

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

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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; an analysis of the utilization and cost of services for adults with ID/ASD who were on the waitlists for home and community based waivers services in SFY 2013; 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 3rd highest annual per person expenditure for ICF-IID services in 2010.
- Maine had the highest annual per person expenditure for comprehensive home and community based waiver services in 2010.
- Maine had the largest disparity between participant and expenditure growth among the comparison states from 2005 to 2010. While participants on the Section 21 Comprehensive waiver grew 10% from 2005 to 2010, expenditures grew by 51% during the same time period.

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.
- 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. These reflect the variation in service needs and the level and mix of services available in the different programs.

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.
- The majority of expenditures in SFY 2010 were for members who used the home and community based waivers.
- 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 for the Section 21 Comprehensive waiver 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 waitlist for 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 during SFY 2010 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.

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.

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.
- 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.