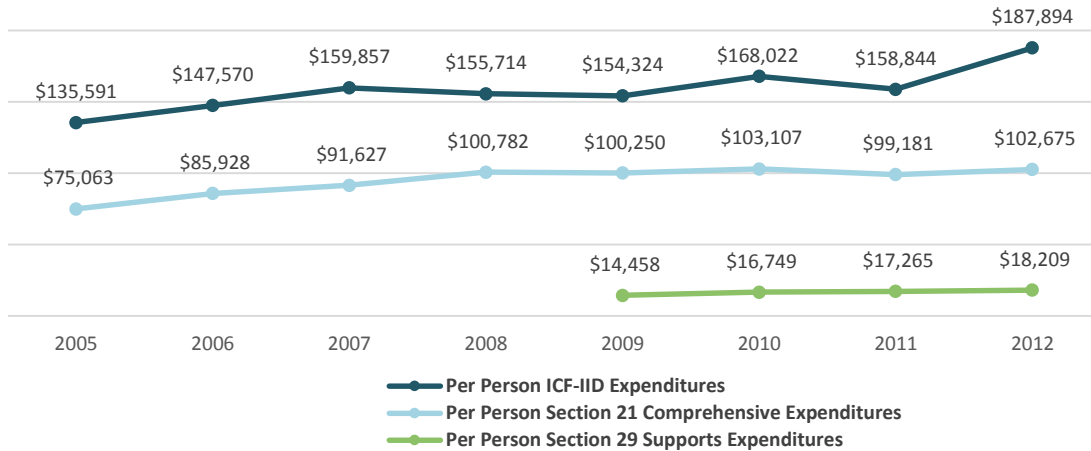
<sup>1</sup> Alaska, which also has no state-owned ICF-IIDs, is not included in this chart because it did not have any expenditures for in-state ICF-IID services in 2010. Per person expenditures for Maine are based on data from the CMS 372 report for SFYs 2010. Per person expenditures for the nation and other states are based on data from the 2012 editions of Larson, Sheryl, et al., *Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends*, (Minneapolis, MN: National Residential Information Systems Project (RISP), University of Minnesota), Table 3.4.

<sup>2</sup> Data for comparison states (except Oregon) are from the 2012 edition of Larson, Sheryl, et al., *Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends*, (Minneapolis, MN: National Residential Information Systems Project (RISP), University of Minnesota), Table 3.7. Maine data are from the Maine CMS 372 report for SFY 2010. Oregon data are from Smith, G. et al., *2007 Gauging the Use of HCBS Supports Waivers for People with Intellectual Disabilities: Final Project Report*, Appendix A: State-by-State Supports Waiver Profiles at <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appenda.htm#OR-A> retrieved May 16, 2014 and Eiken, S. and Lelchook, S. *Medicaid 1915(c) Waiver Data Based on the CMS 372 Report, 2009-2010*, 2013, Centers for Medicare & Medicaid Services (CMS) and Truven Health Analytics.

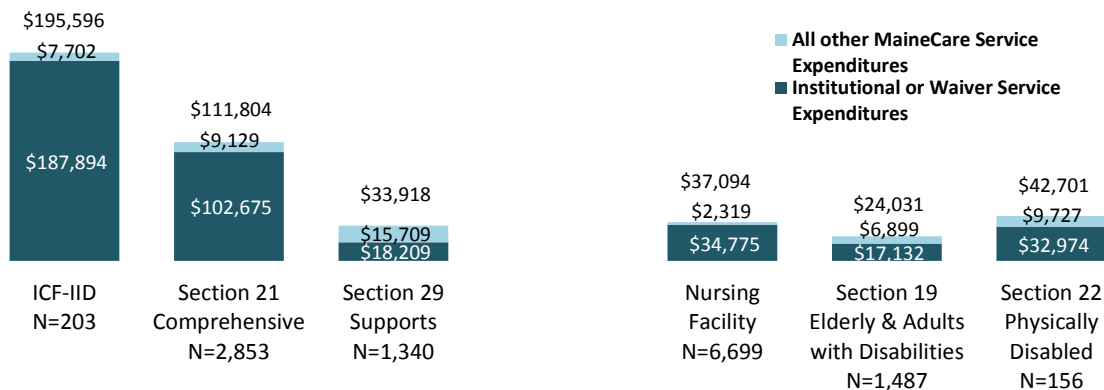
<sup>3</sup> Data for comparison states (except Oregon) are from the 2006 and 2012 editions of Larson, Sheryl, et al., *Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends*, (Minneapolis, MN: National Residential Information Systems Project (RISP), University of Minnesota), Table 3.7. Maine data are from the Maine CMS 372 reports for SFY 2005 and 2010. Oregon percentage growth in waiver expenditures was calculated using data from Smith, G. et al., *2007 Gauging the Use of HCBS Supports Waivers for People with Intellectual Disabilities: Final Project Report*, Appendix A: State-by-State Supports Waiver Profiles at <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appenda.htm#OR-A> retrieved May 16, 2014 and Eiken, S. and Lelchook, S. *Medicaid 1915(c) Waiver Data Based on the CMS 372 Report, 2009-2010*, 2013, Centers for Medicare & Medicaid Services (CMS) and Truven Health Analytics.

A closer look at Maine’s trends in costs and use of institutional and home and community based services from 2005 to 2012 shows:

- Maine’s expenditures for the Section 21 Comprehensive waiver services grew substantially from 2005 to 2008 and have leveled off in recent years.<sup>4</sup>



- Comparing 2012 institutional and home and community based waiver service costs for adults with ID/ASD, older adults, and adults with physical disabilities shows large differences in the cost of long term services and supports for these populations.<sup>5</sup> These reflect the variation in service needs and the level and mix of services available in the different programs.



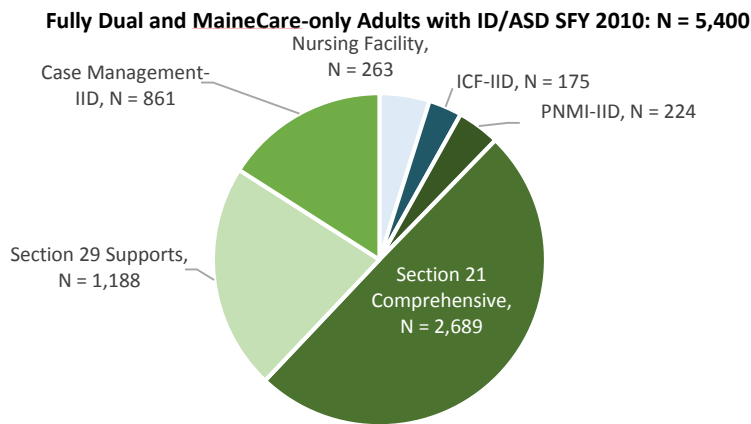
<sup>4</sup> Per person cost calculated based on CMS 372 reports for 2005-2012. The CMS 372 reports for Section 21 Comprehensive services are reported on a fiscal year basis; those for Section 29 Supports are reported on a calendar year basis. The 2012 data for the Section 29 Supports waiver are as filed with CMS

<sup>5</sup> Calculation is based on the CMS 372 reports for 2012: Total Annual Expenditures/Number of Members Served throughout the year.

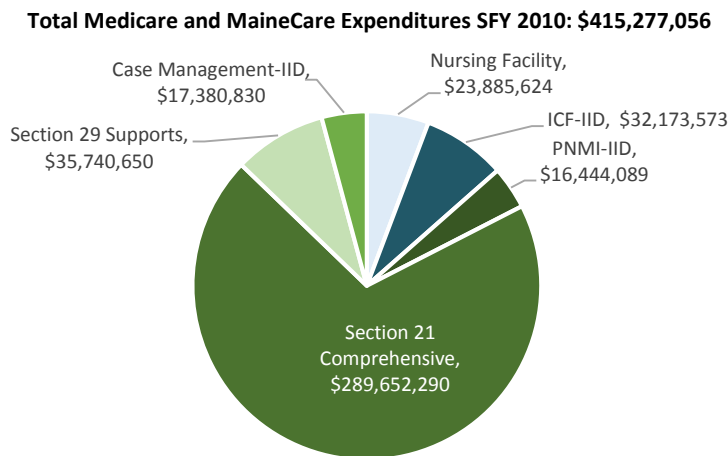
**Key Findings: Claims Analysis of Dually Eligible and MaineCare-only Eligible Adults with ID/ASD in 2010**

Our detailed analysis of adults with ID/ASD in SFY 2010 living in different service settings who were dually eligible for both Medicare and MaineCare and those who were eligible for MaineCare-only showed the following results:

- There were 5,400 adults with ID/ASD who received MaineCare developmental services in 2010.
- The majority of them (64%) were dually eligible for Medicare and MaineCare.
- Total Medicare and MaineCare expenditures in SFY 2010 were over \$415 million.
- Medicare expenditures comprised only 4% of these expenditures.
- The majority of adults with ID/ASD served by MaineCare used one of the home and community based waivers.<sup>6</sup>



- The majority of expenditures in SFY 2010 were for members who were used the home and community based waivers.



<sup>6</sup> The total population of MainCare members with ID/ASD was identified through MDS assessment data, MaineCare claims data in the Maine Claims Management System (MeCMS), and OADS enrollment records for SFY2010. Fully dual or MaineCare-only eligible members were included in the analysis if they had at least 11 months of full MaineCare eligibility in SFY 2010.

- Analysis of the claims by residential setting revealed the vast majority of expenditures for adults on the Section 21 Comprehensive waiver were attributed to the waiver services themselves, whereas the expenditures for adults on the Section 29 Supports waiver were more evenly split between waiver services and regular MaineCare services.
- Across all settings, adults with ID/ASD utilize a wide variety of regular MaineCare services in addition to the developmental services.
- MaineCare Full Service Transportation made up a larger percentage of expenditures for members on the Section 29 Supports waiver than those on the Section 21 Comprehensive waiver.

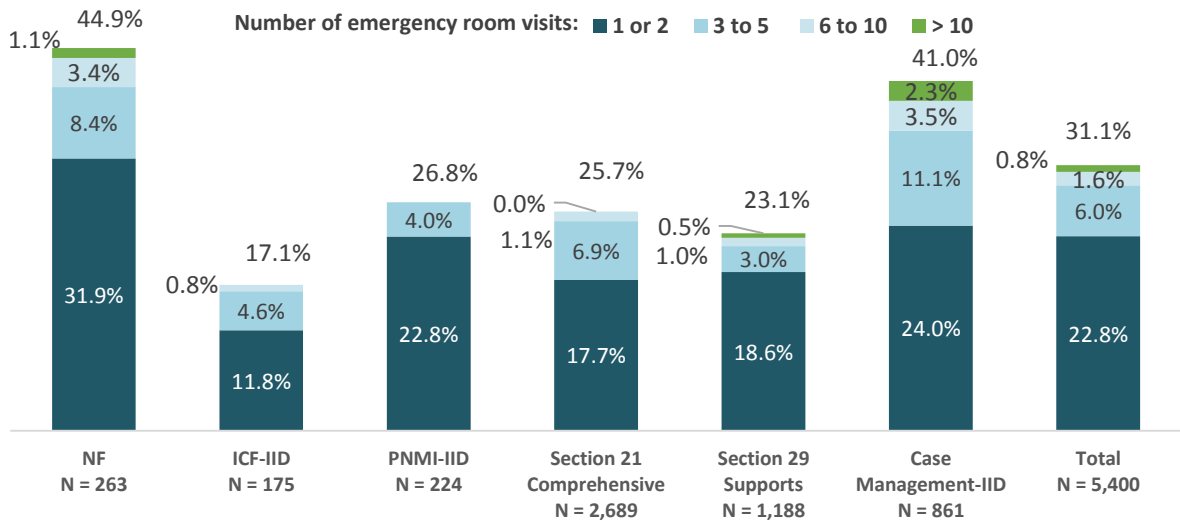
#### **Key Findings: MaineCare Claims Analysis of Members on the HCBS Waitlists, SFY 2013**

- The 991 members on the waitlist for the Section 21 Comprehensive waiver in SFY 20103 accounted for over \$20 million in MaineCare expenditures.
- Over half (524) of the members on the waitlist were receiving Section 29 Supports waiver services in 2013.
- Section 29 Supports waiver services accounted for over \$6 million in expenditures for people on the Section 21 Comprehensive waiver.
- The 224 members who were only on the Section 29 Supports waitlist accounted for close to \$2 million in MaineCare expenditures in SFY 2013.

#### **Key Findings: Quality Measures, SFY 2010**

- Adults with ID/ASD in the intermediate care facility setting had the lowest rate of emergency room use at 17%. The rate of emergency room use during the year was highest for adults with ID/ASD who also had a nursing facility stay during the year.
- About one quarter of adults with ID/ASD living in private non-medical institutions, on the Section 21 Comprehensive waiver, or who were on the Section 29 Supports waiver used the emergency room at least once during the year.
- Over 40% of adults with ID/ASD who only received case management and none of the other developmental residential or support services had at least one emergency room visit during SFY 2010.

### Emergency Room Use by Maine Adults with ID/ASD by Residential Setting, 2010<sup>7</sup>



### Key Findings: Supports Intensity Scale, 2013

- The Supports Intensity Scale (SIS) is a nationally normed tool that estimates the actual supports needs of adults with ID/ASD. Maine ranks lower than the norm in overall supports needs for its members on the Section 21 Comprehensive waiver. This means that while Maine has high per person expenditures for this program, its participants may not be as in need of support compared to other states.<sup>8</sup>

	SIS Supports Need Index
SIS Norm	100.00
New Mexico	106.72
Oregon	106.04
Utah	102.15
Rhode Island	102.02
Kentucky	99.76
<b>Maine</b>	<b>98.60</b>
Georgia	99.40
Louisiana	99.05
Colorado	97.49
New Hampshire	95.55

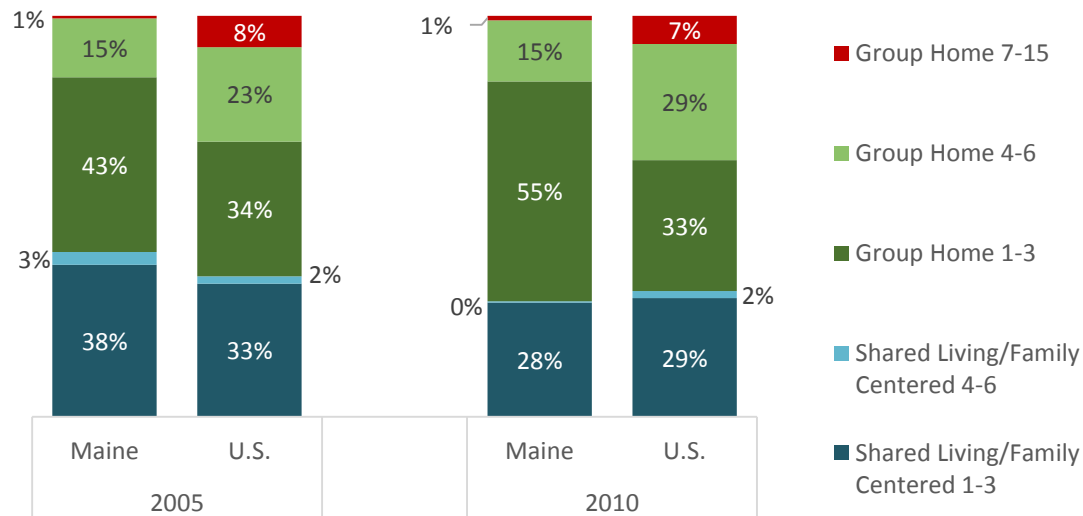
<sup>7</sup> The total population of MaineCare members with ID/ASD was identified through MDS assessment data, MaineCare claims data from MeCMS, and OADS enrollment records for SFY 2010.

<sup>8</sup> Presentation to the Maine Office of Aging and Disability Services by HSRI April 30, 2014.



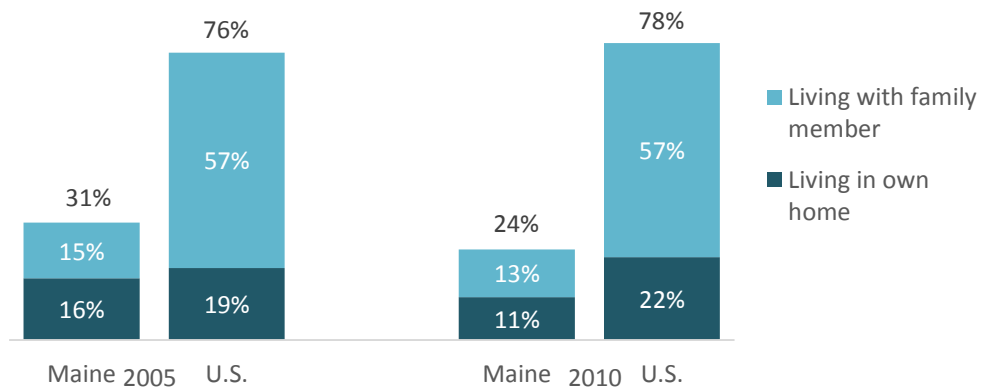
## Key Findings: ID/ASD Providers in Maine Compared to the Nation, 2005-2010

- Data from the University of Minnesota RISP show Maine had proportionally more providers serving one to three individuals than the national average in both 2005 and 2010. Eighty-one percent of providers in Maine served one to three individuals in 2005 compared to 67% nationally; in 2010 these small providers made up 83% of providers in Maine compared to 62% nationally.<sup>9</sup>



<sup>9</sup> The RISP data use the term “Congregate Care” to describe what are called “Group Homes” in Maine. These residential providers are facilities serving people with ID/ASD that are owned, rented, or managed by a residential services provider to provide housing, support, and services for residents. Additionally, RISP uses the term “Host Family/Foster Care” to describe what are called “Shared Living/Family-Centered” homes in Maine. These are homes, owned or rented by an individual or family, in which they live, and in which they provide care and support for one or more unrelated persons with ID. While the charts in this section are based on the RISP data, they use the Maine terms for these providers. Congregate care and host family/foster care data are from Tables 2.6 and 2.7 in the 2006 and 2011 editions of *Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends*, (Minneapolis, MN: National Residential Information Systems Project (RISP), University of Minnesota). In these editions, the data included ICF-IIDs. To show the growth in non-institutional providers in this chartbook, the number of ICF-IIDs reported on Table 3.1 in the RISP reports have been removed from the data in this chart.

- The percentage of adults living in their own home or with family members is much lower in Maine than the national average, 24% in Maine compared to 78% nationwide.<sup>10</sup>



<sup>10</sup> Data are from the RISP Build-a-Report website, <http://www.rtc.umn.edu/risp/build/index.asp> retrieved on September 9, 2014.