CHARTBOOK

Adults with Intellectual Disability or Autism Spectrum Disorder:

Population and Service Use Trends in Maine

2014 Edition

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

Department of Health and Human Services
Maine People Living Safe, Healthy and Productive Lives
Paul R. LePage, Governor Mary C. Mayhew, Commissioner

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

USM University of Southern Maine Muskie School of Public Service

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

Muskie School Project Staff
Kimberly I. Snow
Stuart Bratesman
Taryn Bowe
Julie Fralich
Document design: Sheri Moulton

Office of Aging and Disability Services Leads
Jim Martin
Gary Wolcott
Deb Gellatly
Karen Mason

When referencing or using any of the charts or other materials in the Chartbook, please use the following recommended citation: Snow, K. et al., Adults with Intellectual Disability or Autism Spectrum Disorder: Population and Service Use Trends in Maine, 2014 Edition. (Chartbook). Portland, ME: University Of Southern Maine, Muskie School of Public Service; 2014. Available at: http://muskie.usm.maine.edu/Publications/DA/Adults-with-Intellectual-Disability-or-Autism-Maine-2014.pdf

*This Chartbook was prepared under a contract between the Muskie School of Public Service, University of Southern Maine and the Maine Department of Health and Human Services, Office of Aging and Disability Services, DHHS Agreement # ADS-14-9312; AdvantageME CT # CT-10A 20131119*1936.*

Foreword

The Maine Office of Aging and Disability Services is pleased to present this chartbook on Maine adults with intellectual disability or autism spectrum disorder (ID/ASD). While other chartbooks have described older adults and adults with physical disabilities, this is the first chartbook detailing the service use and cost of adults with ID/ASD in Maine.

As we continue our efforts to serve adults with ID/ASD who have a variety of needs for long term services and supports, it is important to understand our history of meeting those needs, our development of more integrated service settings, and our future directions in providing services to this vulnerable population. This document presents data charting our move away from institutional care toward more home and community based settings; the population's utilization of different types of services and their costs; the implementation of the Supports Intensity Scale as a means of identifying the actual supports needs of adults with ID/ASD; and the complement of providers serving this population in Maine.

It is our sincere hope that this chartbook will help inform the discussion among policy makers, advocates, providers, and consumers themselves as we work together to create a sustainable system of care that meets the needs of all of our citizens. We certainly appreciate all of the hard work and dedication that is observed here in Maine. The commitment to improving the services and supports for individuals with disabilities is clear. We look forward to more conversation and collaboration together.

Jim Martin
Director, Office of Aging and Disability Services
Maine Department of Health and Human Services

Table of Contents

List of Charts

List of Tables

Introduction

This report is one of a series prepared by the Muskie School for the Maine Department of Health and Human Services Office of Aging and Disability Services (OADS). Earlier reports focused on older adults and adults with physical disabilities, individuals who were dually eligible for MaineCare and Medicare and those dually eligible with long term services and supports needs.[1] This chartbook focuses on adults with intellectual disability or autism spectrum disorder (ID/ASD) who are eligible for MaineCare-only or who are dually eligible for MaineCare and Medicare. It describes the services currently available to individuals with ID/ASD; the historical use of institutional and community based services in Maine compared to other states and the nation; the utilization and cost of MaineCare and Medicare services for Maine's adults with ID/ASD in different residential settings in SFY 2010; state-funded services available to adults with ID/ASD; the utilization and cost of MaineCare services for adults who were on the waitlists for Section 21 Comprehensive or Section 29 Supports home and community based waiver services in SFY 2013; the quality of health care this population uses; Maine's use of the Supports Intensity Scale; and the complement of providers in the state.

Data Sources

This report relies on several different sources of information and data. The following is a description of the sources used in each section. Detailed references are listed as endnotes on page 86.

Sources and explanations of data used for charts and tables are listed with the figures as they appear.

Section One: Adults with ID/ASD and Current Developmental Policy and Services Available in Maine

Muskie School staff, through interviews with staff from the OADS/Developmental Services unit (OADS/DS) and reviews of MaineCare policy and other source documents, gathered descriptions of current policy regarding the services available through MaineCare, state general funds, Medicare, and Social Security Income.

Section Two: Historical Trends in ID/ASD Services in Maine and the Nation

Using Maine data from the CMS 372 reports submitted by the state to the Centers for Medicare and Medicaid Services (CMS) and national data available through the National Residential Information Systems Project (RISP) of the Research and Training Center on Community Living at the University of Minnesota, this section describes how institutional and community based care have been utilized in Maine, ten comparison states, and the nation overall. Please note the different time frames that appear in this section: charts showing trends in Maine alone reflect data from **2005-2012**; charts showing national comparisons reflect data from **2005-2010**.

Section Three: A Closer Look at Trends in Costs and Utilization of ICF-IID and HCBS Services in Maine

This section uses data from CMS 372 reports from 2005-2012 to showcase trends specifically in Maine. Trends in HCBS services for people with ID/ASD are shown as well as a comparison of cost and utilization of other institutional and HCBS services by other waiver populations.

Please note that the CMS 372 reports in both Sections 2 and 3 reflect services that were billed under these programs. These reports are used to help CMS and states ensure that their HCBS programs operate at a lesser or equal cost than the alternative institutional care. Additionally, the reports are filed according to the time period under which the waiver operates. In Maine, the Section 21 Comprehensive waiver runs on a state fiscal year basis, while the Section 29 Supports waiver runs on a calendar year basis. These differences will be noted on the charts.

Section Four: Service Use and Cost Patterns of Adults with ID/ASD in Different Residential Settings

The detailed analysis of service use and cost across different residential settings in this section uses both MaineCare claims data from the Maine Claims Management System (MeCMS) for MaineCare-only eligible members and a linked data set of MaineCare and Medicare claims obtained through a license with JEN Associates for dually eligible members. This section focuses on SFY 2010 as it was the most current year for which both MaineCare and Medicare claims data were available.

The linked data set used in this section includes expenditures for Medicare Parts A and B, but it does not include Part D costs which cover pharmacy services. It should be noted that, for this reason, the descriptions of the expenditures for the dual eligible group undercount the amount spent on pharmacy services for this population. Drugs that are administered in the hospital or outpatient setting are included as hospital or outpatient expenditures but cannot be separated out as distinct pharmacy claims.

To analyze the service use patterns of adults with ID/ASD living in different settings in 2010, a hierarchy was established. Members were placed in mutually exclusive groups, according to their utilization of the most service-intensive residential setting. Starting with the nursing facility as the most service-intensive residential setting, members were considered to be a part of a setting if they utilized those services at any time during the year. The following table describes the levels of the hierarchy, definitions of the population in each level, and the data source used to identify members in each level:

Residential Setting	Definition of Population	Data Source
I. Nursing Facility	Adults with ID/ASD who had a nursing facility stay during the year	Minimum Data Set assessments and MaineCare claims data
II. Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID)	Adults with ID/ASD who had an ICF-IID stay but **not** a nursing facility stay	MaineCare claims data
III. Private Non-Medical Institutions for Individuals with ID (PNMI-IID)	Adults with ID/ASD who had a PNMI-IID stay but **neither** a nursing facility **nor** an ICF-IID stay	MaineCare claims data
IV. Section 21 Comprehensive Waiver	Adults with ID/ASD receiving Section 21 Comprehensive waiver services but **none** of the institutional services above	OADS enrollment records and MaineCare claims data
V. Section 29 Supports Waiver	Adults with ID/ASD receiving Section 29 Supports waiver services but **none** of the institutional or waiver services above	OADS enrollment records and MaineCare claims data
VI. Case Management-IID	Adults with ID/ASD who received case management services for adults with ID/ASD but **none** of the institutional or waiver services above	MaineCare claims data

To be included in the hierarchical analysis in this report, members had to be eligible for MaineCare for at least eleven months in SFY 2010. Please note that for this reason, the number of people using services and their costs described in this section will differ from that described in Sections 2 and 3 on Maine's historical use of institutional and community based care. Data from the CMS 372 reports used in Sections 2 and 3 includes data on all members who used institutional and community based waiver services during the year, regardless of the length of time a member was eligible. In Section 4, accurate analysis of the average service use and cost of Maine's adults with ID/ASD across different residential settings in 2010 required a focused look at members with eligibility of eleven months or longer.

In addition to the hierarchical analysis is a description of the SFY 2010 service use patterns of 18 to 21 year olds with ID/ASD across all residential settings. This population may choose to receive services through MaineCare developmental programs for children with ID/ASD until they are 21 years old, or they may opt to obtain services through either the Section 21 Comprehensive or Section 29 Supports waivers for adults.

Section Five: Service Use and Cost of Maine Adults with ID/ASD on the Home and Community Based Waiver Waitlists

This section describes the SFY 2013 MaineCare service use and cost of adults with ID/ASD who qualified for home and community based services provided through the Section 21 Comprehensive or the Section 29 Supports waiver, but for whom a funded opening was unavailable. Similar to the hierarchy used in Section 4, members who were on the waitlist for both waivers were deemed to be on the

Section 21 Comprehensive waitlist for the analysis of service use and cost as this waiver provides a more intensive array of services. Note that this section analyzes SFY 2013 MaineCare data from the Maine Integrated Health Management Solution (MIHMS) and does not include Medicare costs.

Section Six: Quality Measures

To provide a review of the quality of health care that Maine's adults with ID/ASD receive, MaineCare and Medicare claims were analyzed according to measures from the Healthcare Cost and Utilization Project (HCUP) from the Agency for Healthcare Research and Quality found at http://www.ahrq.gov/research/data/hcup/index.html and the Healthcare Effectiveness Data and Information Set (HEDIS) from the National Committee for Quality Assurance (NCQA) found at http://www.ncqa.org/Portals/0/HEDISQM/HEDIS2014/List_of_HEDIS_2014_Measures.pdf .

Section Seven: The Supporting Individual Success Supports Intensity Scale in Maine

Information on Supporting Individual Success and the Supports Intensity Scale and its use in Maine was obtained from the American Association on Intellectual and Developmental Disability (AAIDD) at http://aaidd.org/ and from the Human Services Research Institute (HSRI) reports presented to OADS/DS in 2013 and 2014.

Section Eight: Historical Trends and Current Providers of Services for Adults with ID/ASD in Maine

Historical information on the number of institutions and community based providers by size and the number of residents served compared to the national average was obtained from RISP at the University of Minnesota. Information on the current number of service providers available by county is from the OADS/DS website at http://www.maine.gov/dhhs/oads/disability/ds/resource_directory/index.shtml; the Department of Health and Human Services Enterprise Information System; and email communications and interviews with OADS/DS.

Section 1: Adults with ID/ASD and Current Developmental Policy and Services Available in Maine

What are intellectual disability and autism spectrum disorder?

A general definition of intellectual disability (ID) from the American Association on Intellectual and Developmental Disabilities describes ID as:

*A disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills. This disability originates before the age of 18.*[2]

Causes of intellectual disability include genetic conditions such as Down syndrome; problems during pregnancy including exposure to alcohol, drugs, environmental toxins, or maternal illnesses such as rubella; problems at birth such as low birth weight or birth injury; and problems after birth such as exposure to environmental toxins including lead and mercury or childhood illnesses including whooping cough or chicken pox.[3]

A general definition of autism spectrum disorder (ASD) from the National Institute of Mental Health describes ASD as:

- *Persistent deficits in social communication and social interaction across multiple contexts;*
- *Restricted, repetitive patterns of behavior, interests, or activities;*
- *Symptoms must be present in the early developmental period (typically recognized in the first two years of life); and*
- *Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.*[4]

When determining eligibility for developmental services, described later in this section, states may apply more clinical definitions of ID/ASD. For example, Maine's legal definitions of ID and autism rely on the American Psychiatric Association's clinical definition of mental retardation and autistic disorder found in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). Additionally, states may apply functional limitation criteria to determine whether a person with ID/ASD may be eligible for services.

It should be noted that the clinical definition of autism has been evolving over time. The recent fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) merged all autism disorders (autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified, and Asperger syndrome) under one umbrella diagnosis of ASD.[5] However, currently, Maine statute uses the term autistic disorder as defined in DSM-IV.

How many adults in Maine have intellectual disability or autism spectrum disorder?

Estimating the prevalence of adults with ID or ASD can be difficult as this population is not regularly included in national health surveys.[6] While the American Community Survey includes a question on the topic of "Cognitive Disability", the question is broad-based* and does not reflect the definition of ID described above.[7]

A widely cited study indicates that 1.49% of the general population has either "mental retardation or developmental disabilities", and .79% of the adult population has these conditions.[8] The study, published in 2001, is based on data from the National Health Interview Survey Disability Supplements from 1994 and 1995. Applying the adult prevalence rate to Maine's population from the 2010 census results in an estimated 8,426 adults with these conditions.† However, the surveys on which the study was based did not include institutionalized persons; and there have been changes in the classification and definition of intellectual disability over the years since the surveys were conducted. These factors may impact the accuracy of the estimate.

Another method of estimating the prevalence of ID or ASD is based on the number of individuals accessing public services. But the accuracy of this method is subject to variations in program eligibility or administration. For example, while services for children with ID/ASD are widely available nationally through the education system, once children age-out of eligibility for those services, unless they qualify for adult developmental services, they might not be counted in prevalence estimates.[9] As noted above, states vary in their eligibility criteria for developmental services. Additionally, there may be individuals and families who are unaware of or choose not to utilize public services, and so are not counted in the utilization data. In Maine, for example, in SFY 2010 there were 5,400 adults with ID/ASD who received developmental services through MaineCare. This figure is quite a bit lower than that predicted by the prevalence rate of .79%. There may be Mainers with ID/ASD who either do not qualify for MaineCare coverage or who are unaware of or choose not to access covered services.

To address the issues around estimating this population, the Center for Disease Control and the National Center on Birth Defects and Developmental Disabilities Health Surveillance Work Group has been developing a more robust method of estimating and tracking the adult population with ID, including expanding current or developing new survey instruments and linking available data bases.[10] This project aims to provide information not only on the number of adults with ID, but also their health status and risk factors they face as they age. This information will be valuable to states like Maine as they implement programs to serve these individuals.

* The question regarding cognitive disability on the American Community Survey is phrased: "Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?"

† Prevalence rate applied to Maine census data retrieved from http://quickfacts.census.gov/qfd/states/23000.html on August 26, 2014

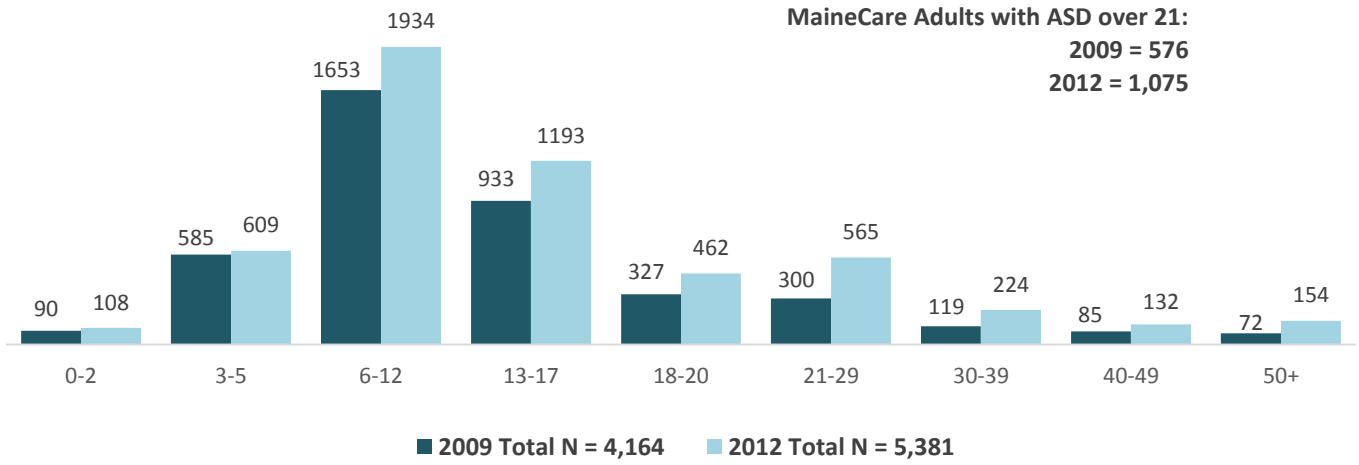
Increases in the Number of People Diagnosed with ASD

While predicting the number of individuals with either ID or ASD is difficult, what has been clear is that the number of people diagnosed with ASD has been increasing over the years. In 2000, the Center for Disease Control estimated that 1 in 150 children had ASD; by 2010, the estimate was 1 in 68 children.[11] In Maine, the Department of Education reported an increase in the number of students with ASD from 594 in 2000 to 2,989 in 2012. [12] It is difficult to know if the increase is due to a real increase in the number of children being affected by ASD or more children being diagnosed with ASD,[13] but the reality of the increase is that as these children reach adulthood, the service system for adults with ID/ASD will likely experience a surge in demand.

MaineCare has also experienced an increase in the number of members with ASD. According to the 2013 *Autism Spectrum Disorders Report*, the number of MaineCare members of all ages with ASD increased from 4,164 in 2009 to 5,381 in 2012.[14]

Chart 1 shows the changing age distribution of MaineCare members with ASD between 2009 and 2012. In 2009, 576 of these members were over 21; in 2012 the number of members with ASD over 21 was 1,075. While not all individuals with ASD require high levels of services, as more children with ASD reach adulthood, there may be areas of need, such as employment services, that may be stretched more than others.

Chart 1: MaineCare Members with ASD by Age Group, 2009 and 2012*



* Data are from the *Autism Spectrum Disorders Report*, 2013, Maine Department of Health and Human Services and Department of Education.

Services Available to Adults with ID/ASD in Maine

The majority of persons with intellectual disabilities can live with some degree of independence when they have access to various levels and types of support. Other people in this group need a higher level of assistance, some requiring total supervision and/or support for daily living activities. The severity of autism spectrum disorder can also vary greatly. Some adults with ASD are able to work and live independently. Others may require a higher level of assistance and supervision.[15]

In Maine, developmental services for adults with ID/ASD are managed by the Office of Aging & Disability Services/Developmental Services (OADS/DS) and are available to persons with a diagnosis of intellectual disabilities (defined as mental retardation in state statute) or autism. To maximize inclusion in the community, persons with ID/ASD may need support with a variety of self-care activities, such as bathing, eating, and dressing, as well as with employment, social activities, decision-making, money management, and other aspects of independent living. Supports include employment and day programs, case management services, crisis services, a range of residential services, and resources that promote the independence, health and safety, dignity, and well-being of a person.

Eligibility for Services in Maine

Eligibility for different developmental services in Maine is tied to different categories of criteria.

- **Diagnosis**: A diagnosis of mental retardation* or autistic disorder is the first threshold that must be met before accessing any developmental service.
- **Financial eligibility**: To access MaineCare-covered developmental services, financial eligibility must also be established.
- **Clinical or functional eligibility**: In addition to a diagnosis, eligibility for certain services is also based on the level or type of care the individual requires. For example, to access either MaineCare home and community based waiver services or Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs), a person must be found to require the level of care provided in an ICF-IID.
- **Need for protective services**: Although not technically eligibility criteria, OADS/DS reserves a portion of MaineCare waiver openings for those persons requiring protective services or at risk of abuse**.**

Persons with intellectual disabilities or autism can have co-occurring conditions, including mental and physical health conditions, and may receive services from other service systems (such as Substance Abuse and Mental Health Services or Department of Labor), as well as from OADS/DS.

Young people transitioning from children's services to the adult service system can be particularly vulnerable to gaps in services. Differing eligibility criteria, different funding streams, different regulations, different array of services and authorizing entities all contribute to a less than seamless transition for some.

Unlike older adults, many of whom grew up in institutions, today's youth have grown up in their own communities with the expectation they will continue to live and work in their communities.

These issues have received concerted attention in past years, and OADS/DS has recently spearheaded a renewed effort to improve the transition system as well as the individual experience for young adults.[16]

* In Maine statute and regulations, the Maine Department of Health and Human Services now more commonly uses the term "intellectual disability" rather than "mental retardation" but continues to rely on the clinical diagnosis of "mental retardation" as a basis for determining eligibility for developmental services. This document uses "mental retardation" when the context requires its specificity. Otherwise, the term "intellectual disability (ID),"is used where possible.

Developmental Services Available through MaineCare

Maine's Office of Aging & Disability Services/Developmental Services (OADS/DS) offers a variety of developmental services funded through MaineCare and general state plan dollars.

Targeted Case Management

Case management services are offered to all individuals eligible for developmental services. Younger adults, aged eighteen through twenty, and children, who are emancipated minors, may choose to receive children's behavioral health and/or developmental services instead of adult's behavioral health and/or intellectual disabilities services, if these better meet their needs.

A mix of state-employed and contracted community-based case managers provide case management to individuals with ID/ASD. Case management services consist of intake/assessment, plan of care development, coordination/advocacy, monitoring, and evaluation.

The underlying goal of all of these services is to improve an individual's opportunities to live a full life by identifying service needs, identifying services available to meet those needs, and facilitating an individual's access to those services.

Person-Centered Planning (PCP) is the required planning process for all adults receiving developmental services. PCP is an ongoing and collaborative process designed to assist people in identifying goals and in describing needed supports and personal desires.

Case managers, who are not employed by agencies providing other services for members, provide neutral, conflict-free facilitation and coordination of the planning process. In this manner, the member's needs and choices remain the focus of the planning effort.

Intermediate Care Facilities for Individuals with Intellectual Disabilities

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IIDs) are institutional settings designed to provide constant, intensive care to individuals with particularly high levels of need. Maine's ICF-IID program has two categories of facilities, Group and Nursing. ICF-IID Nursing residents have more complex medical needs than residents in ICF-IID Group.

To be eligible for ICF-IID Group, individuals must meet the medical level of care and require active treatment of ID/ASD.

To be eligible for ICF-IID Nursing, an individual must meet medical level of care, require active treatment of ID/ASD, **and** need at least eight hours per day of licensed nursing supervision.

All ICF-IIDs must assure the coordination of health and rehabilitative services to assist each member in reaching his or her optimal level of functioning.

Private Non-Medical Institutions

Private Non-Medical Institutions (PNMIs) are licensed group homes that serve four or more individuals. The homes have 24/7 staff and may be either proprietary or agency operated. MaineCare funds are used to pay for staffing and some administrative costs, while state funds and member contributions pay for room and board.

To be eligible, individuals must meet MaineCare eligibility requirements and have documentation of a medical necessity for a specific type of PNMI. Different PNMI types include: Substance Abuse Treatment Facilities, Medical and Remedial Treatment Services Facilities, Child Care Facilities, Community Residences for Persons with Mental Illness, and Non-Case Mixed Medical and Remedial Facilities.

The latter, Non-Case Mixed Medical and Remedial Facilities (sometimes referred to as Appendix F), most frequently provides services to individuals with ID/ASD. In this chartbook, these facilities are referred to as PNMI-IIDs.

Home and Community Based Service Waivers

OADS/DS administers two Medicaid home and community-based (HCBS) waivers for adults with ID/ASD, a Comprehensive waiver and Supports waiver. In the MaineCare Benefits Manual, these waivers are summarized in Section 21 and Section 29 respectively.

Section 21 Comprehensive Waiver

The Section 21 Comprehensive waiver gives eligible adults the option to live in their own home or in another home in the community while receiving an array of benefits that complement natural, family, work, and community relationships. The Section 21 Comprehensive waiver is offered as a community-based alternative for members who would otherwise qualify to live in an ICF-IID.

In addition to meeting medical eligibility criteria for admission to an ICF-IID, the annual cost of services received under the waiver must be equal or less than 200% of the state-wide average annual cost of care for an individual in an ICF-IID.

Covered services include:

- ***Home support*** - A range of residential service options, including supported living, shared living, family-centered support*, and group living.
- ***Community support*** - A variety of social and therapeutic programs provided in a community setting that improve participation in inclusive social and community relationships and support people to develop skills that support health and well-being.
- ***Employment specialist services*** – Targeted employment services necessary to support a member on the job site, including periodic interventions to identify opportunities for improving productivity, minimizing the need for formal supports, adhering to work place policies, etc.
- ***Work support*** – Direct support services provided predominately in a work place to improve a member's ability to maintain employment.
- ***Clinical services*** – These include non-traditional communication consultation and assessment, consultation services, counseling, crisis services, occupational, physical or speech therapy.
- ***Other services***, such as transportation services, home accessibility adaptations, and specialized medical equipment and supplies.

* Family-centered support was no longer approved for participants beginning in 2007, however, MaineCare continues to cover this service for members who were already receiving it prior to 2007.

Enrollment for the Section 21 Comprehensive waiver is currently closed. New openings are offered to waitlisted members on the basis of three priority tiers described below.

Section 29 Supports Waiver

The Section 29 Supports waiver offers community and work support services to members who live with their families or on their own.

A mix of other services, such as home adaptations, transportation, and respite, may be recommended and authorized by the person-centered planning team. Unlike the Section 21 Comprehensive waiver, home support services are not currently covered under this waiver and there is a cap on individual spending.

OADS/DS is in the process of updating this waiver to include intermittent home support services, assistive technology, and increased respite hours.

To be eligible for the Section 29 Supports waiver, a person must be eligible for MaineCare and must meet the medical requirements of an ICF-IID level of care. Also, a funded opening must be available. At the present time, there is a waitlist for enrollment.

Waiver Waiting Lists

OADS/DS maintains a waitlist of eligible MaineCare members who cannot access the Section 21 Comprehensive or Section 29 Supports waivers because of lack of funding and limits on the number of people served within each waiver. Each waiver has a separate policy for prioritizing enrollment of waitlist members.

Individuals on the Section 21 Comprehensive waiver waitlist are assigned to one of three priority levels. First priority is given to adults requiring adult protective services, while second priority is given to those who are at risk of abuse. The final level of priority is reserved for those eligible adults who are not at risk of abuse.

The Section 29 Supports waiver waitlist operates on a first come first serve basis. Members who are on the waitlist for these services are served chronologically based on their date of eligibility for the waiver.

As of September 25, 2014, 1,008 people were on the Section 21 Comprehensive waitlist, and 450 people were on the Section 29 Supports waitlist. Of the 1,008 people on the Section 21 Comprehensive waitlist, 586 were already receiving Section 29 Supports services. And, there were 290 people who were on both waiver waitlists.[17]

As children with ID/ASD age into eligibility for adult services or as adults with ID/ASD become financially eligible for MaineCare, they may opt to be added to the waitlist, just as others are beginning to receive waiver services. While the overall number of people on the waitlists for waiver services has been consistent over the past several years, OADS-DS has been able to move 800 individuals off the waitlists and into services since 2011, with the support of the LePage administration. And in an ongoing effort to maximize the number of people served in the community, in FY15, the DHHS plans to fully fund the Section 29 Supports waiver waitlist that currently consists of over 400 people.[18]

Waitlisted individuals may avail themselves of a number of MaineCare and developmental services, including general MaineCare benefits, such as dental, physician, and hospital services, and MaineCare developmental services, such as case management, ICF-IIDs, or PNMIs. State plan services, ranging from supported housing to supported employment, may help fill in service gaps.

Additionally, a waitlisted individual may be concurrently eligible for and enrolled in one of several other HCBS waivers or programs, such as community mental health services (Section 17); home and community-based services for older adults and adults with disabilities (Section 19); or rehabilitative and community supports for children with cognitive impairments (Section 28).

State-Funded (Non-MaineCare)

OADS/DS uses general fund dollars to procure a variety of services and supports through fee-for-service contracts with provider agencies.

Services funded in this way include: case management, recreation, respite, supported housing, professional services, transportation, community supports, supported employment, rental subsidies, and others. Historically, state-contracted services have provided a safety net for adults with ID/ASD who have unmet support needs and are unable to enroll in the Section 21 Comprehensive waiver. These groups have included:

- Adults with ID/ASD who ***are not currently eligible for MaineCare*** (perhaps because they are in the process of spending down assets to meet MaineCare financial requirements),
- Adults with ID/ASD who ***are not eligible for one of the HCBS waivers*** (because they do not meet level of care requirements),
- Adults with ID/ASD who are eligible but ***are not yet enrolled on one of the HCBS waivers*** (perhaps because they are waitlisted), and/or
- Adults with ID/ASD enrolled in one of the waivers (most likely Section 29) but ***requiring additional services***, such as home supports, that are not covered under the Supports Waiver.

In the past, case managers identified unmet service needs, and resource coordinators approved providers and managed contracts for the provision of services.

Recently, in an effort to gain tighter control over these contracts and establish fixed durations for service delivery, contract language and management has become more standardized and centralized.

OADS/DS has introduced new policy language requiring adults receiving state-funded services to be on one of the two HCBS waiver waitlists.

In addition to these contracts, each year the Department earmarks general fund dollars for family support. Family support dollars, capped annually, are paid directly to families to help support adults with ID/ASD who live in the home. Family support dollars may be used towards respite, fuel, clothes, and/or to help offset the cost of other resources and supports that enable adults with ID/ASD to remain in their homes and communities.

Supplemental Security Income and Medicare

Supplemental Security Income (SSI) for people with ID/ASD is available through the Social Security Disabled Adult Child program[19]. Individuals who qualify for these payments may use them to cover room and board expenses not covered by MaineCare.

Many people receiving developmental services qualify for Medicare, based on their eligibility for SSI. Starting the 25th month after SSI

benefits begin, individuals become eligible for Medicare (Parts A and B).

Medicare covers acute care services, such as hospital stays; post-acute services, such as home health services and skilled nursing facility visits; physician visits; and prescriptions drugs. People who are eligible for both Medicaid (MaineCare) and Medicare benefits are called dual eligible or dually eligible.

Employment First

On June 22, 2013, Maine passed the Employment First Maine Act, *L.D. 1352: An Act to Provide Integrated Community-Based Employment and Customized Employment for Persons with Disabilities*. This law, the result of a collaborative cross-agency effort between DHHS, the Department of Education, the Department of Labor, and community service providers, advocacy organizations, and persons with disabilities, requires that state agencies that provide or fund services and supports to persons with disabilities shall provide, as the first and preferred service option (before all other options including day services), integrated, community-based and/or customized employment as a core component of the service package.

Under this law, OADS/DS is required to self-assess its policies and programs and identify areas where changes are needed to ensure that employment is a core component of services.

The law requires all relevant state agencies (Education, Labor, Bureau of Employment Services and Vocational Rehabilitation) and DHHS (MaineCare, Aging and Disability and Substance Abuse and Mental Health) to coordinate their efforts and share data whenever possible in order to track and evaluate progress in this area.[20]

Full implementation of this legislation over the next decade will likely result in significant changes to both the type and quantity of employment services offered through OADS/DS and other state agencies serving individuals with disabilities. The Person-Centered Planning process may also experience changes, as employment will eventually become the first service option offered to all individuals during planning.

Supporting Individual Success (SIS)

Maine's Supporting Individual Success initiative is another enterprise likely to result in significant changes to the way developmental services are delivered and paid for. Still in the early stages of implementation, Maine's Supporting Individual Success, or SIS, initiative pairs a new strength-based assessment tool, known as the Supports Intensity Scale, with a resource allocation model that will assign Section 21 Comprehensive waiver enrollees to different budget levels based on their service and support needs.
This new model is intended to offer individuals and families more flexibility in choosing services while also ensuring that funding allocations are equitable, efficient, and directly tied to individual support needs.

As of spring 2014, the assessment piece of this initiative is fully implemented. The resource allocation model is expected to be implemented in 2015.

Guardianship and Other Arrangements

Guardianship is a necessary support for some adults receiving developmental services.

When appropriate less restrictive alternatives to guardianship are not available, the Probate Courts may appoint a guardian to act as a substitute decision maker on behalf of an incapacitated individual. Depending on whether an individual's incapacity is global or specific to certain types of decisions (e.g., medical, residential, financial), a

guardianship appointment may be full (plenary) or limited to certain domains. Conservatorship appointments are made to protect, preserve, and manage estates of incapacitated adults.

OADS/DS may serve as public guardian and/or public conservator for mentally incapacitated adults only when there is no suitable, available and willing private individual to serve as private guardian or conservator. In these instances, state case managers serve as the front-line guardians, and regional program administrators authorize certain decisions that exceed the surrogate decision-making authority of case managers.

OADS/DS may also serve as a representative payee when no other person or organization is available. While many people receive government benefits (such as Supplemental Security Income) directly, some adults with ID/ASD need assistance managing their benefits. In these instances, OADS/DS is appointed by the government agency administering the benefit to receive and handle checks provided by that agency to the adult with ID/ASD. Funds are used to provide for the individual's personal needs.

Crisis Services

OADS/DS has developed a comprehensive crisis response system available to anyone with an intellectual disability, autism or brain injury that allows them to remain in their homes and local communities during and after a crisis. Crisis Services provides assistance to individuals, families, guardians, and providers.

The Developmental Services' crisis system is made up of five major components: Prevention Services, 24-hour Crisis Telephone Services, Mobile Crisis Outreach Services, In-home Crisis Services, and Crisis Residential Services.

Acknowledgements:

The Muskie School would like to acknowledge the following people at OADS/DS for their help in developing the description of Maine's current ID/ASD policy and services:

Bridget Bagley
Debora Gellatly
Jeff Lee
Lisa Sturtevant
Joy Swift
Gary Wolcott

Section 2: Historical Trends in ID/ASD Services in Maine and the Nation

The information in this section describes Maine's and other states' use of institutional and community based services for individuals with ID/ASD. Unless otherwise noted, data reflecting trends in Maine are from the CMS 372 reports submitted by the state to the Centers for Medicare and Medicaid Services (CMS) for SFYs 2005-2012. The data reflecting other state and national trends are from the National Residential Information Systems Project of the Research and Training Center on Community Living at the University of Minnesota for the years 2005-2010. Please note that charts showing trends only in Maine show the years 2005-2012, but charts using national data to compare Maine to other states show the years 2005-2010.

The CMS 372 data source in this section differs from the claims data used in the utilization and cost analysis in Section 4. The detailed claims analysis in Section 4 is based on a data source that shows both Medicaid and Medicare expenditures for individuals who were eligible for MaineCare for at least eleven months during state fiscal year 2010. The CMS 372 data in this section reflect the total number of participants and expenditures for institutional and home and community based waiver services claimed during a state fiscal year, regardless of the length of time a participant was eligible for services. For this reason, the number of MaineCare participants and costs shown in this section may differ slightly from the MaineCare participants and costs shown in Section 4.

Maine's History of Institutional Services

As described in Section 1, Maine currently has a wide variety of community based services available to adults with ID/ ASD, but this was not always the case. Nationally, in the early to mid-20th century, institutionalization was typical for individuals with intellectual disabilities.[21] In the 1950s shifting attitudes toward people with ID and their families spurred a movement away from the institutional setting toward community based options. Pineland, one of Maine's large institutions for people with ID, had a peak census of 1,500 residents in 1950; by 1980, that number was reduced to 370. Maine continued to shift more resources to community based settings and, in 1996, closed the Pineland facility.[15] Currently, Maine's largest ICF-IID is licensed to serve 17 residents, and the majority of Maine's ICF-IIDs serve between 7 and 15 residents.[22]

Between 2005 and 2012, the number of ICF-IID residents has remained relatively flat. At the same time, the per person cost for ICF-IID services has been increasing, as shown in Table 1.

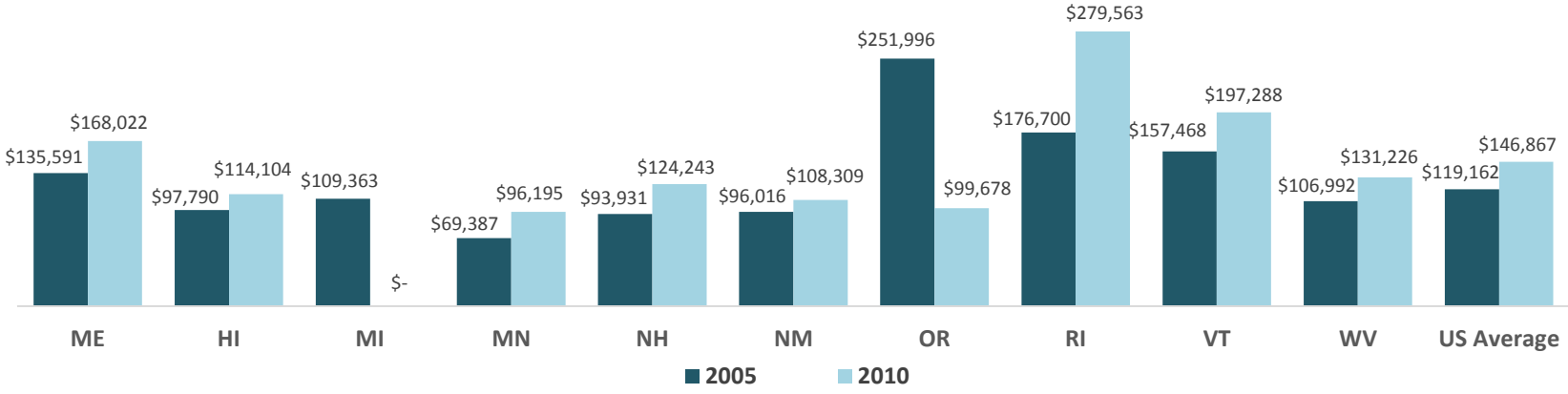
Table 1: Maine ICF-IID Residents and Per Person Cost, 2005-2012*

	2005	2006	2007	2008	2009	2010	2011	2012
ICF-IID Residents	217	211	204	218	217	207	202	203
Per Person ICF-IID Expenditures	$135,591	$147,570	$159,857	$155,714	$154,324	$168,022	$158,844	$187,894

Maine's ICF-IID Experience Compared to other States without Large, State-owned ICF-IIDs over Time

Maine is one of eleven states that no longer have large, state-owned ICF-IIDs. In comparing Maine to national trends, it is useful to look at these other states as they have experienced similar movement away from institutional care toward community-based services. Please note that the national comparison data is from 2005 to 2010. Chart 2 shows that most of these states experienced a growth in their annual per person expenditures for ICF-IID services from 2005 to 2010, with the exception of Michigan which had no residents in ICF-IIDs in 2010.†

Chart 2: Annual per Person Expenditures for ICF-IID Services in States without Large, State-owned ICF-IIDs for 2005 and 2010‡



* Maine CMS 372 reports for SFY 2005-2012.

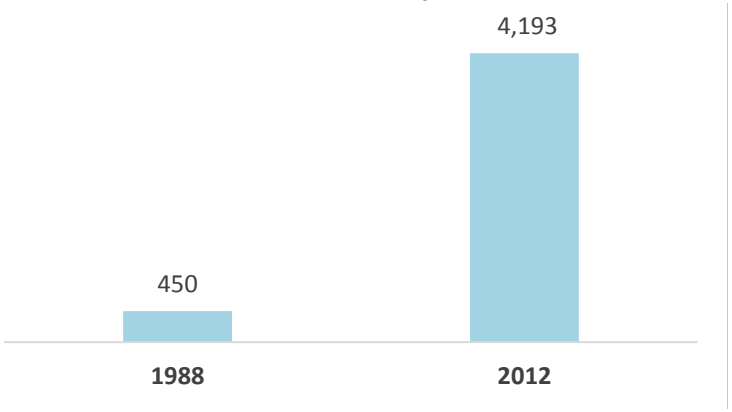
† Alaska, which also has no state-owned ICF-IDs, is not included in this chart because it did not have any expenditures for in-state ICF-IID services in either 2005 or 2010.

‡ Per person expenditures for Maine are based on data from the CMS 372 reports for SFYs 2005 and 2010. Per person expenditures for the nation and other states are based on data 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 3.4.

Maine's History of Community Based Services

As Maine closed its large, public institutions, it began providing more home and community based services to people with ID/ASD. Chart 3 below, provides a picture of the growth in the use of home and community based services (HCBS) over the past two decades. The Section 21 Comprehensive waiver began in 1987, and the Section 29 Supports waiver began over twenty years later in 2009.

Chart 3: Number of HCBS Participants in 1988 and 2012*



While Table 1 showed that per person expenditures for ICF-IID care increased in Maine while the number of residents remained relatively flat from 2005-2012, Table 2 shows that both the number of participants and their per person expenditures have increased for the Section 21 Comprehensive waiver during the same time period.

Table 2: Maine Participants of Section 21 Comprehensive Waiver Services and their per Person Expenditures, 2005-2012†

	2005	2006	2007	2008	2009	2010	2011	2012
Section 21 Comprehensive Waiver Participants	**2,566**	**2,635**	**2,736**	**2,859**	**2,877**	**2,826**	**2,843**	**2,853**
Section 21 Comprehensive Waiver per Person Expenditures	**$75,063**	**$85,928**	**$91,627**	**$100,782**	**$100,250**	**$103,107**	**$99,181**	**$111,804**

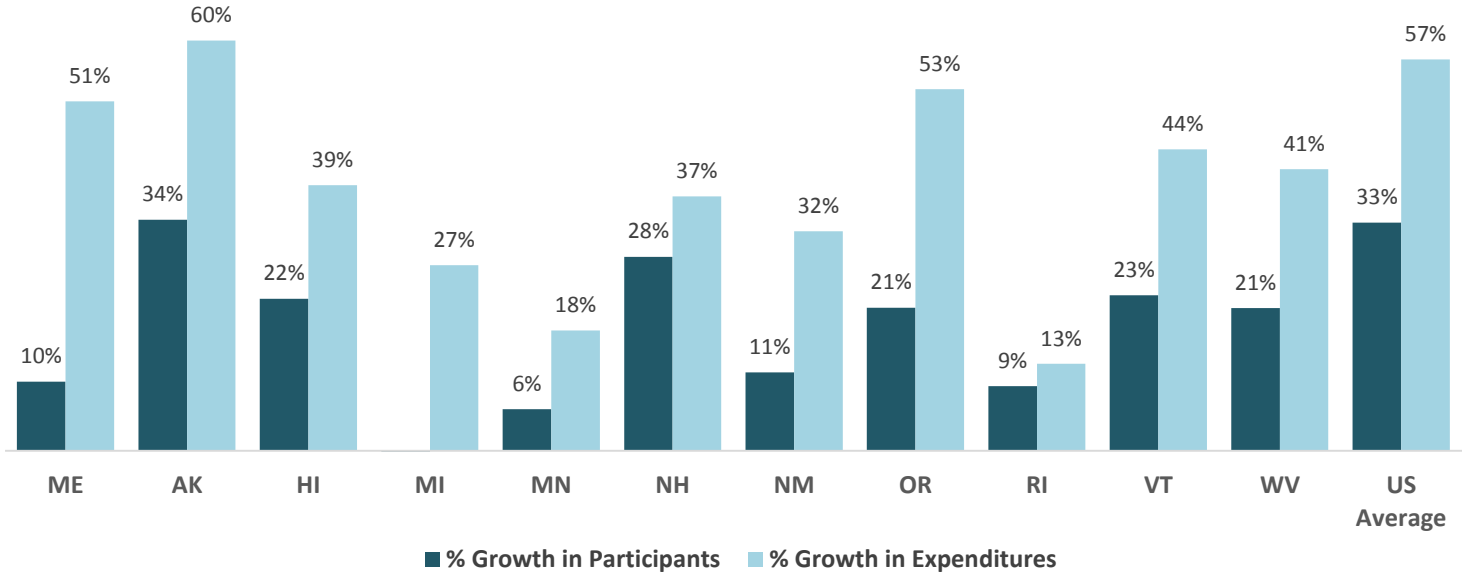
* 1988 data are from Lakin, C. et al., *Intermediate Care Facilities for Persons with Mental Retardation (ICF-MR): Program Utilization and Resident Characteristics*. (Minneapolis, MN: Center for Residential and Community Services, University of Minnesota, 1990), Table 7, p. 29; 2012 data are from the CMS 372 report for SFY 2012.

† Maine CMS 372 reports for 2005-2012.

Maine's HCBS Experience Compared to other States without Large, State-owned ICF-IIDs over Time

Maine is not alone in its experience of increased use and expenditures for HCBS services. For comparison, Chart 4 shows the percentage growth in participants of HCBS programs compared to the percentage growth in total HCBS program expenditures over the same time period in all of the comparison states and nationally; Michigan did not experience an increase in users of HCBS services during this time period.

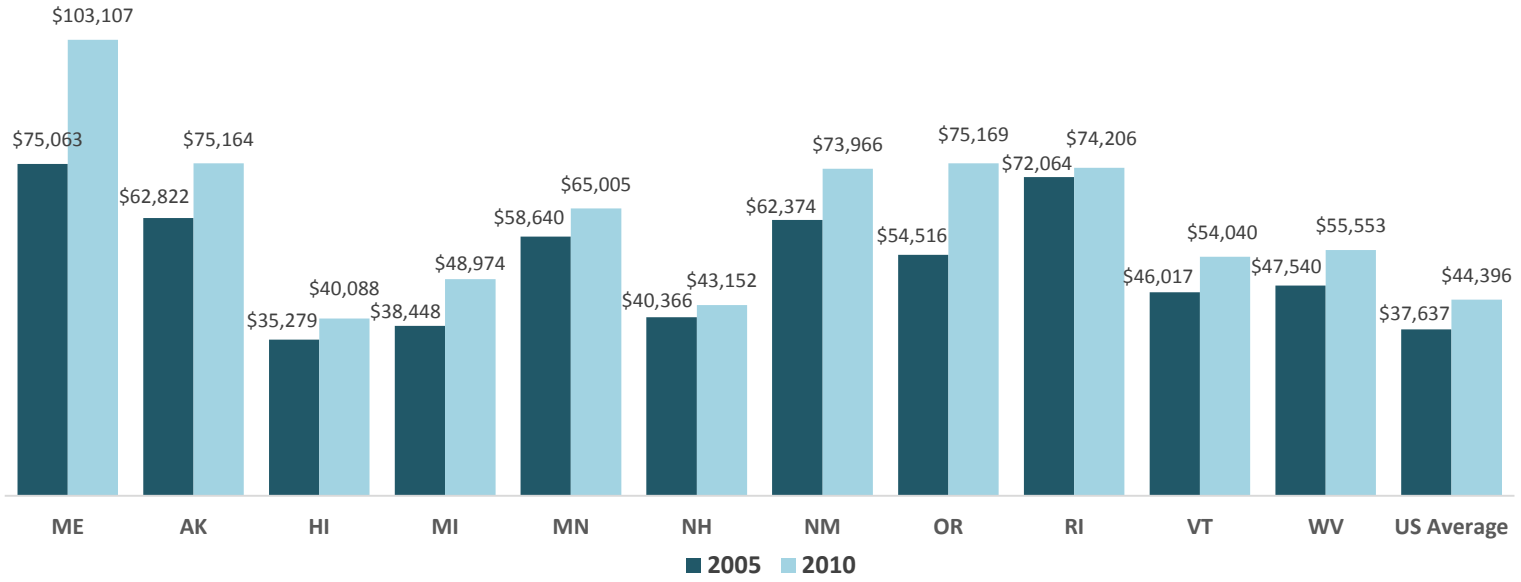
Chart 4: Percentage Growth in HCBS Participants Compared to Total HCBS Spending in States without Large, State-Owned ICF-IIDs and Nationwide, 2005-2010*



Note: Maine and Oregon had both a Comprehensive and a Supports waiver for people with ID/ASD during part of the time period 2005-2010, while the other states had just one waiver for this population. For purposes of consistency across the states in this chart, the data reflect only the costs of the comprehensive waivers in Maine and Oregon during the time period.

* Percentage growth in home and community based waiver expenditures for comparison states (except Oregon) were calculated based on data 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 percentage growth was calculated based on data 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.

Chart 5: Annual per Person Expenditures for HCBS Services in States without Large, State-owned ICF-IIDs, 2005 and 2010*



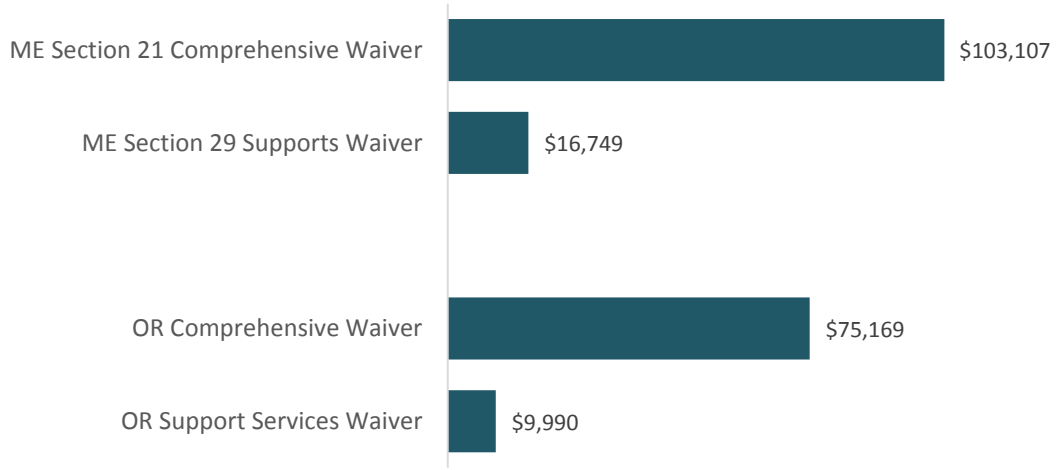
Note: Maine and Oregon had both a Comprehensive and a Supports waiver for people with ID/ASD during the time period 2005-2010, while the other states had just one waiver for this population. For purposes of consistency across the states in this chart, the data reflect only the costs of the comprehensive waivers in Maine and Oregon during the time period.

Chart 5 shows that all states without large, state-owned ICF-IIDs experienced increases in per person expenditures for HCBS waiver services from 2005 to 2010. Maine had the highest per person costs both in 2005 and 2010. During the time period, Maine also had the sharpest increase in costs, $25,000 per person.

* 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.

The preceding charts showed Maine's growth in expenditures for ICF-IID and Section 21 Comprehensive HCBS services. In 2009, Maine began to offer support services for individuals with ID/ASD through the Section 29 Supports waiver. As described earlier, the Section 29 Supports waiver is for individuals who live with their families or on their own and not in a residential care facility or group home. Of the comparison states that do not have large, state-owned ICF-IIDs, Oregon is similar to Maine in its utilization of a supports waiver for individuals with intellectual disabilities. Both Maine and Oregon support services waivers have much lower per person costs compared to their comprehensive waivers.

Chart 6: 2010 per Person Expenditures for Comprehensive and Supports Waiver Services in Maine and Oregon*

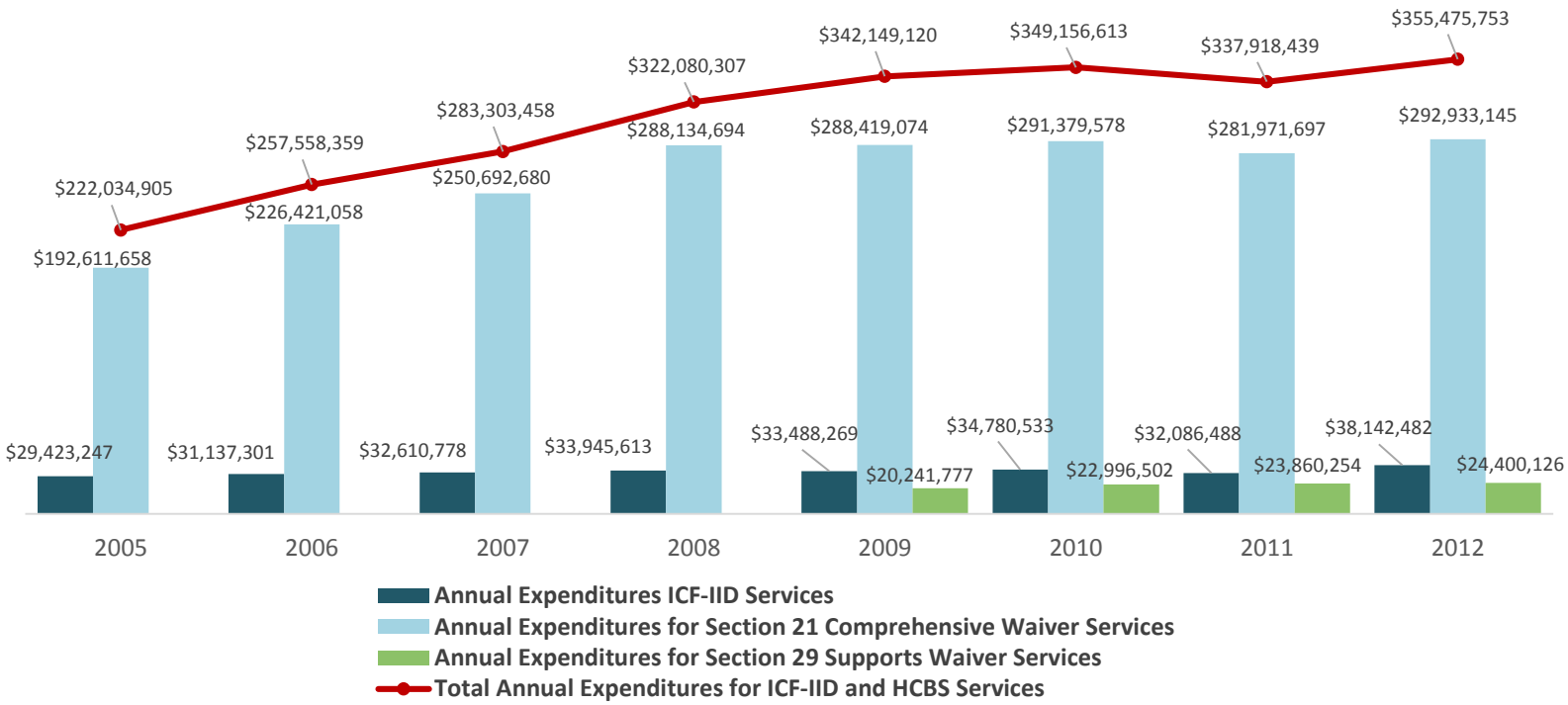


States using supports waivers employ different mechanisms to control costs. Maine's Section 29 Supports waiver has a combination of hourly or spending limits on certain services.[23] Oregon's Support Services waiver has an annual individual budget cap for in-home services, with an exception process that allows an individual to exceed the annual limit on a non-recurring basis.[24]

* Per person expenditures for Maine are from the CMS 372 reports for 2010; Section 21 Comprehensive expenditures are for SFY 2010, and Section 29 Supports expenditures are from CFY 2010. Per person expenditures for Oregon are from 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.

Section 3: A Closer Look at Trends in Costs and Utilization of ICF-IID and HCBS Services in Maine

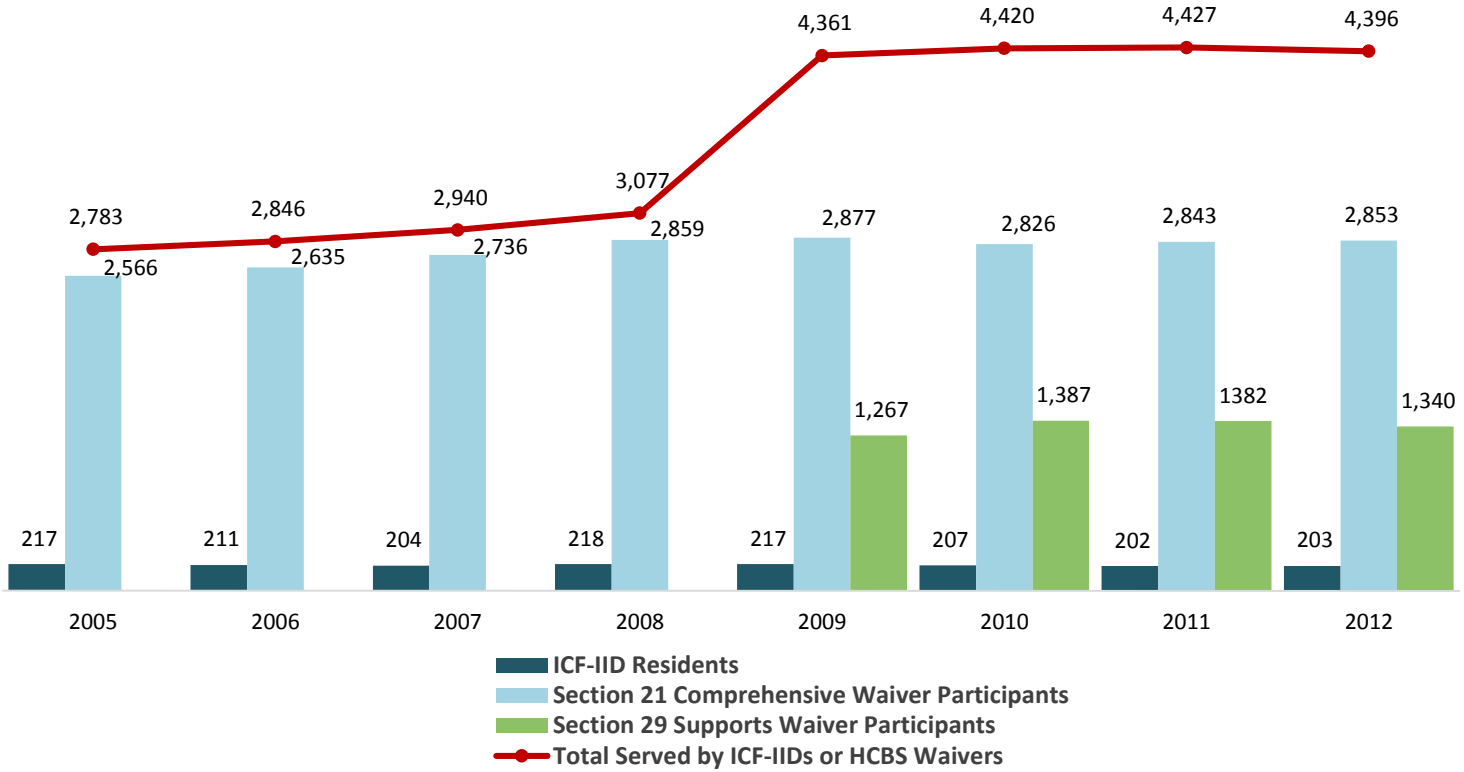
Chart 7: Total Annual Expenditures for ICF-IID and HCBS Services in Maine, 2005-2012*



Maine's total annual expenditures for ICF-IID and HCBS services increased by $133 million from 2005 to 2012. Expenditures for Section 21 Comprehensive waiver services, in particular, rose by over $100 million. Note that these data include only the ICF-IID and HCBS services used by members in these settings during the time period and not all of their MaineCare covered services.

* 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.

Chart 8: Total Number of People Served by ICF-IIDs or HCBS Waivers in Maine, 2005-2012*



While the preceding Chart 7 showed expenditures for the Section 21 Comprehensive waiver increased by over $100 million from 2005 to 2012 (52% growth), Chart 8 above shows enrollment in this waiver increased by 287 people (11% growth) over the same period. Chart 8 also shows the large increase in the number of people served by the HCBS waivers when the Section 29 Supports waiver became available in 2009.

* 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.

Chart 9: Annual per Person Expenditures for ICF-IID Services and HCBS Services in Maine, 2005-2012*

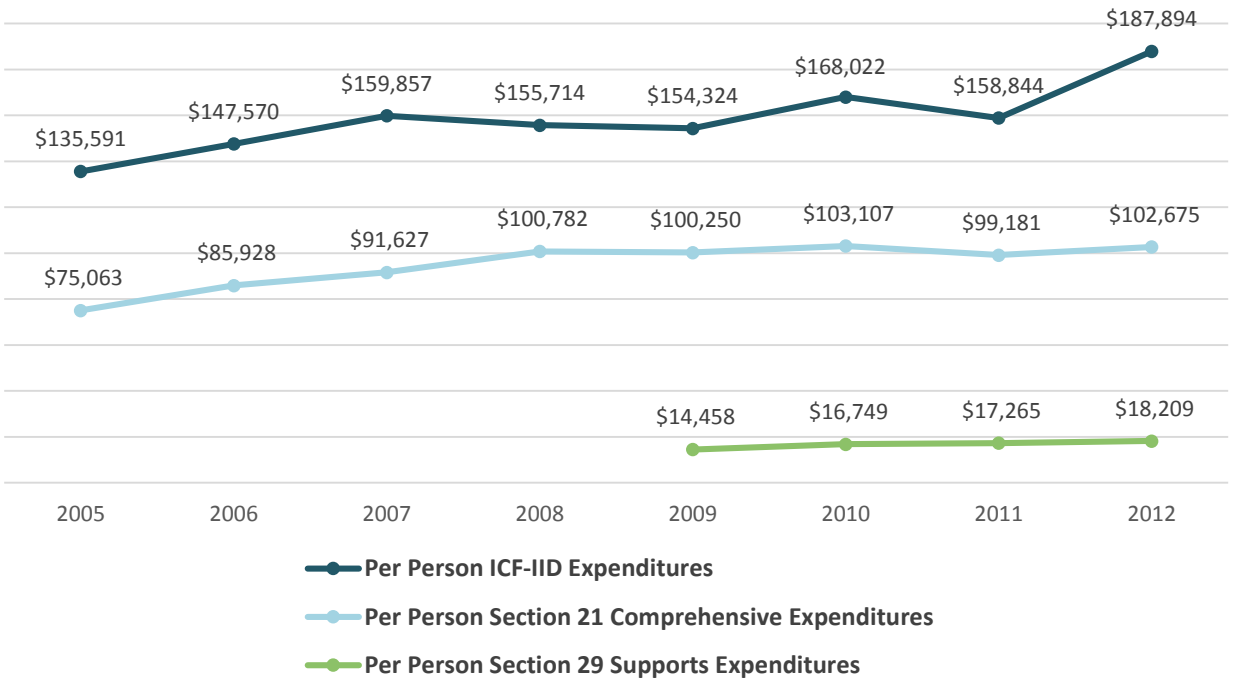


Chart 9 shows the per person costs of ICF-IID services and HCBS services over time. The per person expenditures for services in Maine's two HCBS waivers for adults with ID/ASD vary greatly. As described earlier, the Section 21 Comprehensive waiver includes community-based residential services, whereas the Section 29 Supports waiver does not include these services. Note that these data include only the ICF-IID and HCBS services used by members in these settings during the time period and not all of their MaineCare or Medicare covered services.

* 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.

Chart 10: Maine ICF-IID Residents, HCBS Participants and Total Per Person MaineCare Expenditures by Program, 2012*

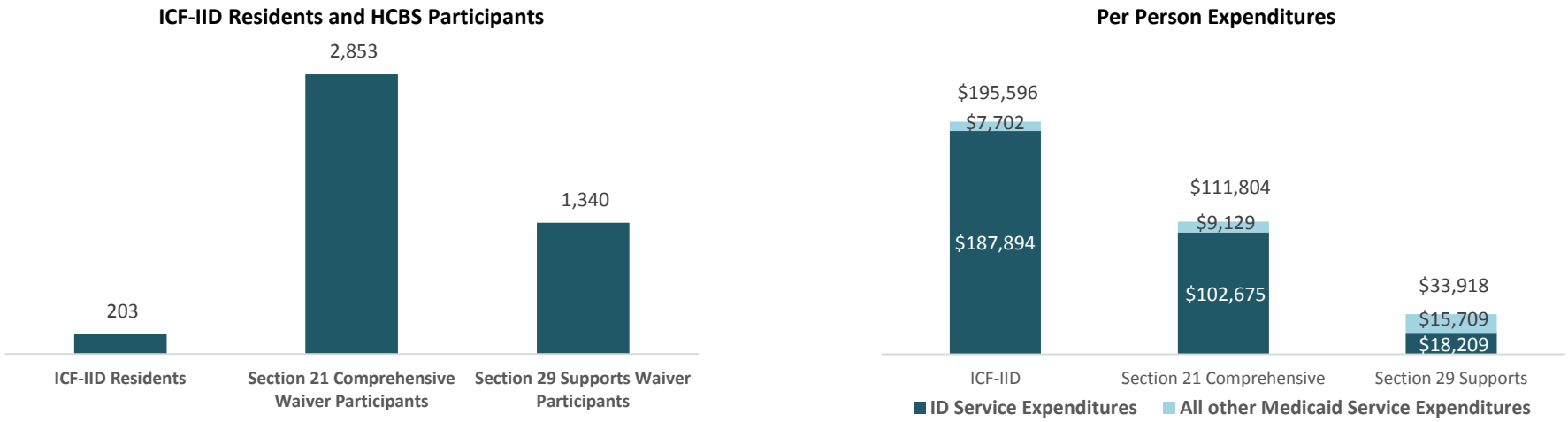


Chart 10 above shows that non-waiver related MaineCare services account for almost half of per person MaineCare expenditures for individuals on the Section 29 Supports waiver.

Table 3 below shows the total MaineCare expenditures for individuals utilizing ICF-IID and HCBS waiver services in 2012.

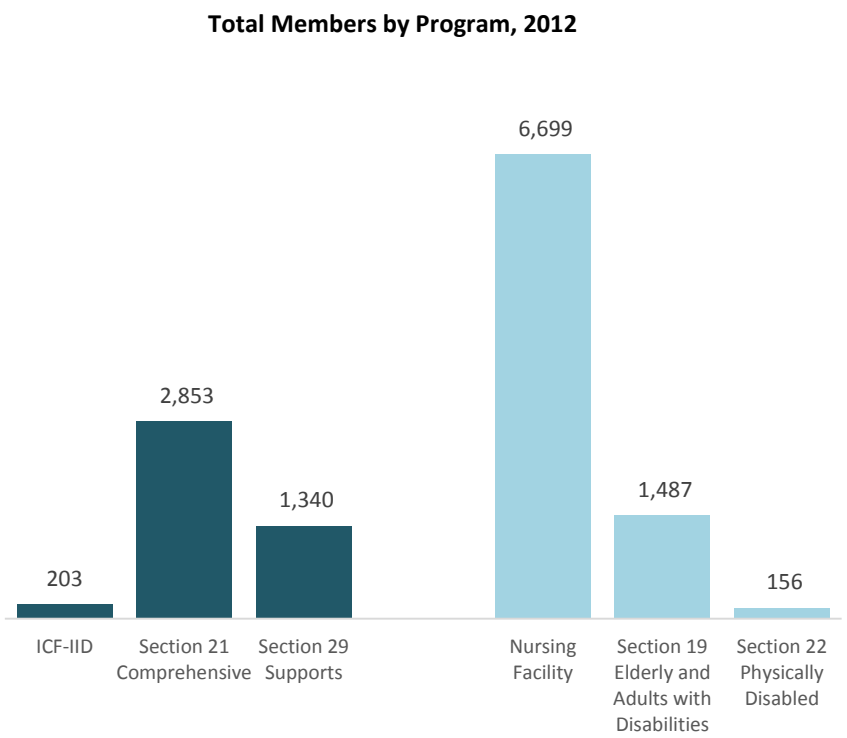
Table 3: Total Expenditures by Program, 2012†

	Waiver Services Expenditures	All Other MaineCare Expenditures	Total Expenditures
Section 21 Comprehensive Waiver	$292,933,145	$26,045,037	$318,978,182
Section 29 Supports Waiver	$24,400,126	$21,050,060	$45,450,186
ICF-IID	$38,142,482	$1,563,506	$39,705,988

* 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 is as filed with CMS.

† CMS 372 reports for 2012. The 2012 data for the Section 29 Supports waiver are as filed with CMS.

Chart 11: Institutional and Waiver Services for Adults with ID/ASD Compared to Institutional and Waiver Services for the Elderly and Adults with Physical Disabilities, 2012*



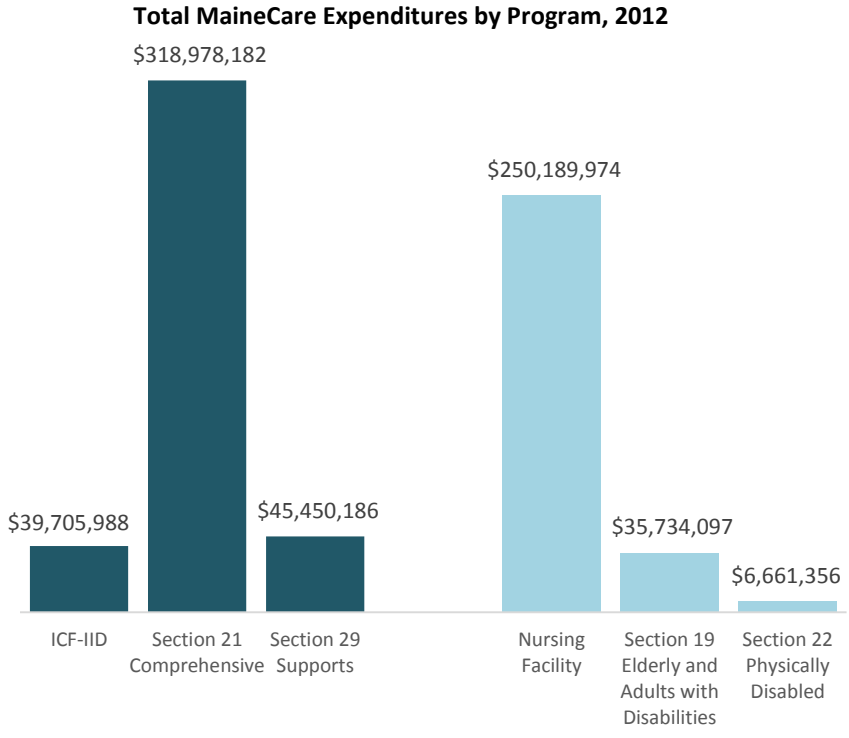


Chart 11 shows the difference between the number of members served and their expenditures by institutional and alternative waiver setting. The Section 21 Comprehensive and Section 29 Supports waivers are the HCBS alternatives to **ICF-IID care**. The Section 19 Elderly and Adults with Disabilities and Section 22 Physically Disabled waivers are the HCBS alternatives to **nursing facility care**. Note that the nursing facility category includes members with both long term and shorter stays throughout the year; this contrasts with the ICF-ID census which is more stable throughout the year. For example, the average monthly census of residents in nursing facilities in SFY 2010 was 4,749 residents.†

* CMS 372 reports for 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.

† Fralich, J. et al., Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine, 2012 Edition. (Chartbook). Portland, ME: University of Southern Maine, Muskie School of Public Service; 2012. Available at: http://muskie.usm.maine.edu/DA/Adults-Disabilities-Maine-Service-Use-Trends-chartbook-2012.pdf

Chart 12: Annual per Person Institutional, Waiver, and all Other MaineCare Service Expenditures and Number of Participants, by Program, 2012*

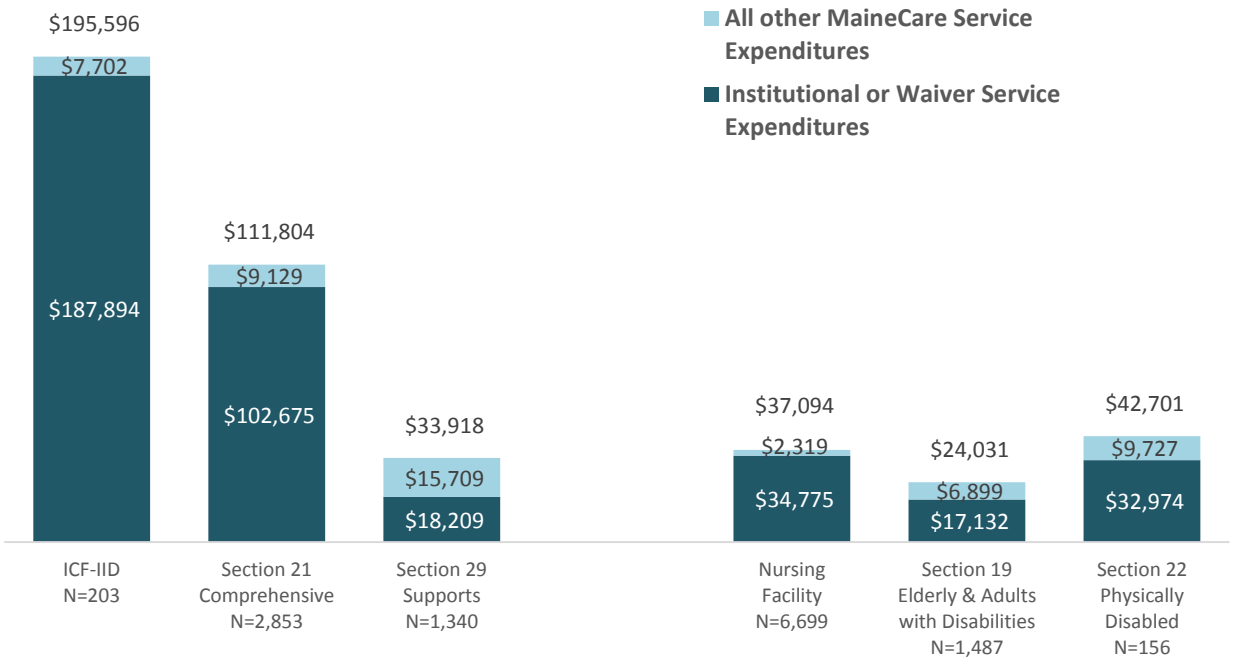


Chart 12 shows the difference between the number of members and their expenditures by institutional and alternative waiver setting. The Section 21 Comprehensive and Section 29 Supports waivers are the HCBS alternatives to **ICF-IID care**. The Section 19 Elderly and Adults with Disabilities and Section 22 Physically Disabled waivers are the HCBS alternatives to **nursing facility care**. Note that the Section 29 Supports waiver is the only setting with a near even split between waiver services and all other MaineCare services. The per person costs in other institutional or waiver settings are driven mainly by the actual services those facilities or waivers provide. Also note that the nursing facility per person cost calculation in this chart reflects the costs of members with both long term and shorter stays. For example, using the average monthly nursing facility census of 4,749 residents, Fralich et al. (2012) report an average annual nursing facility per person expenditure of $49,800 in SFY 2010.[†]

[*] Calculation is based on the CMS 372 reports for 2012: Total Annual Expenditures/Number of Members Served throughout the year.
[†] Fralich et al. 2012.

Section 4: Service Use and Cost Patterns of Adults with ID/ASD in Different Residential Settings

This section describes the service use and cost of adults with ID/ASD who were fully dual eligible for Medicare and MaineCare or who were eligible for MaineCare-only in SFY 2010. The first charts describe the population as a whole, while the subsequent charts describe the service use and cost across different residential settings, according to the hierarchy established for the analysis described in the introduction to this chartbook.

The map on the right shows the geographic distribution of the 5,400 ID/ASD service users who had full MaineCare eligibility for at least eleven months in SFY 2010. The size of the circles shows the relative size of this population by county. The information in this map is based on the county of residence identified through MaineCare claims data in MeCMS. For some members, the place of residence could be a nursing facility, ICF-IID or residential care setting.

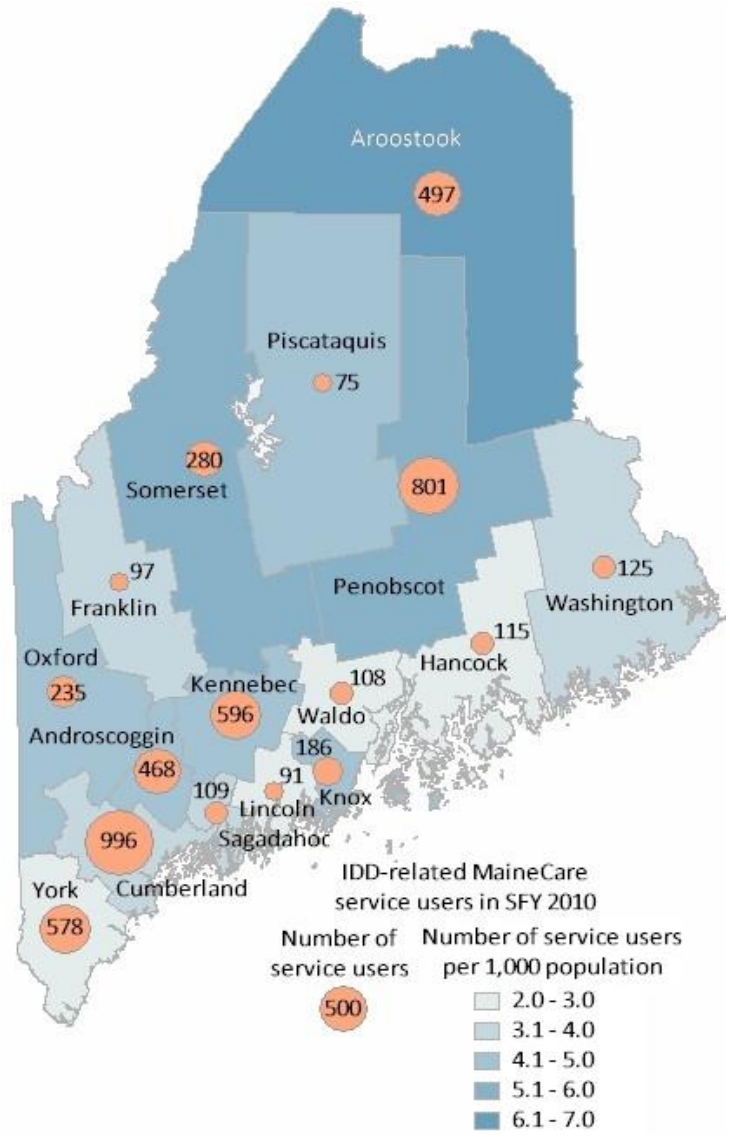
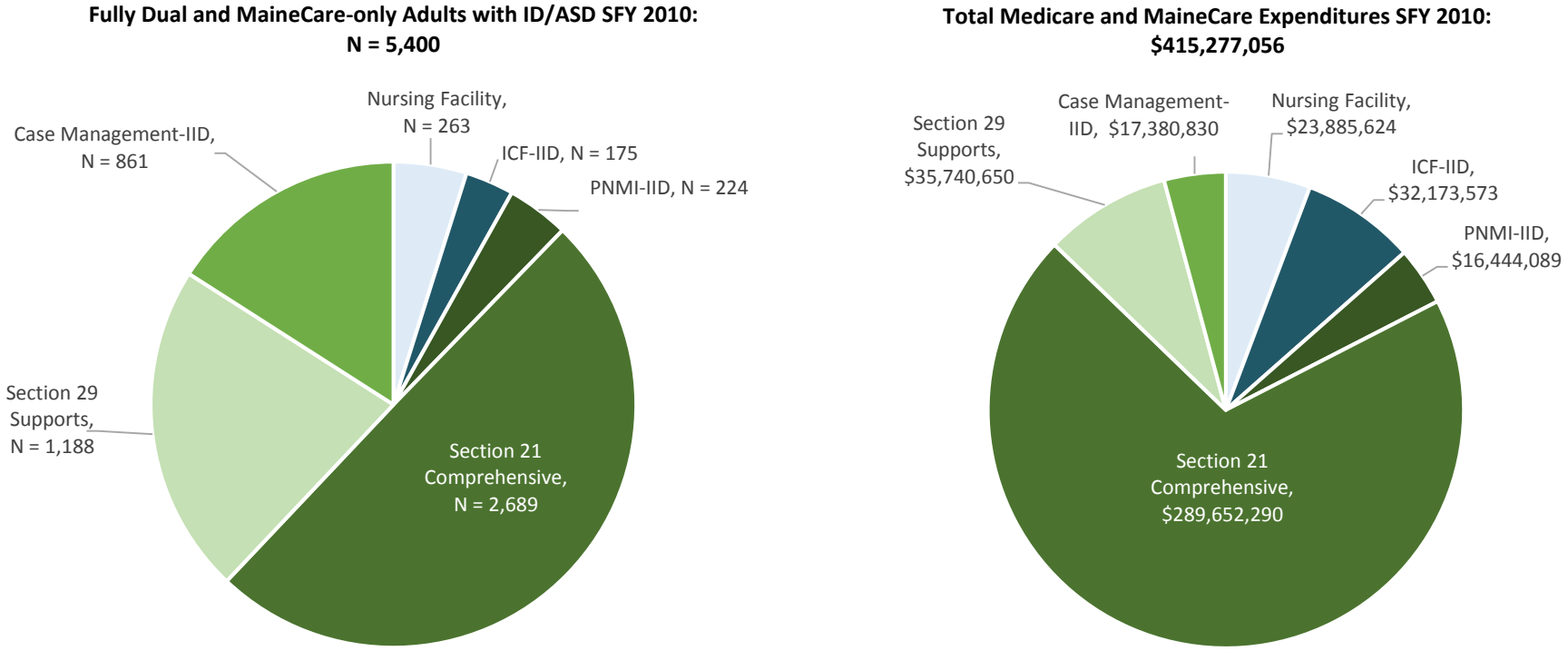


Chart 13: Total Number of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD and Total Medicare and MaineCare Expenditures by Setting, SFY 2010*



The chart above shows the number of members in each of the six settings: Nursing Facility, ICF-IID, PNMI-IID, Section 21 Comprehensive, Section 29 Supports, and Case Management-IID. According to the hierarchy established for this analysis, members were grouped according to the most restrictive and intensive service setting they experienced during SFY 2010. For example, a member with ID/ASD who had a nursing facility stay at any time during the year was placed in the Nursing Facility group for the analysis of service use and cost for that year. At the other end of the spectrum, a member who received only case management and no waiver or institutional services was placed in the least restrictive Case Management-IID group.

* The total population of MaineCare 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 SFY 2010. 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.

Chart 14: Proportion of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010 *

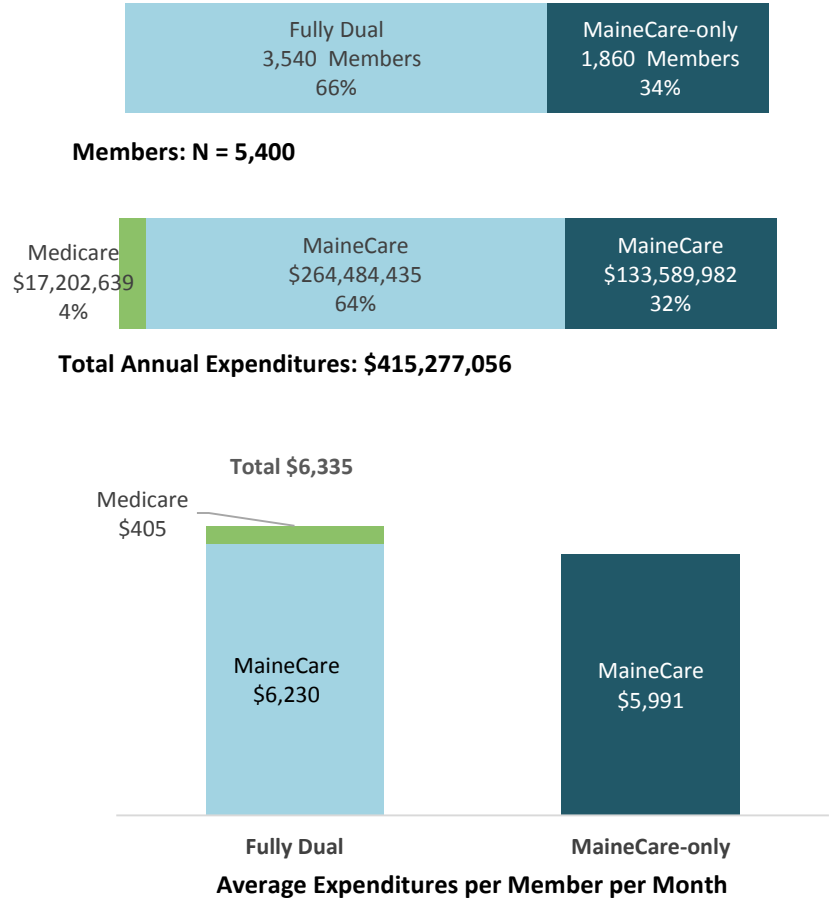


Chart 14 shows how many of the total group of 5,400 members with ID/ASD were fully dual or MaineCare-only eligible and the proportionate share of their Medicare and MaineCare costs.

* 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. 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.

Chart 15: Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD by Setting, SFY 2010*

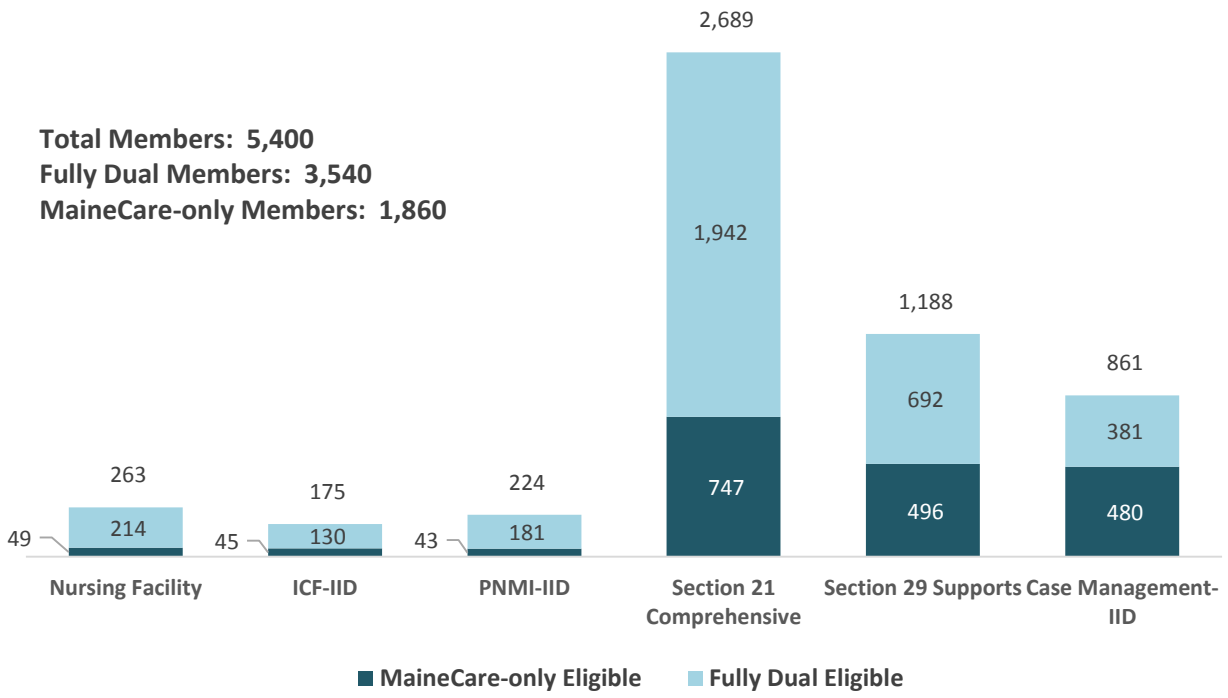


Chart 15 shows the proportion of fully dual eligible and MaineCare-only eligible adults with ID/ASD across the different service settings. The group receiving only case management services for adults with ID/ASD was the only population for which MaineCare-only eligible members out-numbered the fully dual eligible members.

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

Chart 16: Annual Medicare and MaineCare Expenditures for Adult Members with ID/ASD by Setting, in Millions, SFY 2010*

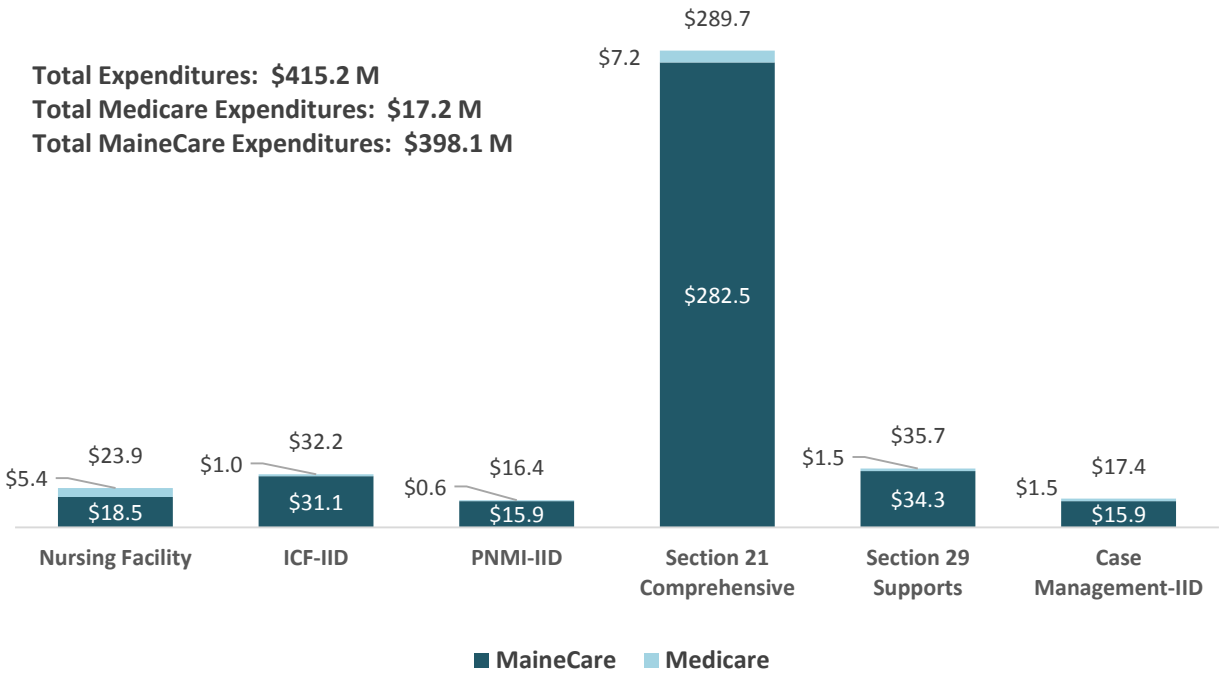


Chart 16 shows the distribution of Medicare and MaineCare expenditures across the different service settings. As seen in previous charts, although the majority of MaineCare members with ID/ASD are dually eligible, Medicare makes up a small fraction of expenditures across these population groups.

* 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. 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.

Chart 17: Age Distribution of Adults with ID/ASD, by Setting, SFY 2010*

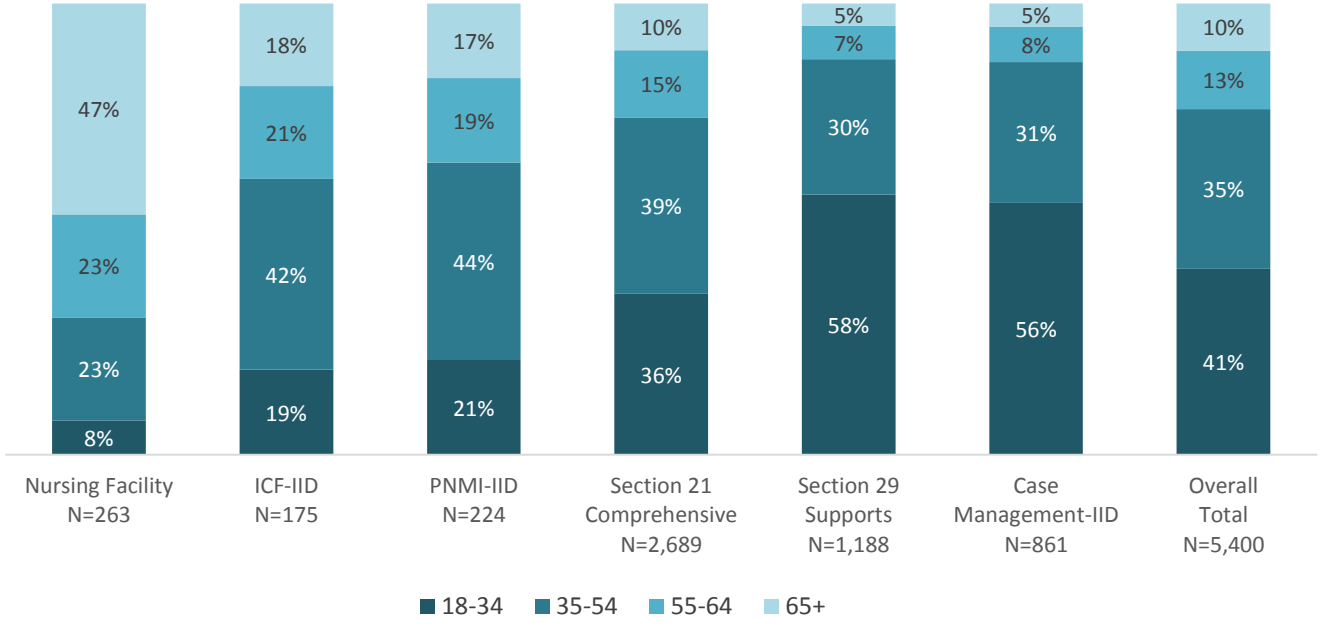
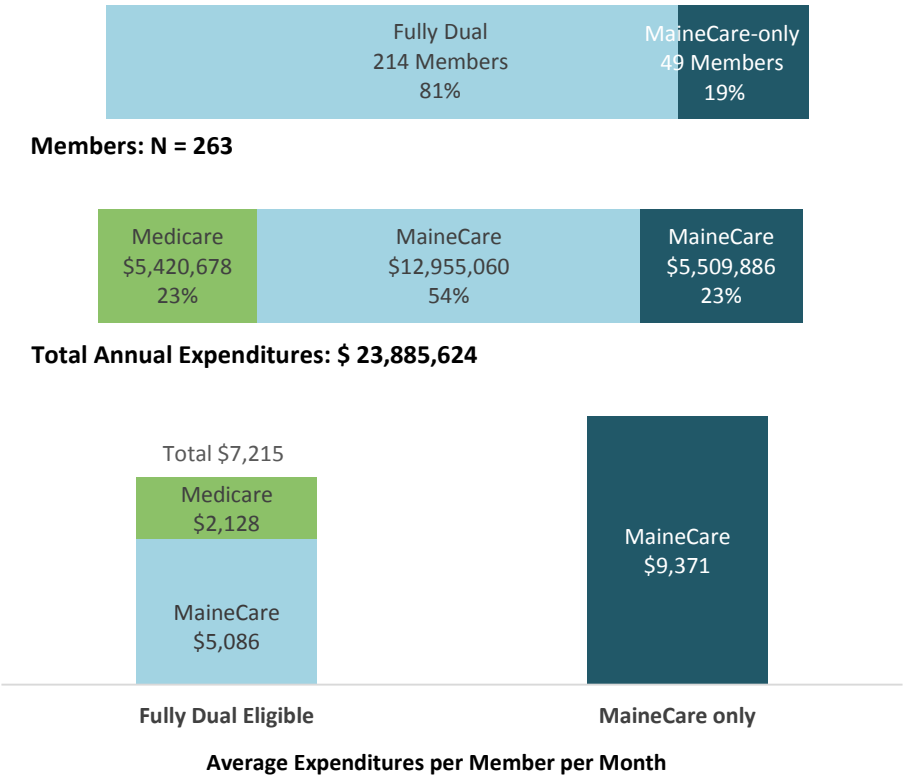


Chart 17 shows the age distribution of adults with ID/ASD across the six service settings and over the total population. Note that the institutional settings, especially the nursing facility, have an older population than the waiver or case management settings. The distribution of younger members in the Section 29 Supports waiver may reflect the requirement of the waiver that members live on their own or with family members. Older members with ID/ASD may not have as many family supports as younger members with ID/ASD.

* 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. 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.

Nursing Facility

Chart 18: Proportion of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD in Nursing Facilities Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010*

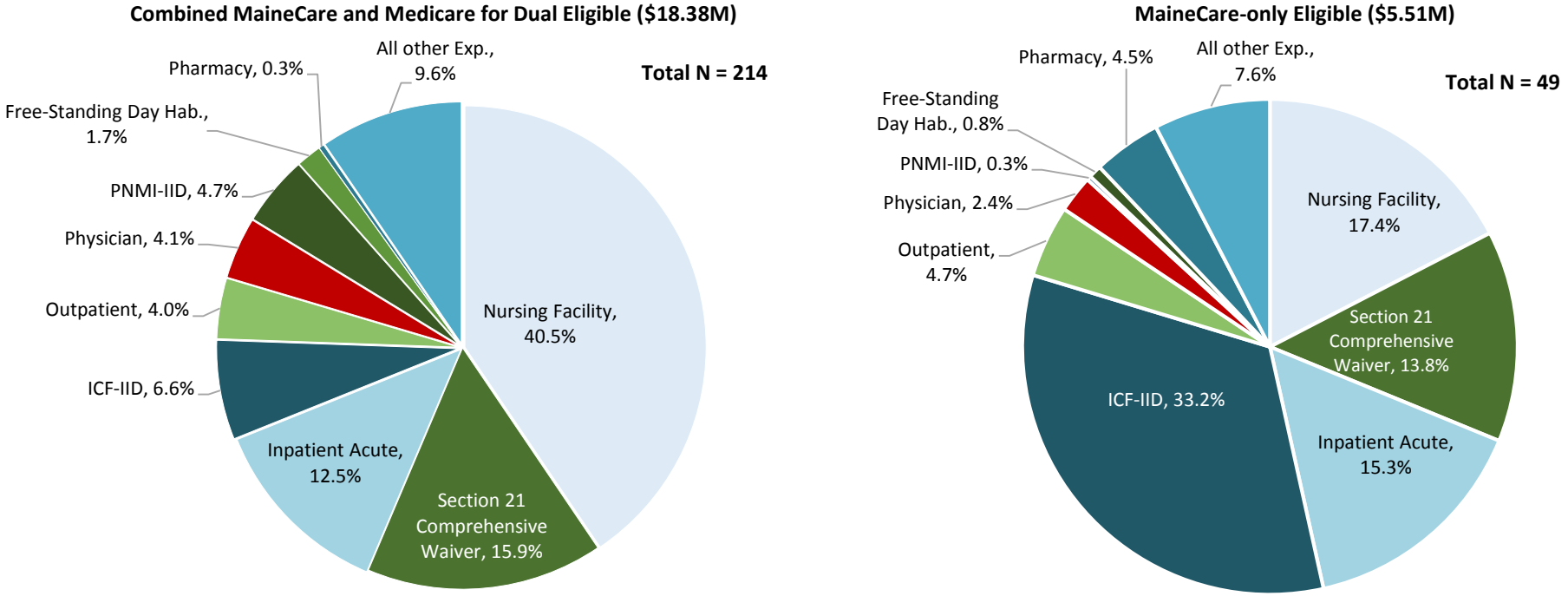


Of the members with ID/ASD who had a nursing facility stay in 2010, the vast majority (81%) were dually eligible for Medicare and MaineCare services and accounted for 77% of total expenditures. Please note that this population of nursing facility residents with ID/ASD is a small subset of the total number of Maine nursing facility residents.

* Nursing facility residents with ID/ASD were identified through MDS assessment data and MaineCare claims data from MeCMS identifying members living in ICF-IIDs who also had a nursing facility stay in 2010. For purposes of analysis in this chartbook, members who had both an ICF-IID stay and a nursing facility stay were deemed to be part of the nursing facility population with ID/ASD and were removed from the ICF-IID population presented in subsequent charts. 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.

Nursing Facility

Chart 19: Share of Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD who had a Nursing Facility Stay, by Service, SFY 2010*



The chart above shows the different proportion of expenditures for services for dual eligible and MaineCare-only eligible members with ID/ASD who had a nursing facility stay in 2010. Note that members with ID/ASD in nursing facilities may have accessed the above services, such as ICF-IID or waiver, at any time during the year. They are included in this setting if they had any nursing facility stay during the year. Medicare Part D pharmacy expenditures for the fully dual eligible are not included in the data.

* Nursing facility residents with ID/ASD were identified through MDS assessment data and MaineCare claims data from MeCMS identifying members living in ICF-IIDs who also had a nursing facility stay in 2010. For purposes of analysis in this chartbook, members who had both an ICF-IID stay and a nursing facility stay were deemed to be part of the nursing facility population with ID/ASD and were removed from the ICF-IID population presented in subsequent charts. 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.

Nursing Facility

Table 4: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD who had a Nursing Facility Stay, by Service, SFY 2010*

	Fully Dual Eligible			MaineCare-only Eligible	Total MaineCare Expenditures
	MaineCare	Medicare	Combined		
Persons Served	**214**	**214**	**214**	**49**	**263**
Total Expenditures	**$12,955,060**	**$5,420,678**	**$18,375,738**	**$5,509,886**	**$18,464,946**
Nursing Facility	$5,971,494	$1,475,807	$7,447,301	$958,846	$6,930,340
Section 21 Comprehensive Waiver	$2,914,018	-	$2,914,018	$759,799	$3,673,817
Inpatient Acute	$119,488	$2,183,147	$2,302,635	$844,828	$964,316
ICF-IID	$1,220,332	-	$1,220,332	$1,826,852	$3,047,184
Outpatient	$101,888	$640,322	$742,210	$259,149	$361,037
Physician	$109,516	$649,055	$758,571	$133,385	$242,901
PNMI	$864,499	-	$864,499	$15,278	$879,777
Free-Standing Day Habilitation	$305,766	-	$305,766	$46,266	$352,032
Pharmacy	$63,077	-	$63,077	$245,779	$308,856
All other Expenditures	$1,284,982	$472,347	$1,757,329	$419,704	$1,704,686

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

* Nursing facility residents with ID/ASD were identified through MDS assessment data and MaineCare claims data from MeCMS identifying members living in ICF-IIDs who also had a nursing facility stay in 2010. For purposes of analysis in this chartbook, members who had both an ICF-IID stay and a nursing facility stay were deemed to be part of the nursing facility population with ID/ASD and were removed from the ICF-IID population presented in subsequent charts. 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.

Nursing Facility

Chart 20: Percentage of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD with a Nursing Facility Stay Using Select Services, SFY 2010*

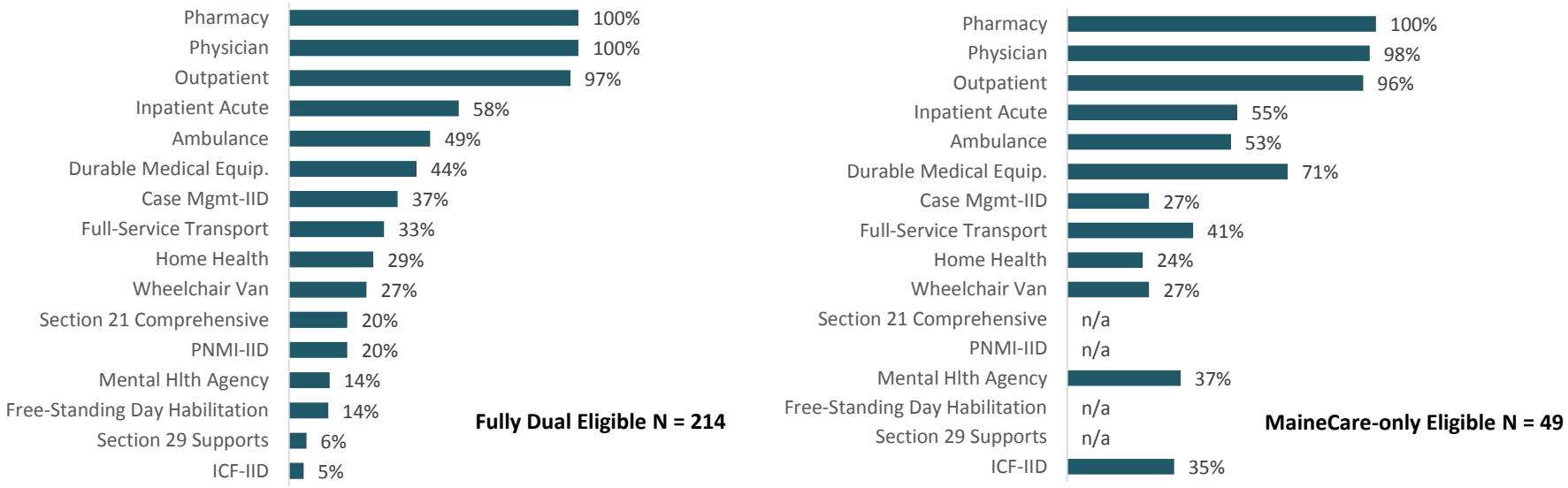


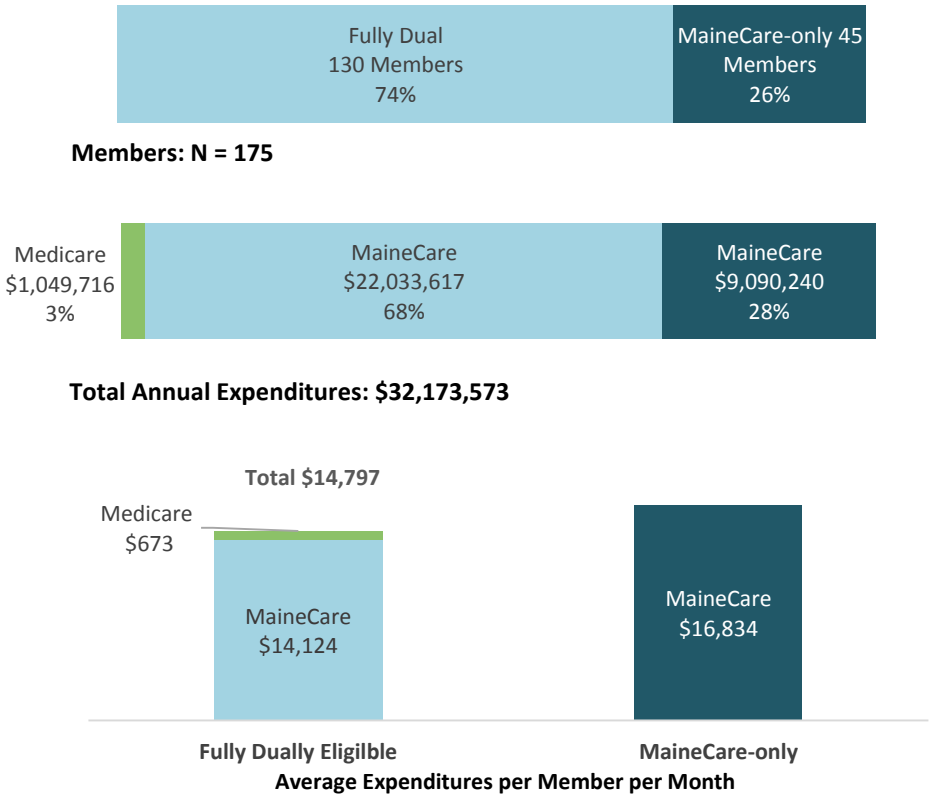
Chart 20 shows the different service use patterns of fully dual eligible and MaineCare-only eligible members with ID/ASD who had a nursing facility stay in 2010. Both groups had similar use patterns across many services. Due to the small number of MaineCare-only eligible adults in this setting, it is difficult to determine whether some of the service categories showing large differences in use (e.g., ICF-IID) are a product of actual differences in the populations or the small population size.

The charts on the preceding pages showed that the MaineCare-only eligible group had expenditures for Free-Standing Day Habilitation, home and community based waiver services, and PNMI-IID services. However, due to the small group of MaineCare-only eligible adults in this setting and privacy regulations, we are not able to show the percentage of service users of a particular service if the number of users is fewer than eleven individuals; these are marked by "n/a".

* Nursing facility residents with ID/ASD were identified through MDS assessment data and MaineCare claims data from MeCMS identifying members living in ICF-IIDs who also had a nursing facility stay in 2010. For purposes of analysis in this chartbook, members who had both an ICF-IID stay and a nursing facility stay were deemed to be part of the nursing facility population with ID/ASD and were removed from the ICF-IID population presented in subsequent charts. 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.

ICF-IID

Chart 21: Proportion of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD in ICF-IIDs Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010*



Of the individuals with ID/ASD who lived in ICF-IIDs, but who did not have a nursing facility stay, 74% were dually eligible for Medicare and MaineCare services and 26% were eligible for MaineCare only. Among the dually eligible group, the majority of the expenditures were covered by MaineCare.

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for ICF-IID services who did not have a nursing facility stay in 2010. 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.

ICF-IID

Chart 22: Share of Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members in ICF-IIDs by Type of Service, SFY 2010*

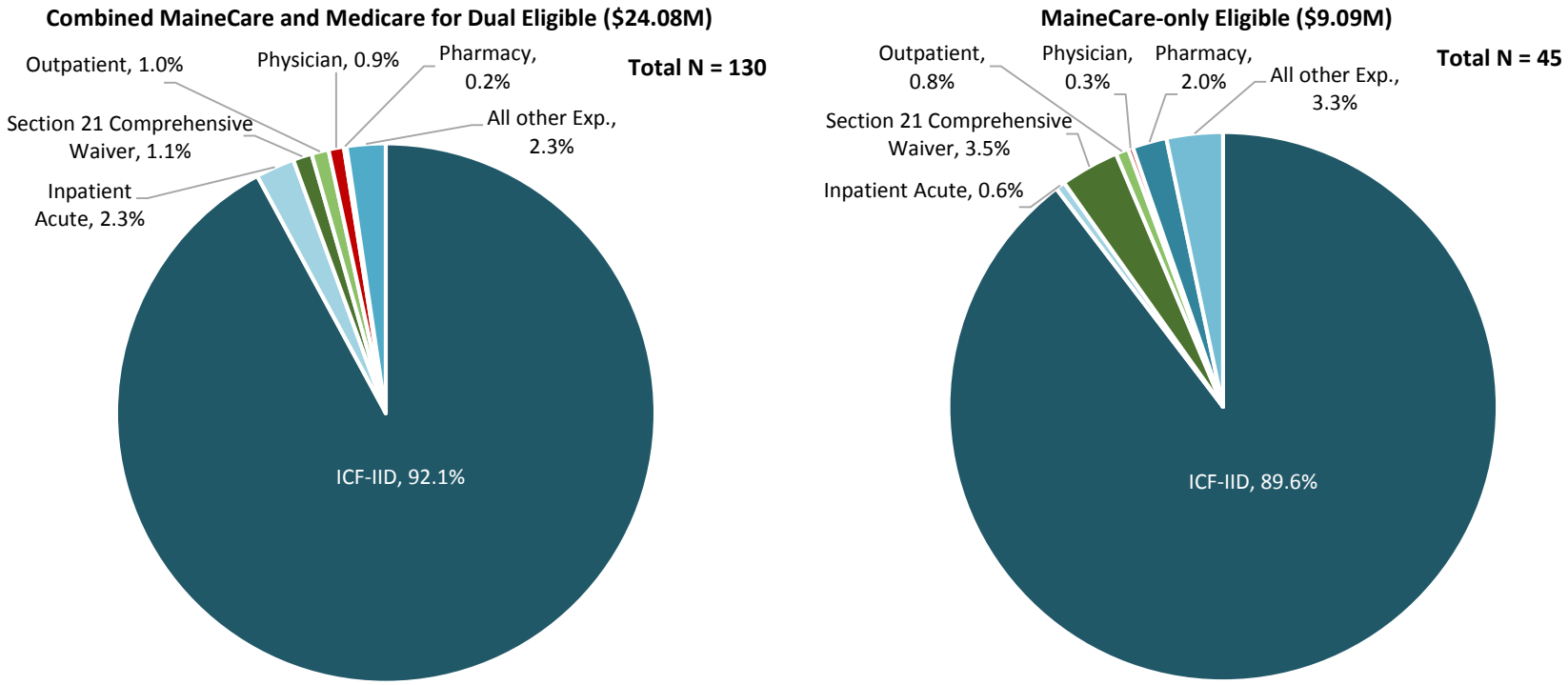


Chart 22 shows that of the expenditures for members with ID/ASD who had an ICF-IID stay but not a nursing facility stay during the year, most were for the ICF-IID service itself. Dual eligible individuals had a higher percentage of their expenses attributable to inpatient acute care services. MaineCare-only eligible individuals had a higher percentage of their expenses attributable to the Section 21 Comprehensive waiver services. However, due to the small number of MaineCare-only eligible adults in this setting, it is difficult to determine if these differences are a product of actual variations in the populations or the small population size.

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for ICF-IID services who did not have a nursing facility stay in 2010. 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.

ICF-IID

Table 5: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members in ICF-IIDs by Service, SFY 2010*

	Fully Dual Eligible			MaineCare-only Eligible	Total MaineCare Expenditures
	MaineCare	Medicare	Combined		
Persons Served	**130**	**130**	**130**	**45**	**175**
Total Annual Expenditures	**$22,033,617**	**$1,049,716**	**$23,083,333**	**$9,090,240**	**$31,123,857**
ICF-IID	$21,258,880	-	$21,258,880	$8,145,817	$29,404,697
Inpatient Acute	$8,732	$529,213	$537,945	$51,664	$60,396
Section 21 Comprehensive Waiver	$262,198	-	$262,198	$313,783	$575,981
Outpatient	$16,675	$220,284	$236,959	$68,911	$85,586
Physician	$33,843	$178,426	$212,269	$25,728	$59,571
Pharmacy	$37,092	-	$37,092	$183,158	$220,250
All other Expenditures	$416,197	$121,793	$537,990	$301,179	$717,376

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for ICF-IID services who did not have a nursing facility stay in 2010. 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.

ICF-IID

Chart 23: Percentage of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD Living in ICF-IIDs Using Select Services, SFY 2010*

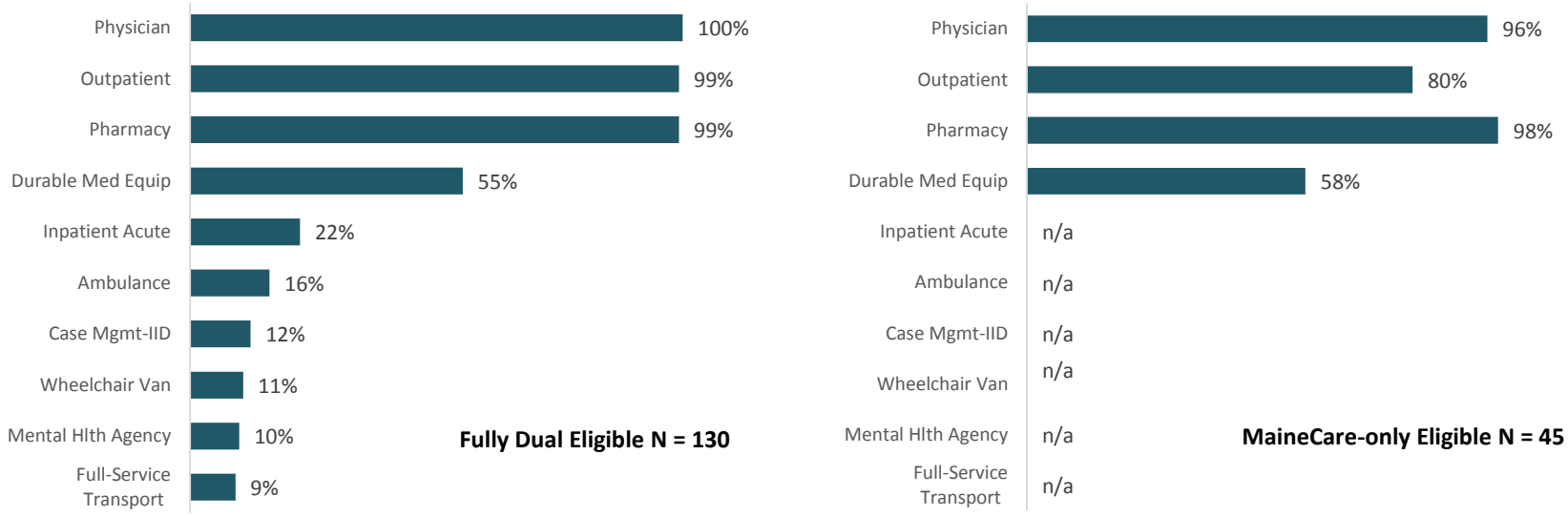
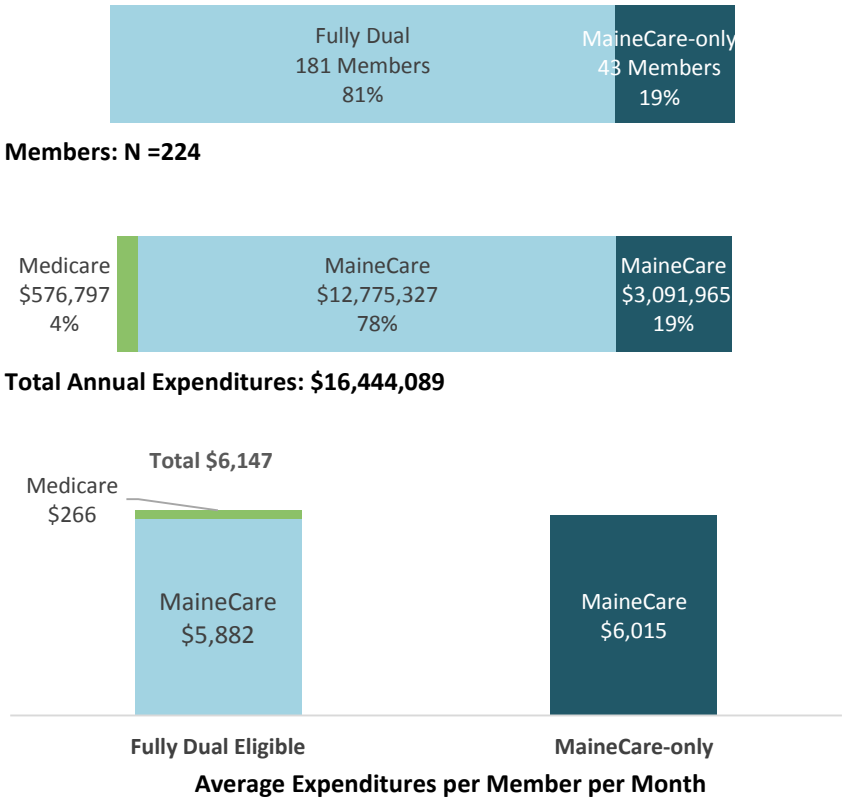


Chart 23 shows the different use patterns of fully dual eligible and MaineCare-only eligible members with ID/ASD who lived in ICF-IIDs in 2010. Both groups had similar use patterns. Due to the small group of MaineCare-only eligible adults in ICF-IIDs and privacy regulations, we are not able to show the percentage of service users of a particular service if the number of users is fewer than eleven individuals; these are marked by "n/a".

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for ICF-IID services who did not have a nursing facility stay in 2010. 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.

PNMI-IID

Chart 24: Proportion of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD in Private Non-Medical Institutions (PMNI-IIDs) Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010*

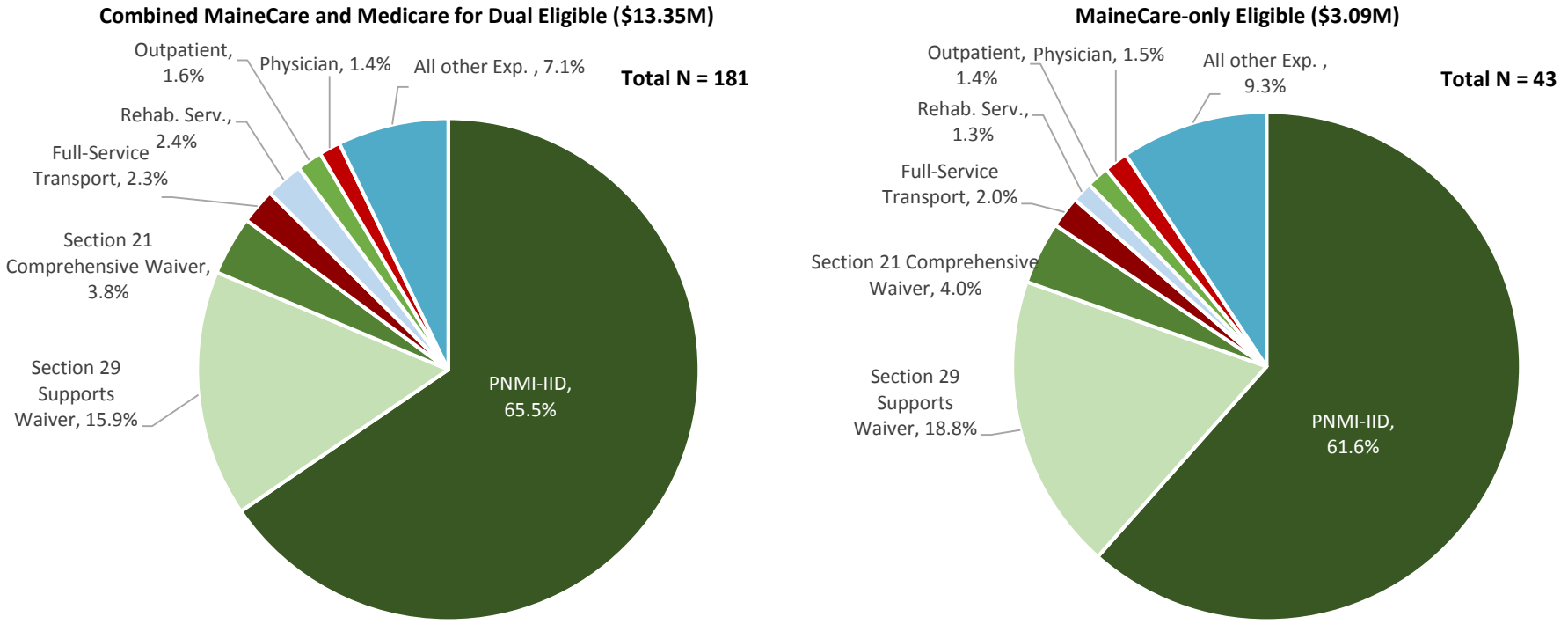


Average monthly MaineCare expenditures for services for individuals with ID/ASD in PNMI-IIDs were similar for both dual eligible members and MaineCare-only eligible members. Medicare accounted for only 4% of total expenditures for dual eligible members.

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for PNMI-IIDs who did not have a nursing facility or an ICF-IID stay in 2010. 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.

PNMI-IID

Chart 25: Share of Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD in PNMI-IIDs by Type of Service, SFY 2010*



The chart above shows that both dual eligible and MaineCare-only eligible members with ID/ASD in PNMI-IIDs had similar service expenditure patterns, with the majority of expenses on the PNMI-IID services themselves.

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for PNMI-IIDs who did not have a nursing facility or an ICF-IID stay in 2010. 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.

PNMI-IID

Table 6: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD in PNMI-IIDs by Service, SFY 2010*

	Fully Dual Eligible			MaineCare-only Eligible	Total MaineCare Expenditures
	MaineCare	Medicare	Combined		
Persons Served	**181**	**181**	**181**	**43**	**224**
Total Annual Expenditures	**$12,775,327**	**$576,797**	**$13,352,124**	**$3,091,965**	**$15,867,292**
PNMI-IID	$8,741,673	-	$8,741,673	$1,903,438	$10,645,111
Section 29 Supports Waiver	$2,117,817	-	$2,117,817	$582,346	$2,700,163
Section 21 Comprehensive Waiver	$507,825	-	$507,825	$123,329	$631,154
Full-Service Transport	$304,468	-	$304,468	$62,136	$366,604
Rehabilitation Services	$324,020	-	$324,020	$40,180	$364,200
Outpatient	$12,325	$205,984	$218,309	$44,315	$56,640
Physician	$48,305	$135,378	$183,683	$47,265	$95,570
All other Expenditures	$718,894	$235,435	$954,329	$288,956	$1,007,850

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for PNMI-IIDs who did not have a nursing facility or an ICF-IID stay in 2010. 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.

PNMI-IID

Chart 26: Percentage of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD in PNMI-IIDs Using Select Services, SFY 2010*

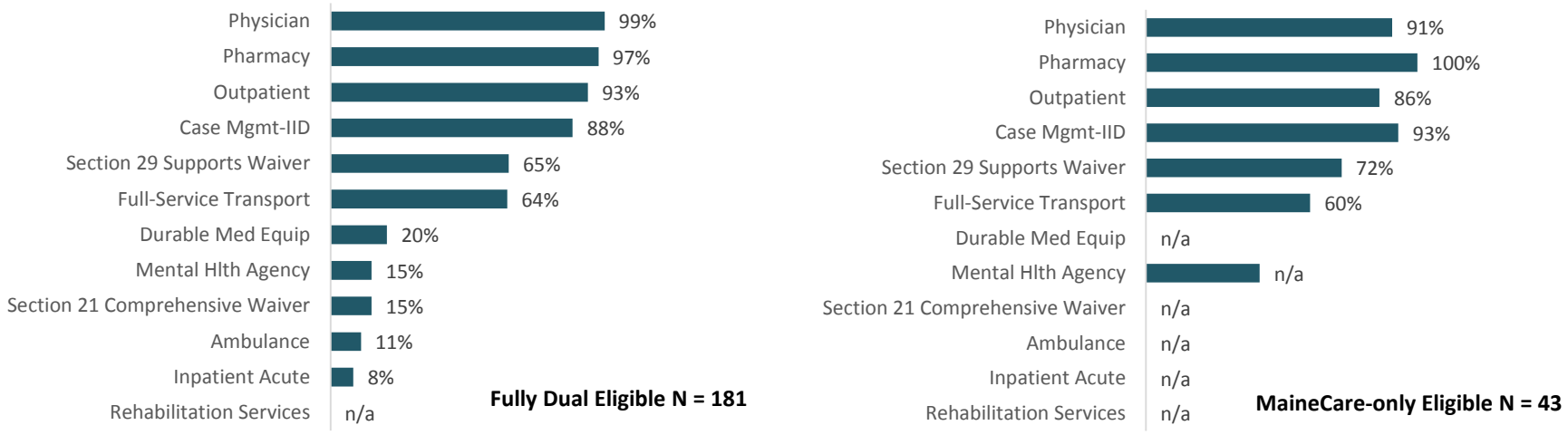


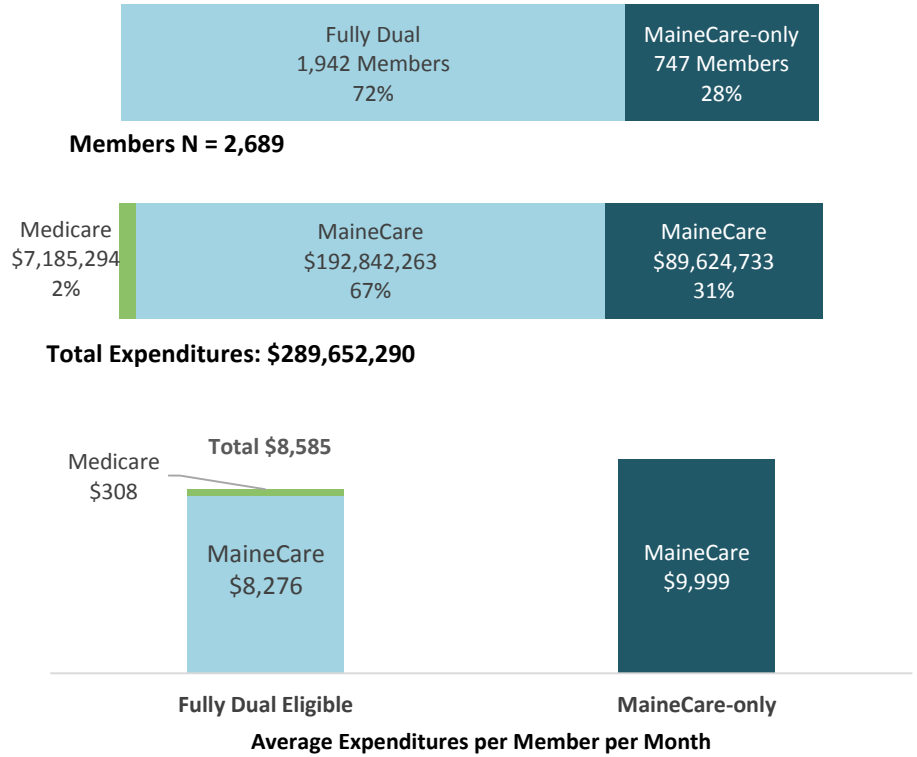
Chart 26 shows the different service use patterns of fully dual eligible and MaineCare-only eligible members with ID/ASD in PNMI-IIDs in 2010. Both groups had similar usage of physician, pharmacy, and full-service transport services.

While not shown on the above chart, the MaineCare-only eligible group also utilized durable medical equipment, Section 21 Comprehensive waiver, ambulance and inpatient acute care services. Additionally, as shown on the preceding charts, members of both the dual eligble group and the MaineCare-only eligible group used rehabilitation services. However, due to privacy regulations, we are not able to show the percentage of service users of a particular service if the number of users is fewer than eleven individuals; these are marked by "n/a".

* This population was identified through MaineCare claims data from MeCMS and consists of members with claims for PNMI-IIDs who did not have a nursing facility or an ICF-IID stay in 2010. 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.

Section 21 Comprehensive

Chart 27: Proportion of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD on the Section 21 Comprehensive Waiver for Individuals with ID/ASD Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010*

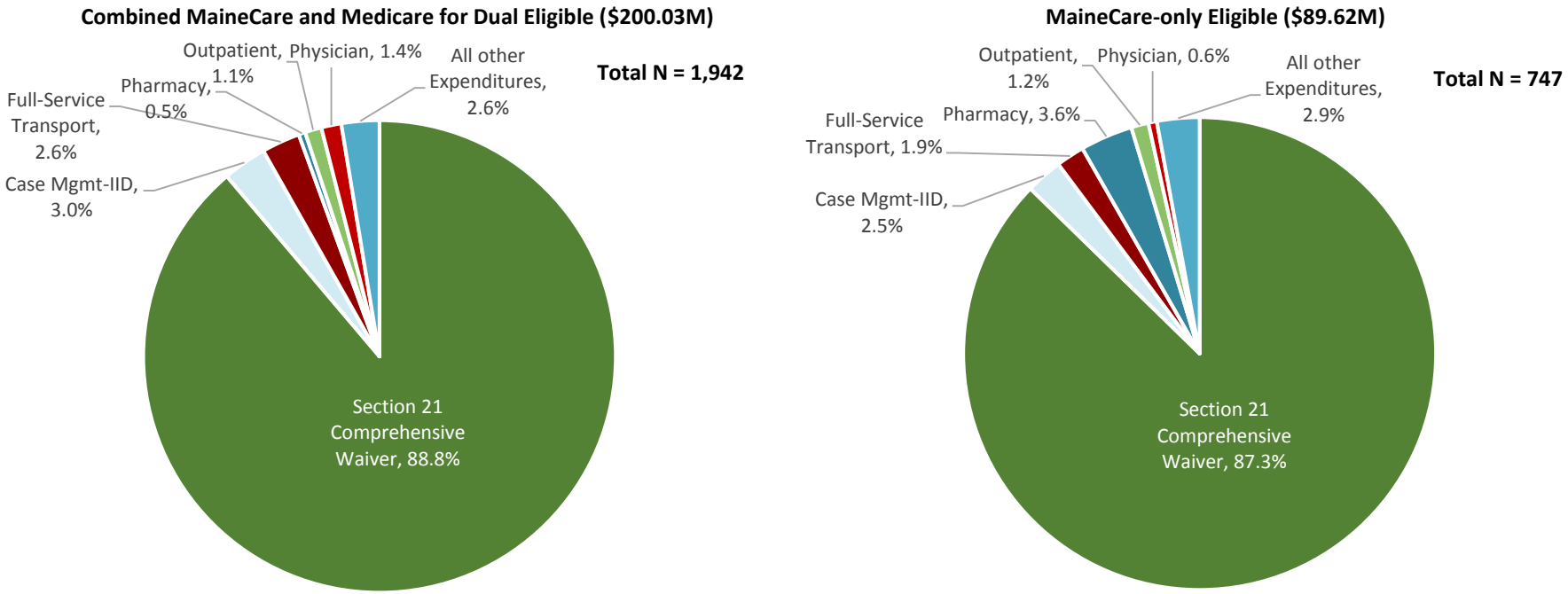


The majority of members with ID/ASD who utilized the Section 21 Comprehensive waiver services in 2010 were dually eligible for Medicare and MaineCare. For the dual eligible group, Medicare made up only 2% of their total expenditures.

* The Section 21 Comprehensive waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 21 Comprehensive waiver services and excludes individuals who used either nursing facility, ICF-IID, or PNMI-IID services in 2010. 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.

Section 21 Comprehensive

Chart 28: Share of Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD on the Section 21 Comprehensive Waiver by Service, SFY 2010*



The majority of expenditures for both fully dual and MaineCare-only members with ID/ASD on the Section 21 Comprehensive waiver in 2010 were for the waiver services themselves.

* The Section 21 Comprehensive waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 21 Comprehensive waiver services and excludes individuals who used either nursing facility, ICF-IID, or PNMI-IID services in 2010. 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.

Section 21 Comprehensive

Table 7: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD on the Section 21 Comprehensive Waiver by Service, SFY 2010*

	Fully Dual Eligible			MaineCare-only Eligible	Total MaineCare Expenditures
	MaineCare	Medicare	Combined		
Persons Served	**1,942**	**1,942**	**1,942**	**747**	**2,689**
Total Annual Expenditures	**$192,842,263**	**$7,185,294**	**$200,027,557**	**$89,624,733**	**$282,466,996**
Section 21 Comprehensive Waiver	$177,641,178	-	$177,641,178	$78,204,048	$255,845,226
Case Management-IID	$5,513,682	-	$5,513,682	$2,092,375	$7,606,057
Full-Service Transport	$5,256,073	-	$5,256,073	$1,737,872	$6,993,945
Pharmacy	$909,983	-	$909,983	$3,219,328	$4,129,311
Outpatient	$232,610	$2,039,523	$2,272,133	$1,062,966	$3,335,099
Physician	$581,144	$2,156,750	$2,737,894	$515,106	$3,253,000
All other Expenditures	$2,707,593	$2,989,021	$5,696,614	$2,793,038	$5,500,631

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

* The Section 21 Comprehensive waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 21 services and excludes individuals who used either nursing facility, ICF-IID, or PNMI-IID services in 2010. 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.

Section 21 Comprehensive

Chart 29: Percentage of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD on the Section 21 Comprehensive Waiver Using Select Services, SFY 2010*

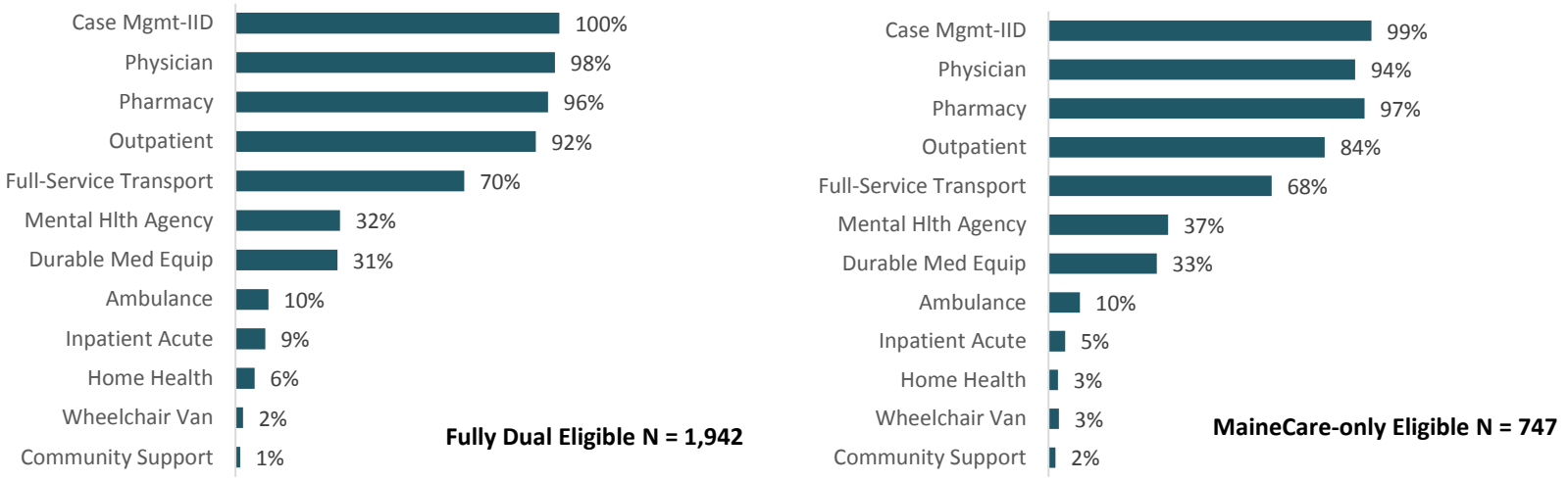
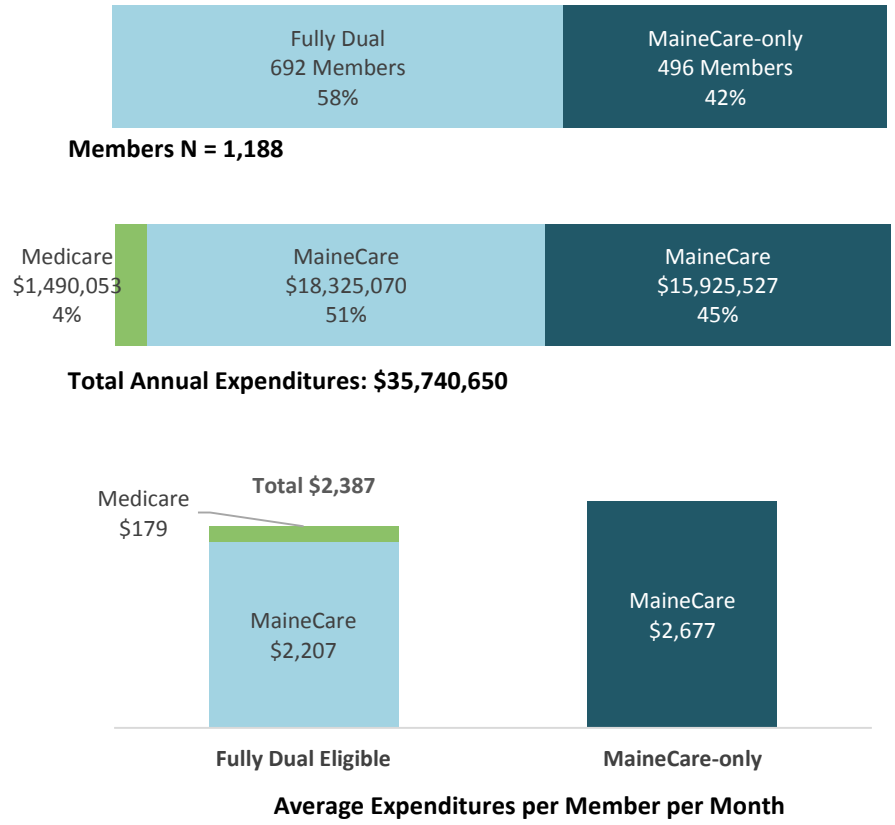


Chart 29 shows that the fully dual eligible and MaineCare-only eligible groups had similar service use patterns in 2010. Highly utilized services were Case Management-IID, Outpatient, Pharmacy, Physician and Full Service Transport.

* The Section 21 Comprehensive waiver population was identified through OADS enrollment records and MaineCare claims from MeCMS data for Section 21 Comprehensive waiver services and excludes individuals who used either nursing facility, ICF-IID, or PNMI-IID services in 2010. 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.

Section 29 Supports

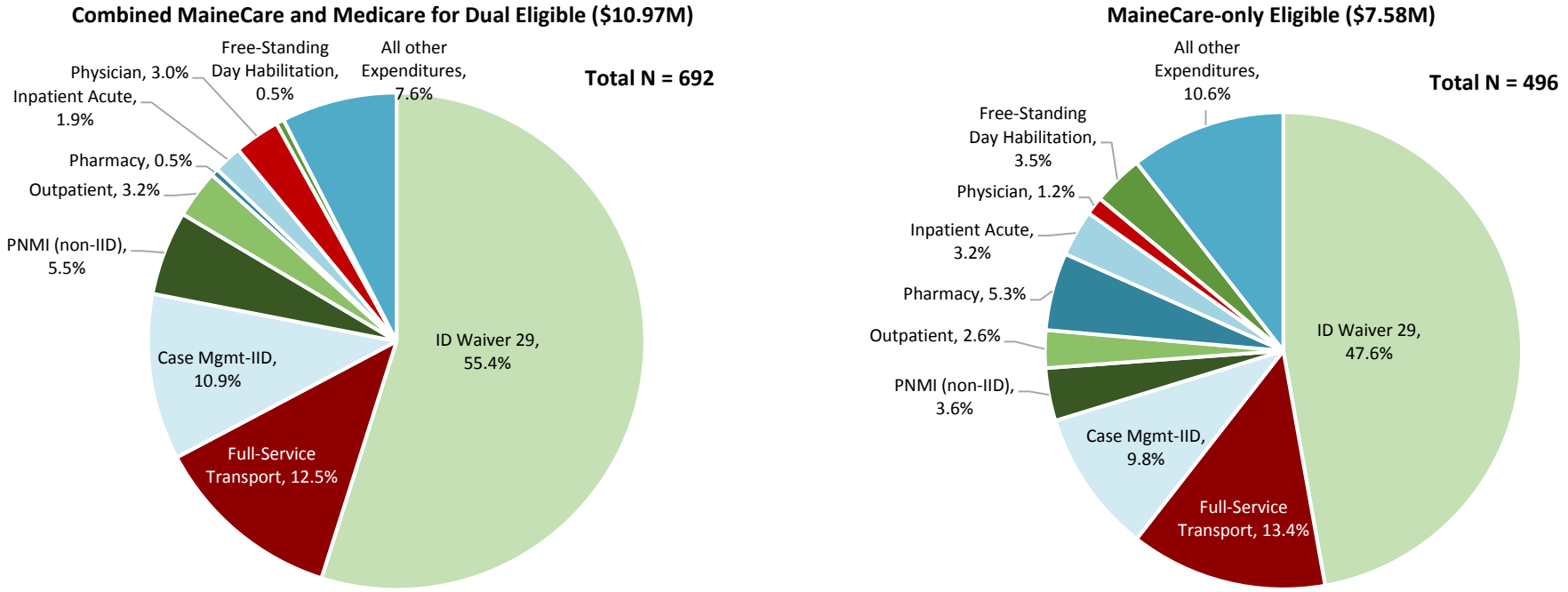
Chart 30: Proportion of Adult Fully Dual and MaineCare-only Eligible Members on the Section 29 Supports Waiver for Individuals with ID/ASD Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010*



* The Section 29 Supports waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 29 Supports waiver services and excludes individuals who used either nursing facility, ICF-IID, PNMI-IID, or Section 21 Comprehensive waiver services in 2010. 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.

Section 29 Supports

Chart 31: Share of Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD on the Section 29 Supports Waiver by Service, SFY 2010*



Over half of expenditures for fully dual eligible members and nearly half of expenditures for MaineCare-only eligible members on the Section 29 Supports waiver were attributable to the waiver services themselves. This is in stark contrast to the share of expenditures attributable to the Section 21 Comprehensive waiver which made up nearly 90% of expenditures of participants on that waiver.

Note that the PNMI (non-IID) expenditures are for PNMIs that do not specifically serve individuals with ID/ASD.

* The Section 29 Supports waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 29 Supports waiver services and excludes individuals who used either nursing facility, ICF-IID, PNMI-IID, or Section 21 Comprehensive waiver services in 2010. 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.

Section 29 Supports

Table 8: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD on the Section 29 Supports Waiver by Service, SFY 2010*

	Fully Dual Eligible			MaineCare-only Eligible	Total MaineCare Expenditures
	MaineCare	Medicare	Combined		
Persons Served	**692**	**692**	**692**	**496**	**1,188**
Total Annual Expenditures	**$18,325,070**	**$1,490,053**	**$19,815,123**	**$15,925,527**	$34,250,597
Section 29 Supports Waiver	$10,973,301	-	$10,973,301	$7,575,061	$18,548,362
Full-Service Transport	$2,473,448	-	$2,473,448	$2,141,930	$4,615,378
Case Management-IID	$1,982,276	-	$1,982,276	$1,435,947	$3,418,223
PNMI (non-IID)	$1,093,468	-	$1,093,468	$573,684	$1,667,152
Outpatient	$46,333	$581,217	$627,550	$409,625	$455,958
Pharmacy	$98,058	-	$98,058	$844,050	$942,108
Inpatient Acute	$10,154	$358,041	$368,195	$504,784	$514,938
Physician	$160,927	$432,690	$593,617	$196,125	$357,052
Free-Standing Day Habilitation	$103,382	-	$103,382	$551,228	$654,610
All other Expenditures	$1,383,723	$118,105	$1,501,828	$1,693,093	$3,076,816

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

Please note that the PNMI (non-IID) expenditures are for PNMIs that do not specifically serve individuals with ID/ASD.

* The Section 29 Supports waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 29 Supports waiver services and excludes individuals who used either nursing facility, ICF-IID, PNMI-IID, or Section 21 Comprehensive waiver services in 2010. 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.

Section 29 Supports

Chart 32: Percentage of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD on the Section 29 Supports Waiver Using Select Services, SFY 2010*

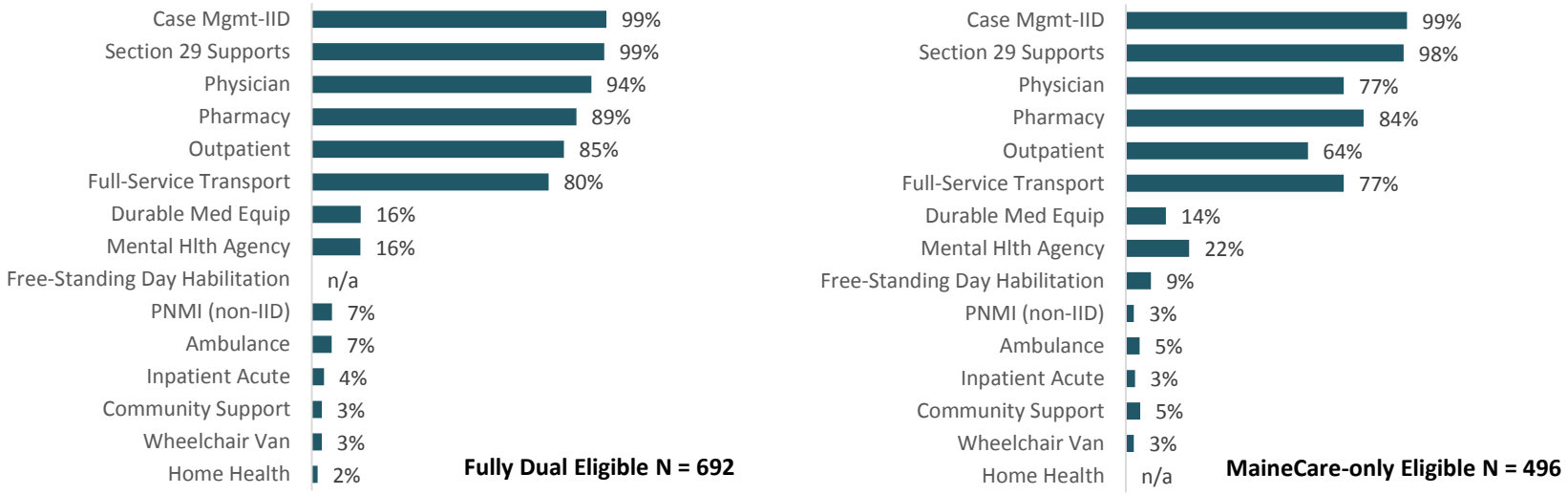
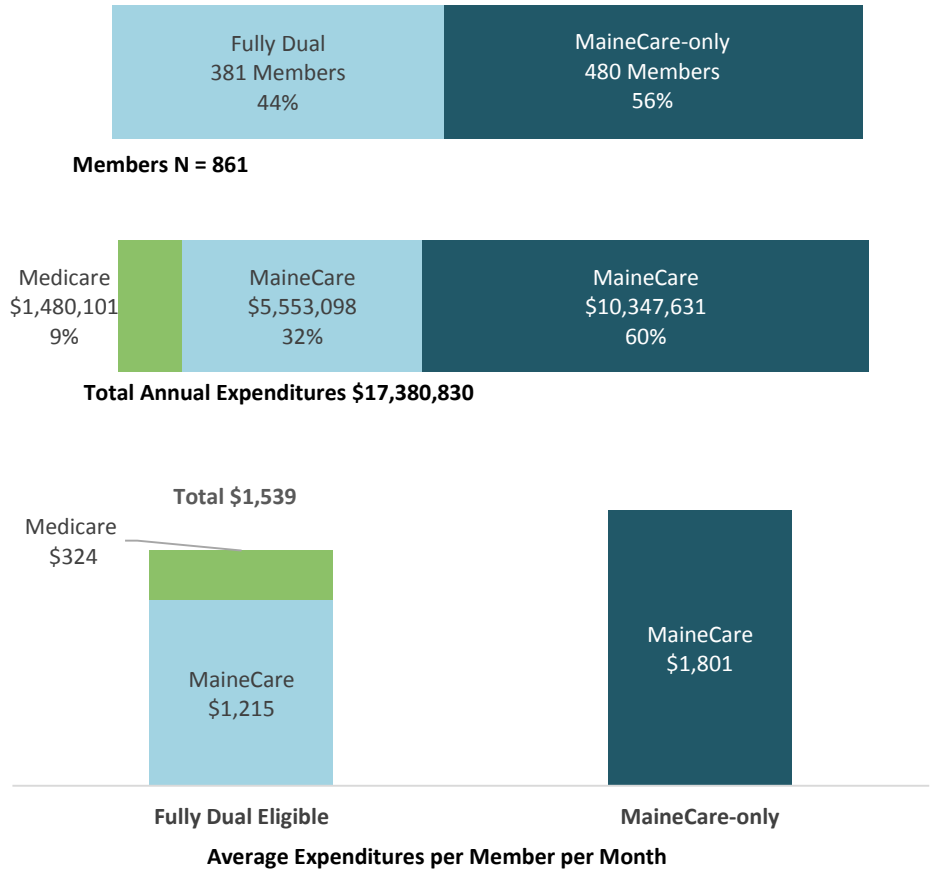


Chart 32 shows that fully dual eligible members have different service utilization patterns from the MaineCare-only eligible group. A higher proportion of MaineCare-only members utilized free-standing day habilitation; there were dually eligible members who used this service, but privacy regulations prohibit us from showing the percentage of service users of a particular service if the number of users is fewer than eleven individuals; these are marked by "n/a". The MaineCare-only group had a higher utilization rate of mental health agency services, but lower rates of physician and outpatient services. Both groups had similar usage of full service transportation.

* The Section 29 Supports waiver population was identified through OADS enrollment records and MaineCare claims data from MeCMS for Section 29 services and excludes individuals who used either nursing facility, ICF-IID, PNMI-IID, or Section 21 Comprehensive waiver services in 2010. 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.

Case Management-IID

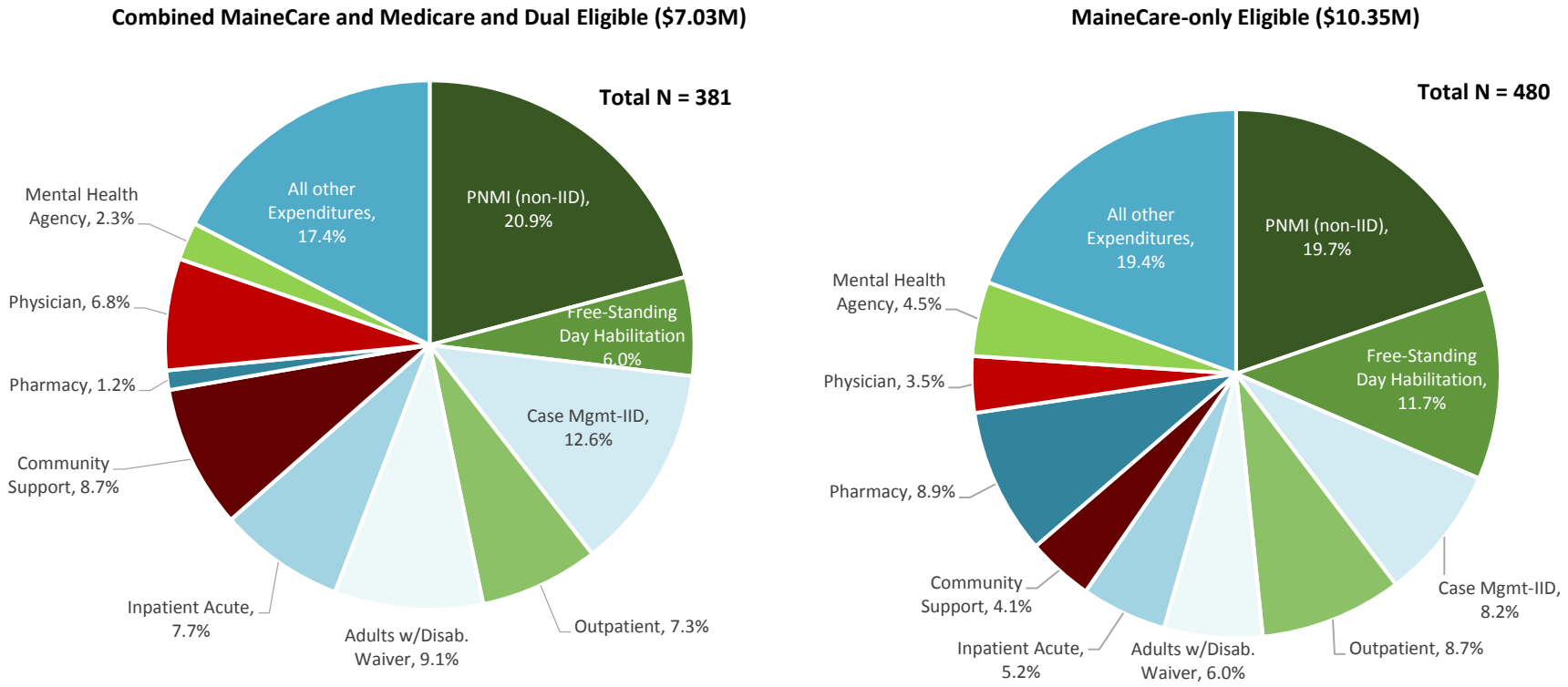
Chart 33: Proportion of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD only Receiving Case Management-IID Services Compared to their Share of Medicare and MaineCare Expenditures, SFY 2010*



* The population was identified through MaineCare claims data from MeCMS and includes members who received case management services for people with ID/ASD but who did not have a nursing facility, ICF-IID, or PNMI-IID stay and who also did not participate in either the Section 21 Comprehensive or Section 29 Supports waivers. 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.

Case Management-IID

Chart 34: Share of Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD only Receiving Case Management-IID Services, by Service, SFY 2010*



The chart above shows that members with ID/ASD who did not live in an institution or receive HCBS waiver services had varied expenditures, with those for PNMI (non-IID) services making up the largest share. Note that these PNMI services are for PNMIs that do not specifically serve people with ID/ASD.

* The population was identified through MaineCare claims data from MeCMS and includes members who received case management services for people with ID/ASD but who did not have a nursing facility, ICF-IID, or PNMI-IID stay and who also did not participate in either the Section 21 Comprehensive or Section 29 Supports waivers. 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.

Case Management-IID

Table 9: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD only Receiving Case Management-IID Services, by Service, SFY 2010*

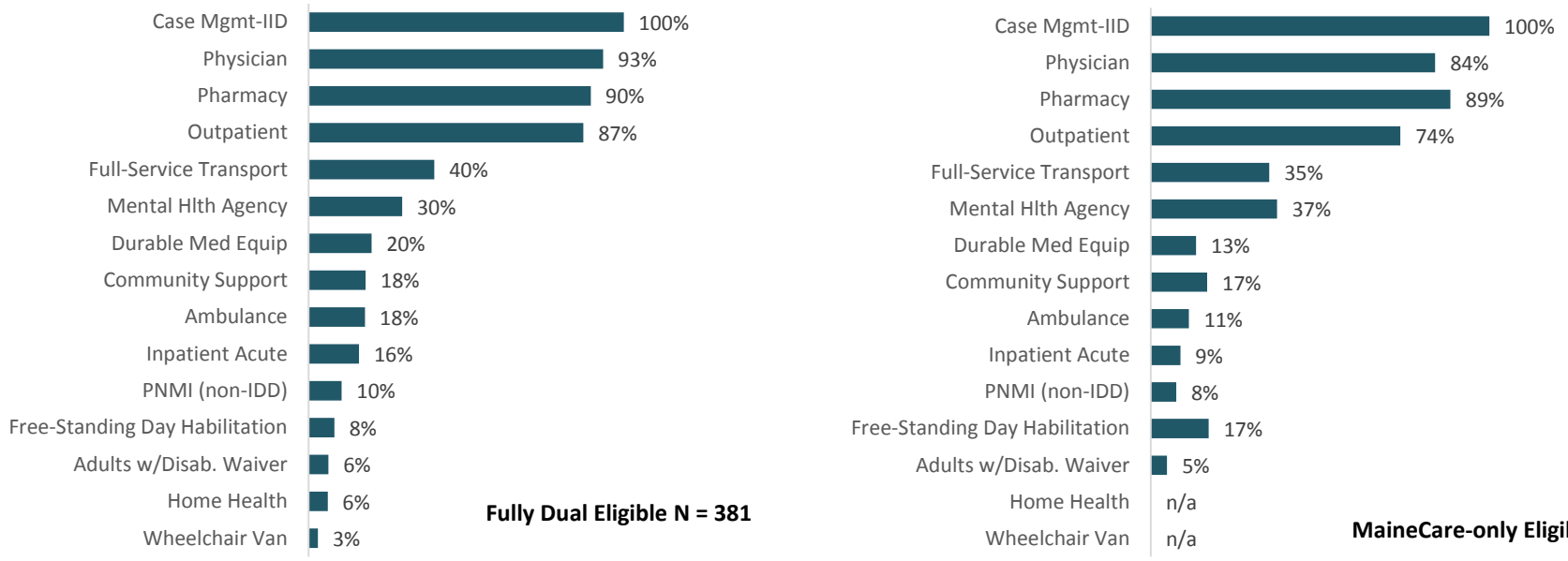
	Fully Dual Eligible			MaineCare-only Members	Total MaineCare Expenditures
	MaineCare	Medicare	Combined		
Persons Served	**381**	**381**	**381**	**480**	**861**
Total Annual Expenditures	**$5,553,098**	**$1,480,101**	**$7,033,199**	**$10,347,631**	**$15,900,729**
PNMI (non-IID)	$1,466,951	-	$1,466,951	$2,041,974	$3,508,925
Free-Standing Day Habilitation	$424,377	-	$424,377	$1,214,150	$1,638,527
Case Management-IID	$813,831	-	$813,831	$803,492	$1,617,323
Outpatient	$79,226	$432,427	$511,653	$900,549	$979,775
Adults w/Disabilities Waiver	$638,734	-	$638,734	$621,979	$1,260,713
Inpatient Acute	$27,516	$513,838	$541,354	$540,063	$567,579
Community Support	$615,211	-	$615,211	$420,171	$1,035,382
Pharmacy	$83,744	-	$83,744	$924,320	$1,008,064
Physician	$110,864	$369,025	$479,889	$357,414	$468,278
Mental Health Agency	$162,533	-	$162,533	$470,750	$633,283
All other Expenditures	$1,130,111	$164,811	$1,294,922	$2,052,769	$3,182,880

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

* The population was identified through MaineCare claims data from MeCMS and includes members who received case management services for people with ID/ASD but who did not have a nursing facility, ICF-IID, or PNMI-IID stay and who also did not participate in either the Section 21 Comprehensive or Section 29 Supports waivers. 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.

Case Management-IID

Chart 35: Percentage of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD only Receiving Case Management-IID Services Using Select Services, SFY 2010*



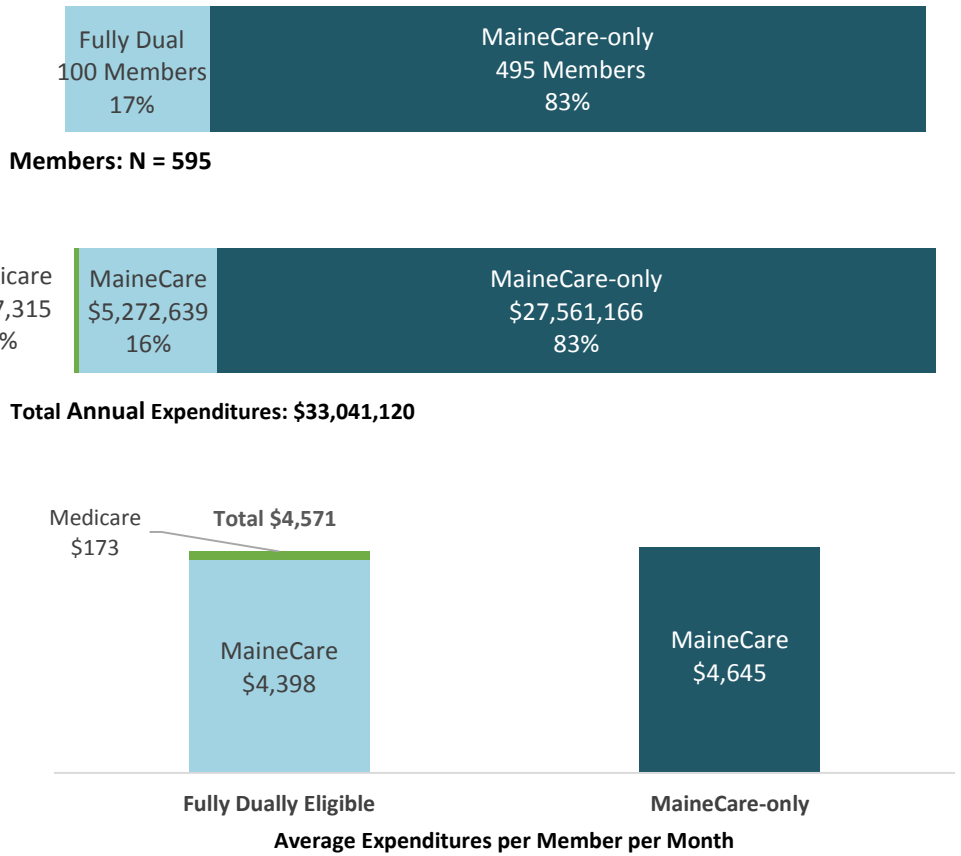
The chart above shows the different service utilization patterns for fully dual and MaineCare-only eligible members with ID/ASD who did not live in an institution or receive HCBS waiver services in 2010. Note that while 8% to 10% of these groups utilize PNMI (non-IID) services, these services made up nearly 20% of expenditures for both groups.

Privacy regulations prohibit us from showing the percentage of service users of a particular service if the number of users is fewer than eleven individuals; these are marked by "n/a".

* The population was identified through MaineCare claims data from MeCMS and includes members who received case management services for people with ID/ASD but who did not live in a nursing facility, ICF-IID, or PNMI-IID and who also did not participate in either the Section 21 Comprehensive or Section 29 Supports waivers. 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.

18 to 21 Year Old Adults

Chart 36: Proportion of Adult Fully Dual Eligible and MaineCare-only Eligible Members with ID/ASD between the Ages of 18 and 21 Compared to their Proportional Share of Medicare and MaineCare Expenditures, SFY 2010*



The majority (83%) of young adults between 18 and 21 years old are eligible for MaineCare only, while 17% are dually eligible for both Medicare and MaineCare. Both groups have similar per member per month expenditures.

* The population of adult MaineCare members with ID/ASD who were 18 to 21 years old was identified through MDS assessment data, MaineCare claims data from MeCMS, and OADS enrollment records for SFY 2010. 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.

18 to 21 Year Old Adults

Chart 37: Share of Total Annual Expenditures for Fully Dual and MaineCare-only Eligible Members with ID/ASD between 18 and 21 Years Old, by Service, SFY 2010 *

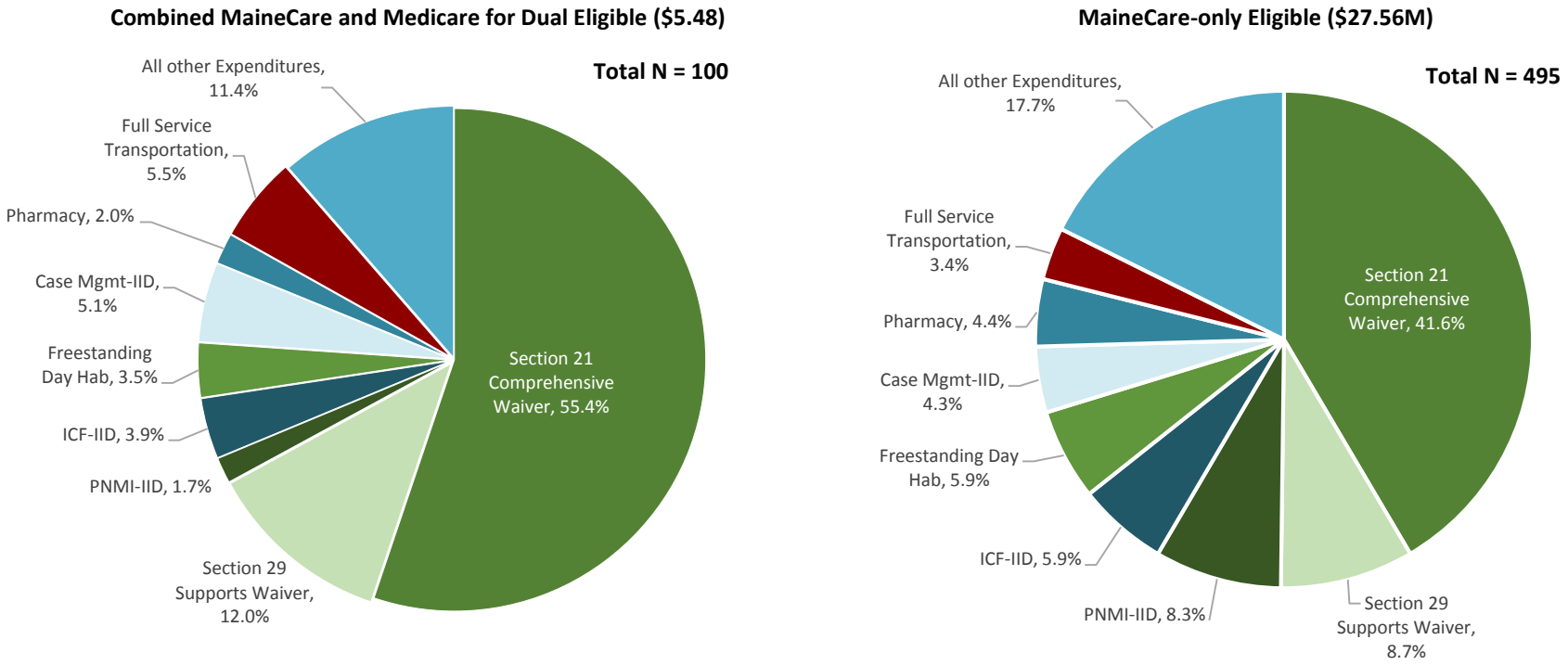


Chart 37 shows that the majority of expenditures (67.4%) for fully dual eligible members and half of expenditures for MaineCare-only members who were between 18 and 21 years old were for HCBS waiver services.

* The population of adult MaineCare members with ID/ASD who were 18 to 21 years old was identified through MDS assessment data, MaineCare claims data from MeCMS, and OADS enrollment records for SFY 2010. 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.

18 to 21 Year Old Adults

Table 10: Total Annual Expenditures for Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD between 18 and 21 Years Old by Service, SFY 2010*

	Fully Dual Eligible			MaineCare-only Eligible	Total MaineCare Combined
	MaineCare	Medicare	Combined		
Persons Served	**100**	**100**	**100**	**495**	**595**
Total Annual Expenditures	**$5,272,639**	**$207,315**	**$5,479,954**	**$27,561,166**	**$32,833,805**
Section 21 Comprehensive Waiver	$3,036,994	-	$3,036,994	$11,473,119	$14,510,113
Section 29 Supports Waiver	$654,999	-	$654,999	$2,396,511	$3,051,510
PNMI	$90,447	-	$90,447	$2,282,590	$2,373,037
ICF-IID	$214,005	-	$214,005	$1,621,630	$1,835,635
Freestanding Day Habilitation	$191,476	-	$191,476	$1,638,996	$1,830,472
Case Management-IID	$277,857	-	$277,857	$1,189,333	$1,467,190
Pharmacy	$107,754	-	$107,754	$1,207,344	$1,315,098
Full Service Transportation	$301,734	-	$301,734	$943,565	$1,245,299
All other Expenditures	$419,565	$207,315	$626,880	$4,881,124	$5,300,689

The table above shows the share of MaineCare and Medicare expenditures for the categories of services accounting for the largest expenditures by eligible population group. The column on the far right shows the combined MaineCare expenditures for both fully dual eligible and MaineCare-only eligible members. Medicare Part D pharmacy expenditures for fully dual eligible members are not included in the data.

* The population of adult MaineCare members with ID/ASD who were 18 to 21 years old was identified through MDS assessment data, MaineCare claims data from MeCMS, and OADS enrollment records for SFY 2010. 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.

18 to 21 Year Old Adults

Chart 38: Percentage of Adult Fully Dual and MaineCare-only Eligible Members with ID/ASD between 18 and 21 Years Old Using Select Services, SFY 2010*

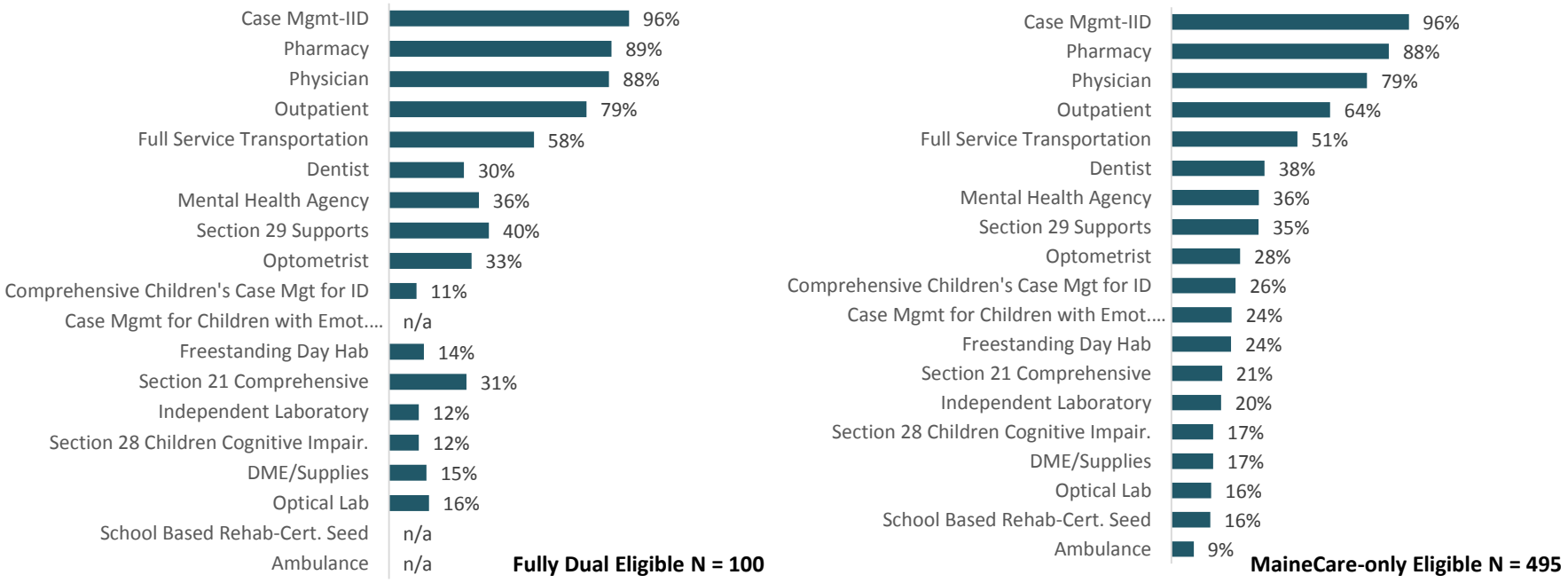


Chart 38 shows similar use patterns between fully dual eligible and MaineCare-only eligible 18 to 21 year-olds with ID/ASD. Over half of each group utilized full service transportation. Forty percent of fully dual eligible and 35% of MaineCare-only 18 to 21 year-olds chose to and were able utilize the Section 29 Supports waiver; and 31% of the fully dual eligible and 21% of the MaineCare-only group chose to and were able to utilize the Section 21 Comprehensive waiver. This chart shows the utilization of services throughout the year by anyone in this population group; therefore, there may be some members who utilized one of the waivers during one part of the year and the other waiver at a different part of the year.

Due to the small group of fully dual eligible adults age 18 to 21 with ID/ASD and privacy regulations, we are not able to show the percentage of service users of a particular service if the number of users is fewer than eleven individuals; these are marked by “n/a”.

* The population of adult MaineCare members with ID/ASD who were 18 to 21 years old was identified through MDS assessment data, MaineCare claims data from MeCMS, and OADS enrollment records for SFY 2010.

State-Funded Additional Services

In addition to Medicare and MaineCare services, some adults with ID/ASD may receive state-funded services that are administered through OADS/DS. In SFY 2010, there were 23 different services provided through fee-for-service contracts to adults with ID/ASD who were deemed by OADS/DS to have unmet need. These persons may be on the waitlists for waiver services or may be in the process of spending down resources to qualify for MaineCare.

Table 11: Number of Contractors who Provided State-Funded (Non-MaineCare) Activities or Services for Adults with ID/ASD with Unmet Need, SFY 2010[*]

Service/Activity	Number of Contractors Providing Services	Expenditures through Contracts
Recreation, Social Leisure	2	$19,145
Peer Support	1	$5,000
Case Management	2	$2,119,629
Respite	11	$911,572
Wraparound & Flexible Funds	1	$10,000
Community support	21	$171,089
Crisis	3	$2,360
Emergency Involuntary Admissions	1	$200,000
Clinical Consultation	2	$14,000
Diagnosis & Evaluation	14	$189,199
Residential Treatment	1	$10,000
Community Residential	10	$108,326
Supported Housing	27	$741,921
Supported Education	1	$68,494
Supported Employment	10	$164,105
Guardianship	2	$1,125
Interpretation & Communication Services	3	$21,000
Rental Subsidies	52	$3,977,336
Transportation	10	$109,288
Professional Services-Client Related	21	$171,089
Research, Evaluation, Training Staff	2	$68,304
Other	1	$104,232
Overhead	5	$30,165
Total Expenditures		**$9,729,751**

[*] Data are from the Office of Aging and Disability Services.

Section 5: Service Use and Cost Patterns of Maine Adults with ID/ASD on the Home and Community Based Waiver Waitlists, 2013

Adults with ID/ASD may qualify for developmental services provided by either the Section 21 Comprehensive or the Section 29 Supports waivers. However, there may not be a funded opening on the waiver available to them. In such cases, individuals are placed on a waiting list for waiver services as described in the first section of this chartbook. While on the waitlist, adults can avail themselves of many different MaineCare covered services, including developmental services such as case management, ICF-IID, and PNMI-IID services along with all general MaineCare services such as hospital, physician, and home care.

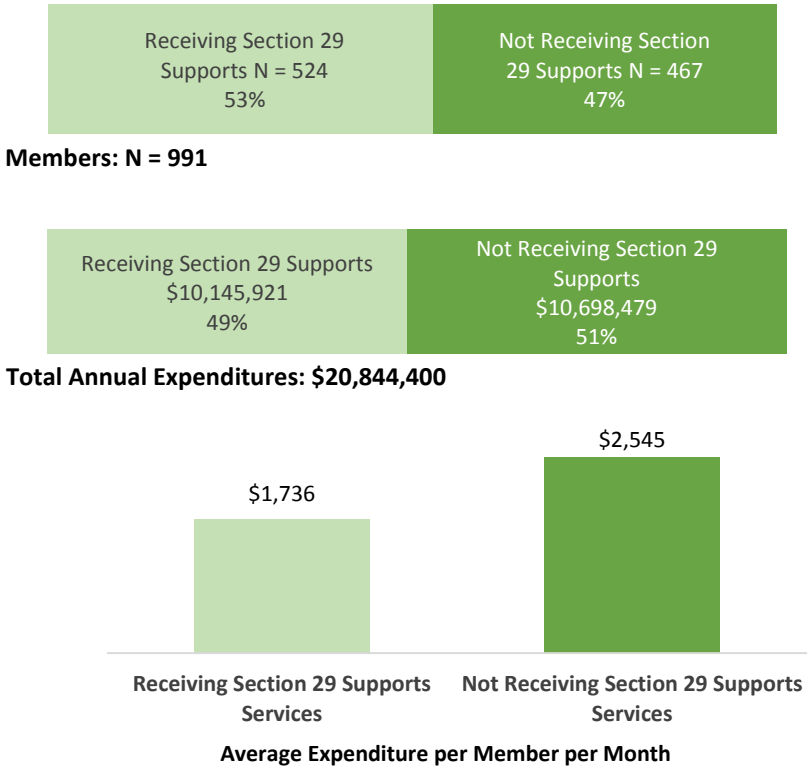
Notes on the analysis: The charts in this section describe the service use and cost of individuals who were on the waitlists for the two different waivers in 2013. For this analysis, we used a hierarchy similar to that used in the claims analysis in Section 3. Working under the assumption that the Section 21 Comprehensive waiver provides a more intense level of service, members who were on both waitlists at the same time, were deemed to be on the Section 21 Comprehensive waitlist for purposes of this analysis and excluded from the analysis of the Section 29 Supports waitlist. As the Section 29 Supports waiver requires participants to live either on their own or with family members, the members exclusively on this waitlist may have more natural supports that can be supplemented with waiver services than those who would also qualify for Section 21 Comprehensive services if an opening became available.

Waiver	Population Included in Analysis
Section 21 Comprehensive Waiver Waitlist	• Members already receiving Section 29 Supports services but who indicate a need for residential services through Section 21 • Members on both Section 21 and Section 29 waitlists • Members exclusively on the Section 21 Comprehensive waitlist
Section 29 Supports Waiver Waitlist	• Members exclusively on the Section 29 Supports waitlist

Section 21 Comprehensive Waitlist

To provide a complete picture of the service use and cost of members on the waitlist for Section 21 Comprehensive waiver services, the waitlist population was broken into two groups: 1) Members on the Section 21 Comprehensive waitlist who were already receiving Section 29 Supports waiver services, and 2) Members exclusively on the Section 21 Comprehensive waitlist plus members who were on both Section 21 Comprehensive and Section 29 Supports waiver waitlists. These two groups are identified in the following charts as either "Receiving Section 29 Supports Services" or "Not Receiving Section 29 Supports Services".

Chart 39: Proportion of Adults on the Waitlist for Section 21 Comprehensive Services, Receiving or Not Receiving Section 29 Supports Services, Compared to their Proportional Share of MaineCare Expenditures, SFY 2013*

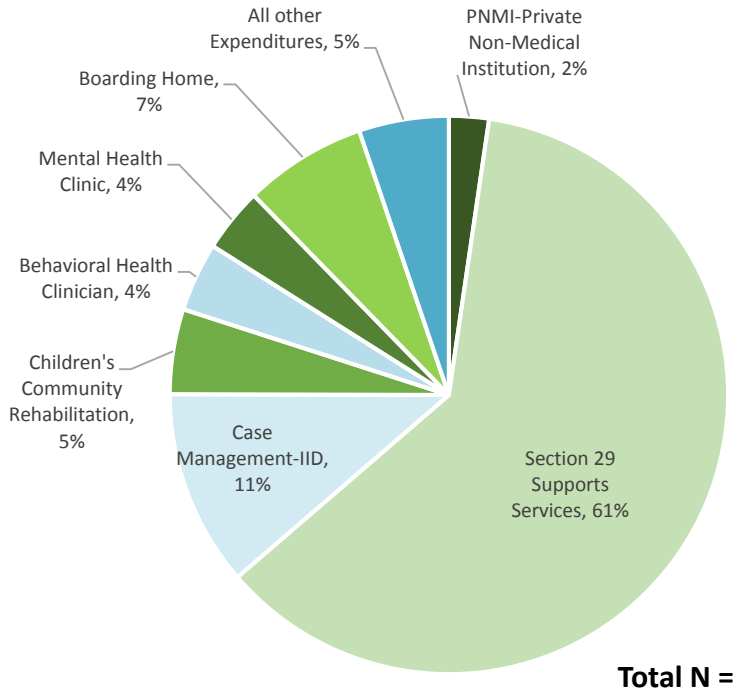


* Waitlist members were identified by OADS; MaineCare claims data are from the Maine Integrated Health Management Solution (MIHMS).

Section 21 Comprehensive Waitlist

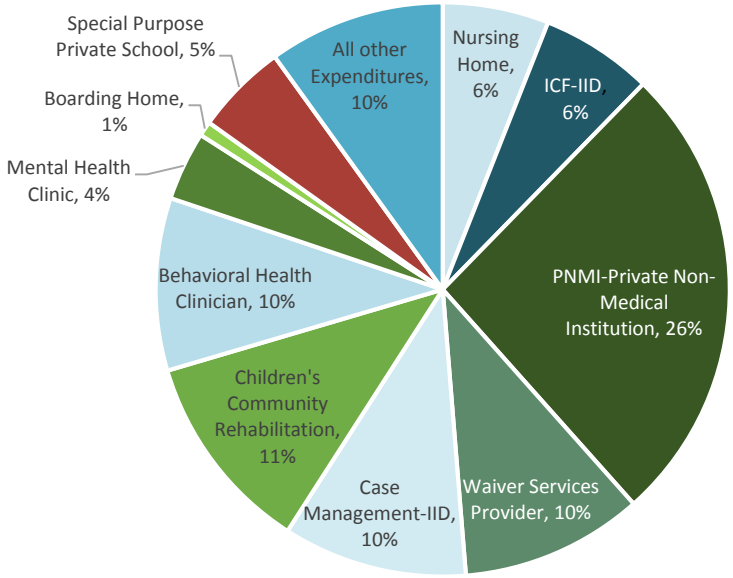
Chart 40: Share of Total Annual MaineCare Expenditures for Adults on the Section 21 Comprehensive Waiver Waitlist, by Service, SFY 2013*

Receiving Section 29 Supports Services ($10.15M)



Total N = 524

Not Receiving Section 29 Supports Services ($10.79M)



Total N = 467

Note that waiver services for members on the waitlist who are not receiving Section 29 Supports services are for services provided under one of the other home and community based waivers.

* Waitlist members were identified by OADS; MaineCare claims data are from MIHMS.

Section 21 Comprehensive Waitlist

Table 12: Total Annual Expenditures for Adults with ID/ASD on the Section 21 Comprehensive Waiver Waitlist, by Service, SFY 2013*

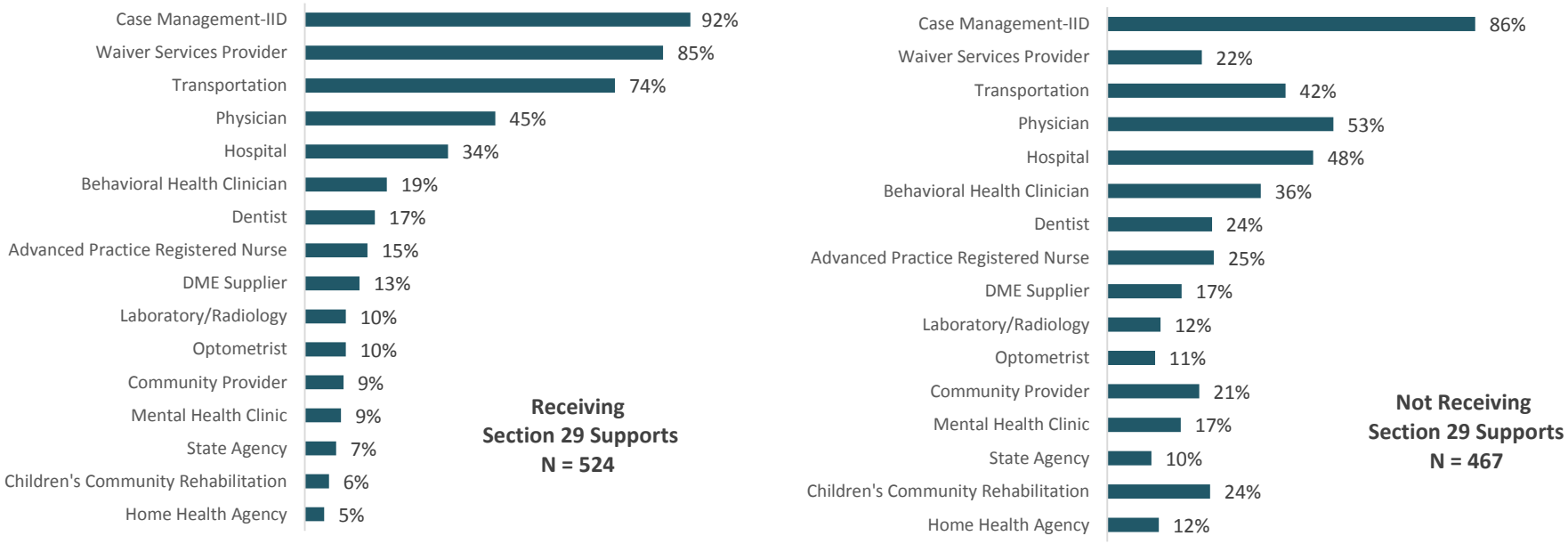
	Receiving Section 29 Supports Services	Not Receiving Section 29 Supports Services	Total MaineCare Expenditures
Persons Served	**524**	**467**	**991**
Total Expenditures	**$10,145,921**	**$10,698,479**	**$20,844,400**
Nursing Home	$19,349	$640,125	$659,474
ICF-IID	$24,406	$676,536	$700,942
PNMI-Private Non-Medical Institution	$232,595	$2,793,496	$3,026,092
Waiver Services Provider	$6,177,702	$1,101,048	$7,278,750
Case Management-IID	$1,143,941	$1,110,458	$2,254,399
Children's Community Rehabilitation	$495,968	$1,214,153	$1,710,120
Behavioral Health Clinician	$401,302	$1,039,641	$1,440,943
Mental Health Clinic	$375,143	$415,955	$791,098
Boarding Home	$715,749	$88,443	$804,192
Special Purpose Private School	$35,855	$554,044	$589,900
All other Expenditures	$523,911	$1,064,579	$1,588,490

Note that waiver services for members on the waitlist who are not receiving Section 29 Supports services are for services provided under one of the other home and community based waivers.

* Waitlist members were identified by OADS; MaineCare claims data are from MIHMS

Section 21 Comprehensive Waitlist

Chart 41: Percentage of Adults on the Section 21 Comprehensive Waitlist, Receiving or Not Receiving Section 29 Supports Services, Using Select Services, SFY 2013*



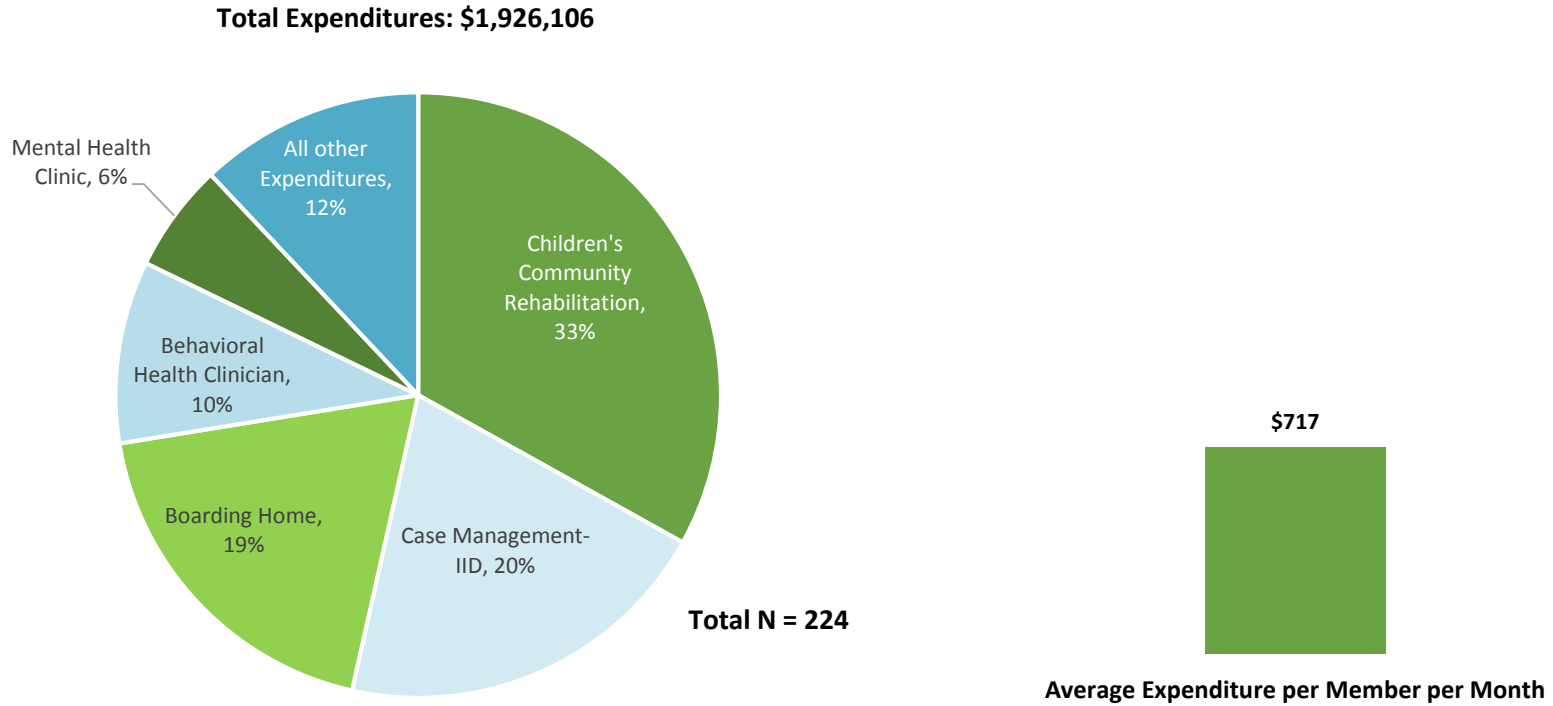
Adults with ID/ASD who are on the waitlist for Section 21 Comprehensive services utilize a wide variety of MaineCare covered services. The chart above shows select services that were utilized by at least 10% of either those who were already receiving Section 29 Supports services or those who were not receiving those services. For the latter category, it should be noted that the "Waiver Services Provider" indicates other MaineCare home and community based waivers. Additionally, while not shown on the utilization chart above, 8% of members on the Section 21 Comprehensive waitlist who were not receiving Section 29 Supports services utilized PNMI services which accounted for over 25% of this group's expenditures.

* Waitlist members were identified by OADS; MaineCare claims data are from MIHMS

Section 29 Supports Waitlist

The analysis of the Section 29 Supports waitlist focuses on the members who were on this waitlist exclusively, and not on the Section 21 Comprehensive waitlist as well. For the time period analyzed, there were 224 members on this waitlist, and total MaineCare expenditures for this group were $1,926,106.

Chart 42: Share of Total Annual MaineCare Expenditures for Adults on the Section 29 Supports Waiver Waitlist, by Service, and Average per Member per Month, SFY 2013*



* Waitlist members were identified by OADS; MaineCare claims data are from MIHMS

Section 29 Supports Waitlist

Table 13: Total Annual Expenditures for Adults on the Section 29 Supports Waiver Waitlist, by Service, SFY 2013*

	MaineCare Expenditures
Persons Served	**224**
Total Expenditures (in thousands)	**$1,926,105**
Children's Community Rehabilitation	$636,459
Case Management-IID	$392,885
Boarding Home	$364,196
Behavioral Health Clinician	$187,335
Mental Health Clinic	$111,562
All other Expenditures	$233,669

Table 13 shows the categories of services accounting for the highest expenditures for the population of adults with ID/ASD on the Section 29 Supports waitlist. Children's Community Rehabilitation services are provided to children with developmental disabilities up to age 21; these services accounted for one-third of the MaineCare expenditures incurred by adults on the Section 29 Supports waitlist.

* Waitlist members were identified by OADS; MaineCare claims data are from MIHMS

Section 29 Supports Waitlist

Chart 43: Percentage of Adults on the Section 29 Supports Waiver Waitlist Using Select Services, SFY 2013*

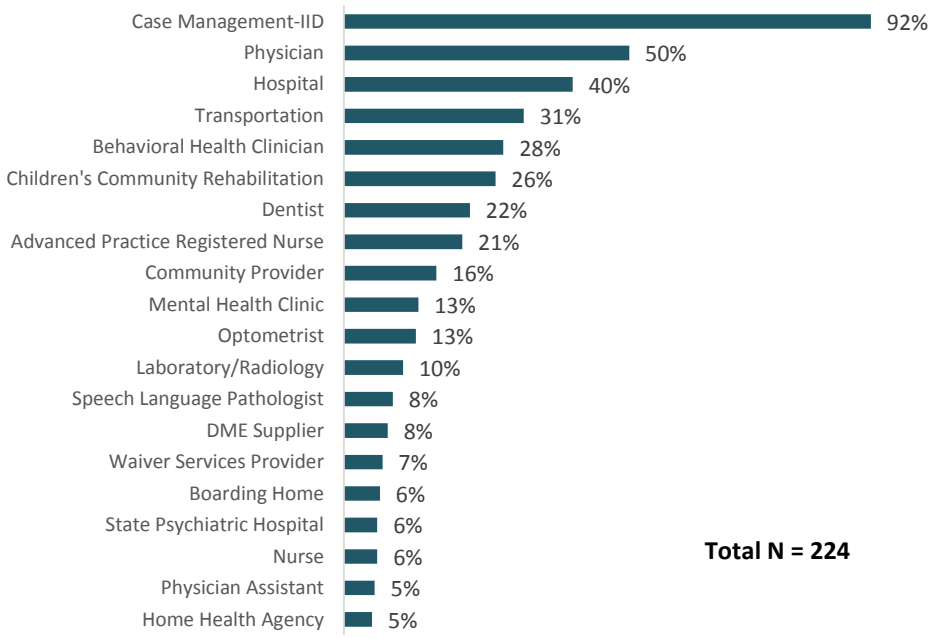


Chart 43 shows the utilization pattern of adults on the Section 29 Supports waitlist. Note that while 26% of this population used the Children's Community Rehabilitation services, they accounted for 33% of expenditures. And while 6% used Boarding Home services, they accounted for 19% of expenditures. Waiver Services in this chart include other MaineCare home and community based waivers that target vulnerable populations such as older adults and adults with physical disabilities.

* Waitlist members were identified by OADS; MaineCare claims data are from MIHMS

Emergency Room Use

Chart 44: Percentage of Adult Members with ID/ASD with Emergency Room Visits, by Residential Service Setting and Number of Visits, SFY 2010*

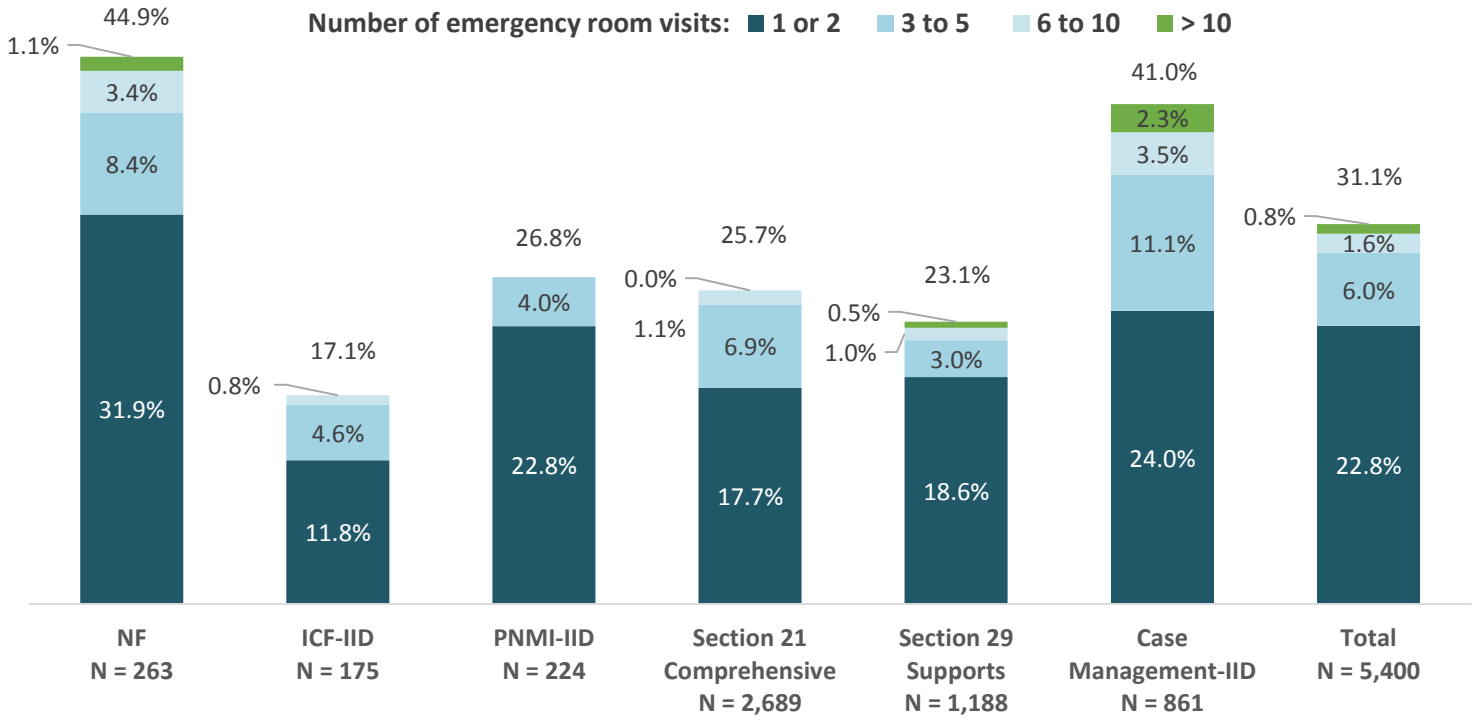


Chart 44 shows the emergency room usage by adult members with ID/ASD in 2010 across the different residential settings established by the claims analysis hierarchy used in Section 4. Members in the Case Management-IID category are those members with ID/ASD who did not use institutional or home and community based waiver services but who did receive case management services for adults with ID/ASD. This group had the second highest rate of emergency room use, behind those members in nursing facilities.

* 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.

Hospital Admissions

Chart 45: Percentage of Adults with ID/ASD with Hospital Admissions, by Residential Service Setting, SFY 2010*

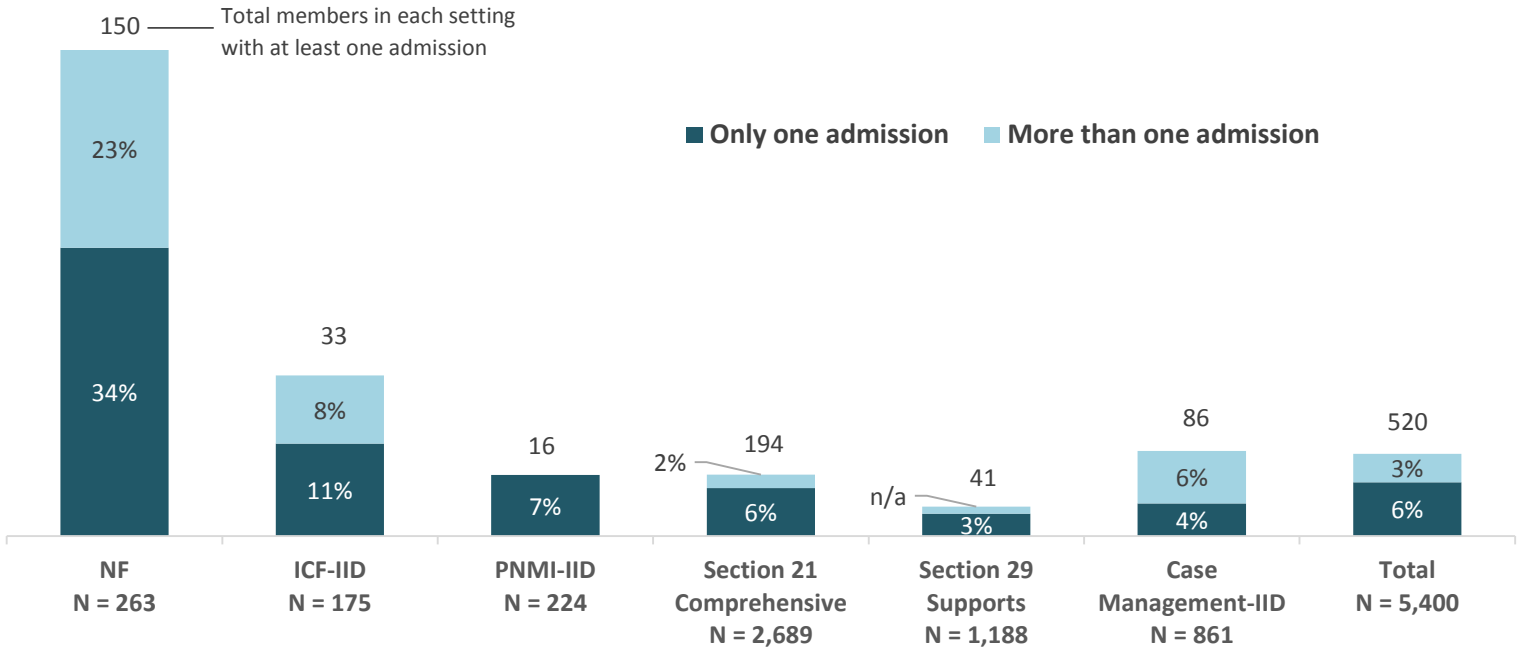
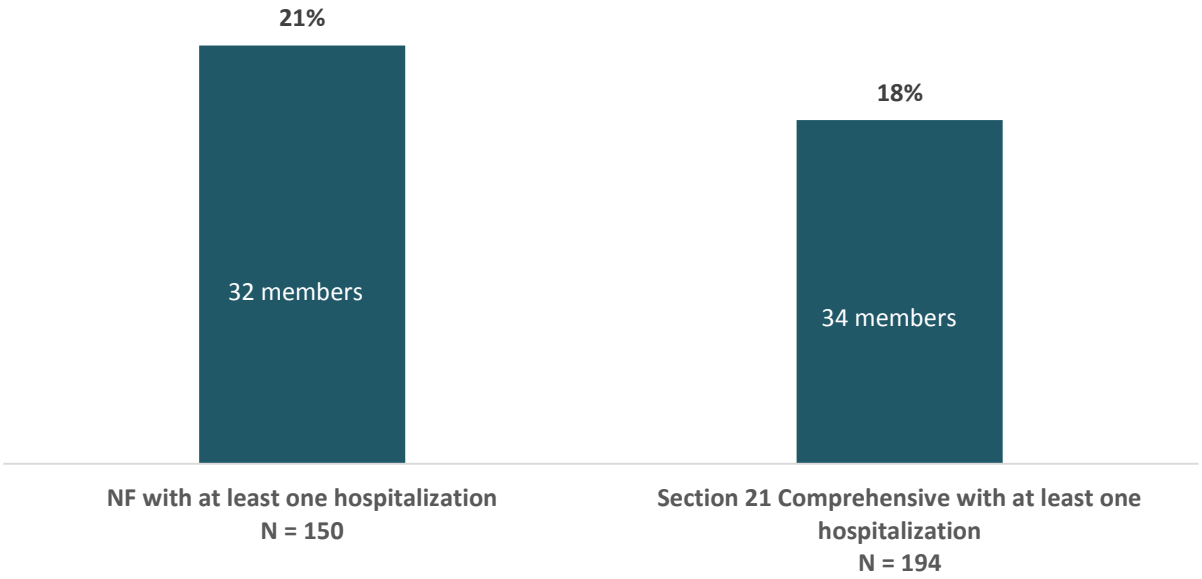


Chart 45 above shows the percentage of adult members with ID/ASD across the different residential service settings with hospital admissions in 2010. The total number of residents in each setting is listed below the setting name. The total number of people with at least one admission is listed above the setting column. For example, 150 members (or 57%) out of the 263 adults with ID/ASD in nursing facilities had at least one admission during the year. In this particular population, the hospital admission could have occurred prior to the nursing facility stay. Future analyses may include looking at the timing of the hospital admission as well as length of stay in the nursing facility. Members in the Case Management-IID category are those members with ID/ASD who did not use institutional or home and community based waiver services. Note that this group was the only one with a higher rate of having more than one admission during the year than having only one admission during the year. Due to privacy regulations, we are not able to show the percentage of service users if the number of users is fewer than eleven individuals; this is marked by "n/a".

* 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.

Hospital Readmissions

Chart 46: Percentage of Adult Members with ID/ASD with at least One Hospital Admission who were Re-hospitalized within 30 Days at Least Once, by Residential Service Setting, SFY 2010*



Building on the previous chart, the chart above shows that 32 members (21%) who had a nursing facility stay **and** who had at least one hospital admission during the year were re-hospitalized within 30 days of discharge. Likewise 34 members, or 18% of those on the Section 21 Comprehensive waiver who **also** had at least one hospital admission during the year were re-hospitalized within 30 days of discharge. The adults having a hospital discharge in the other populations groups (ICF-IID, PNMI-IID, Section 29 Supports waiver, and Case Management-IID) did not experience re-admissions within 30 days of discharge during the time period.

* 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.

Access to Preventive or Ambulatory Care

Chart 47: Percentage of Adult Members (age 20+) with ID/ASD Who Accessed Preventive/Ambulatory Care, SFY 2010*

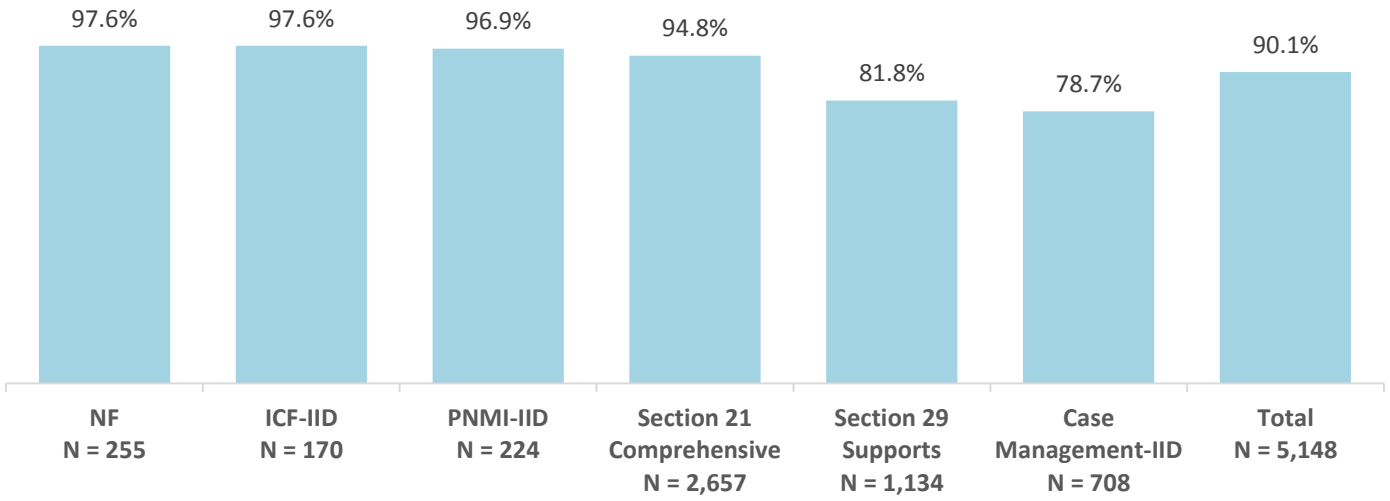


Chart 47 shows the HEDIS quality measure reflecting the percentage of adult members age 20 and older with ID/ASD who accessed preventive or ambulatory care. This care is defined as receiving services from a physician, nurse practitioner, ophthalmologist or optometrist at least once during the year. The population with the lowest access to these services is the group that received case management services for adults with ID/ASD but who did not receive any of the institutional or waiver services during the year. Note that the HEDIS measure specifies adults age 20 and older rather than those 18 and older. This lowers the total number of residents shown across the different residential settings than what is reported elsewhere in this chartbook.

* 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.

Section 7: The Supporting Individual Success Supports Intensity Scale in Maine

The Supporting Individual Success Supports Intensity Scale (SIS) assessment is a nationally recognized and normed tool that directly assesses a person's needs in daily life and the types of supports needed to maintain mental and physical well-being. The SIS assessment provides a measure of support needs in 57 "life activities" as well as 13 behavioral and 15 medical areas. Assessments are conducted through an interview with the individual and those who know the person well. Support needs in the areas of home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy are ranked on a scale of frequency, amount, and type of support needed. The results generate a Supports Intensity Level based on the Total Support Needs Index which is a standard score based on the scores of the scale[25].

More information about the SIS, its development, and assessment interview questions can be found on the American Association on Intellectual and Developmental Disabilities website: http://aaidd.org/sis/product-information#.U4YG_BAsOSq.

Maine has been using the SIS to assess the practical support requirements of adults with intellectual disabilities who are served by the Section 21 Comprehensive home and community based waiver, with the goal of creating a fair and equitable approach to allocating resources. Eventually, levels of need can be established that correspond to resources available to meet those needs. While implementation of the SIS is not complete at this time, an analysis of 2,209 individuals on the Section 21 Comprehensive waiver who were assessed between October 2012 and March 2014 was conducted by the Human Services Research Institute (HSRI) in April 2014. Some of the findings are summarized in this section.

Scores on the Support Need Index (SNI) reflect the level of support a person needs, with higher numbers indicating a higher need for support. Likewise, higher scores for the medical and behavioral need sections of the SIS indicate a higher need for extra support to address particular medical and behavioral conditions beyond what is covered by regular daily living supports.

Table 14: SIS Scores—Maine Compared to the National Norm, 2014*

	Number of Individuals	Support Need Index	Total Medical Score	Total Behavioral Need Score
Total - Maine	2,209	98.60	2.06	4.66
SIS Norm	1,306	100.00	3.23	4.99

The results of the SIS assessment show that Maine scored below the norm on each of the sections, meaning that individuals receiving Section 21 Comprehensive waiver services had fewer daily support needs, lower medical supports needs, and lower behavioral supports needs than the national norm.

* Presentation to the Maine Office of Aging and Disability Services by HSRI April 30, 2014.

Table 15: SIS Scores—Maine Compared to other States that have Implemented the SIS, 2014*

	SIS Supports Need Index	Total Medical Need Score	Total Behavioral Need Score
SIS Norm	100.00	3.23	4.99
New Mexico	106.72	3.18	5.12
Oregon	106.04	1.97	5.01
Utah	102.15	2.22	4.09
Rhode Island	102.02	1.99	4.00
Kentucky	99.76	1.92	4.28
Maine	**98.60**	**2.06**	**4.66**
Georgia	99.40	1.39	2.69
Louisiana	99.05	3.48	3.38
Colorado	97.49	2.99	5.55
New Hampshire	95.55	2.46	4.00

Of the states in Table 15, Oregon, New Mexico, Rhode Island, and New Hampshire are similar to Maine in that they also do not have large, public ICF-IIDs, and so, serve individuals with ID primarily in community settings through Medicaid home and community based service waivers. Of the non-ICF-IID states, only New Hampshire had a lower Supports Need Index than Maine.

* Presentation to the Maine Office of Aging and Disability Services by HSRI April 30, 2014.

Table 16: Maine SIS Scores by Waiver Service, 2014*

Waiver Service	Number of Individuals	Supports Need Index	Total Medical Need Score	Total Behavioral Need Score
Home Support	131	85.78	1.13	2.44
Home Support—Shared Living	218	95.55	1.62	3.58
Home Support—Family Centered	84	104.21	2.64	3.99
Agency Home Support	767	100.94	2.17	5.52
Other/Employment Only	28	85.79	.96	2.04

Table 16 shows the average SIS scores of people who use the different home support services available through the Section 21 Comprehensive waiver. The MaineCare Benefits Manual defines Home Support as direct support provided in a member's home by a Direct Support Professional to improve and maintain a member's ability to live as independently as possible in his or her own home. This type of home support can be provided in a Shared Living arrangement, a Family-Centered support model, or by an Agency.[23]

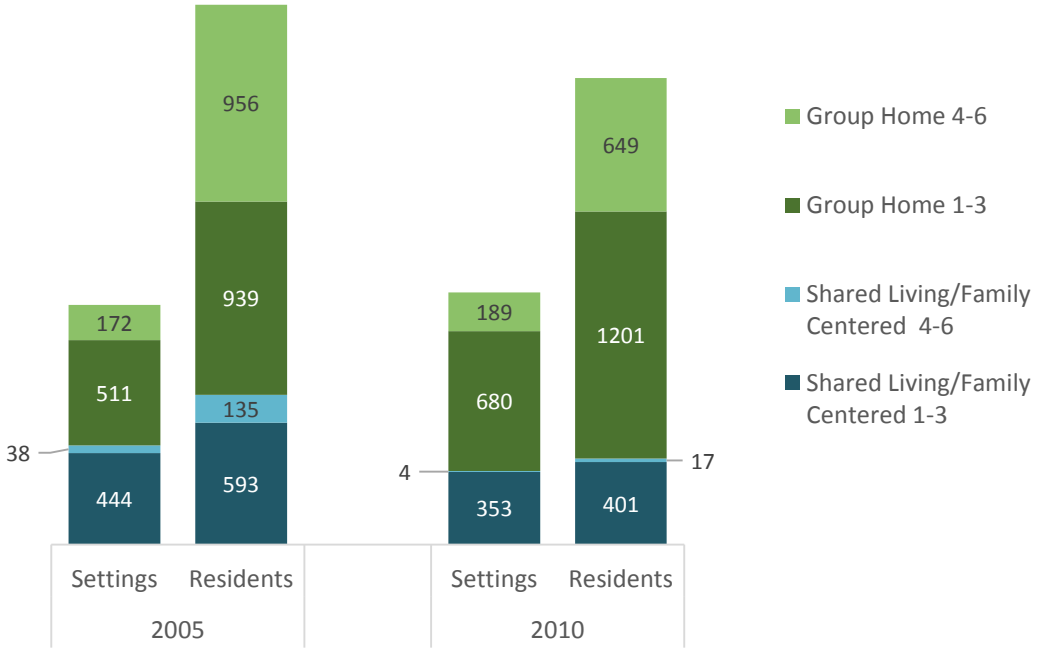
Table 16 shows that the individuals with the highest need use the Family-Centered model of Home Support, and the next highest need group uses Agency Home Support. Those living independently in their own homes and those using Other/Employment Services only have the lowest supports needs.

* Maine Supporting Individual Success: An Analysis of Individual Expenditures for those Receiving the Supports Intensity Scale. (Tualatin, OR: Human Services Research Institute). June 26, 2013.

Section 8: Historical Trends and Current Providers of ID/ASD Services in Maine

With the shift from institutional care to community based residential services for people with intellectual disabilities, the number and type of providers has changed over the years. This section describes the number of residential settings by type and size. Data on historical trends 2005-2010 are from the National Residential Information Systems Project (RISP) of the Research and Training Center on Community Living at the University of Minnesota.[26]

Chart 48: Number of Non-ICF-IID Out-of-Home Settings and the Number of Individuals they served in Maine for Selected Years, 2005 and 2010*



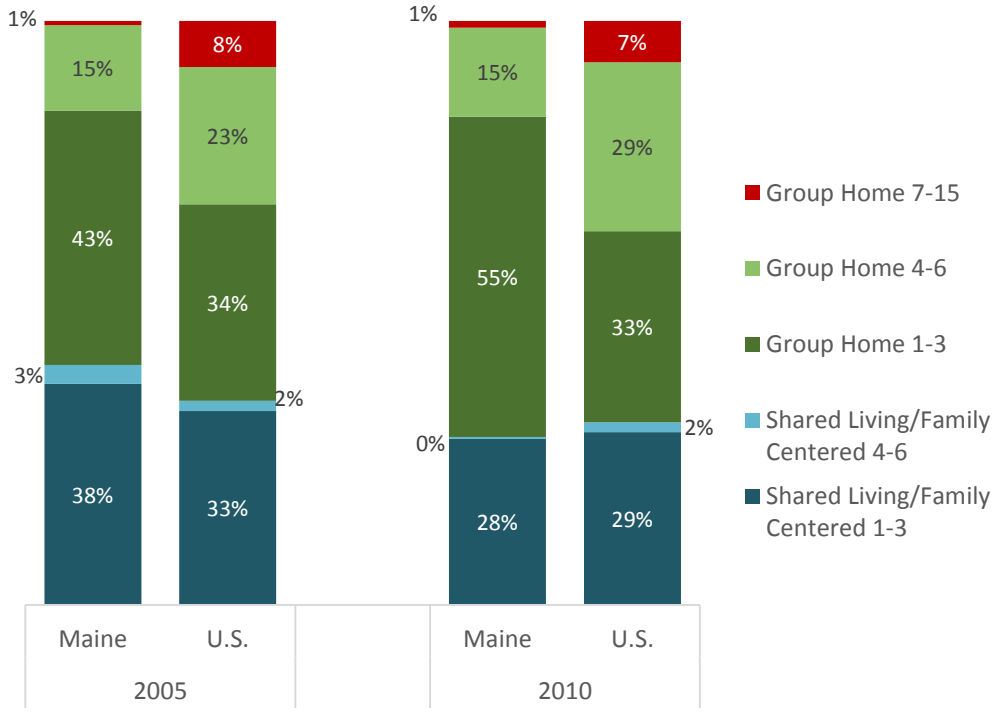
The number and type of facilities that serve individuals with intellectual disabilities has changed over the years with an increase in the number of providers serving 1 to 3 residents in a Group Home arrangements

Reflecting the changes in provider supply, the number of individuals served by facilities for one to three individuals has increased as well, with the percentage of people served by them growing from 58% in 2005 to 71% in 2010.

Note that new Family Centered providers have not been approved since 2007.

* 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.

Chart 49: Distribution of Types of Non-ICF-IID Out-of-Home Settings in Maine and the Nation, for Selected Years 2005 and 2010*



This chart shows that Maine has proportionally more providers serving one to three individuals than the national average. This distribution has been stable over the time period from 2005 to 2010. Roughly 80% of non-ICF-IID providers in Maine served one to three individuals whereas nationally, 60% of these providers served one to three individuals. The number of group homes serving 7-15 residents has been negligible in Maine during the time period, whereas nationally, these group homes make up about 7% of the out-of-home settings. Note that new Family Centered providers have not been approved since 2007.

* 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.

Chart 50: Percentage of Individuals Receiving ID/ASD Services Living in their Own Home or in the Home of a Family Member in Maine and the Nation, for Selected Years 2005 and 2010[*]

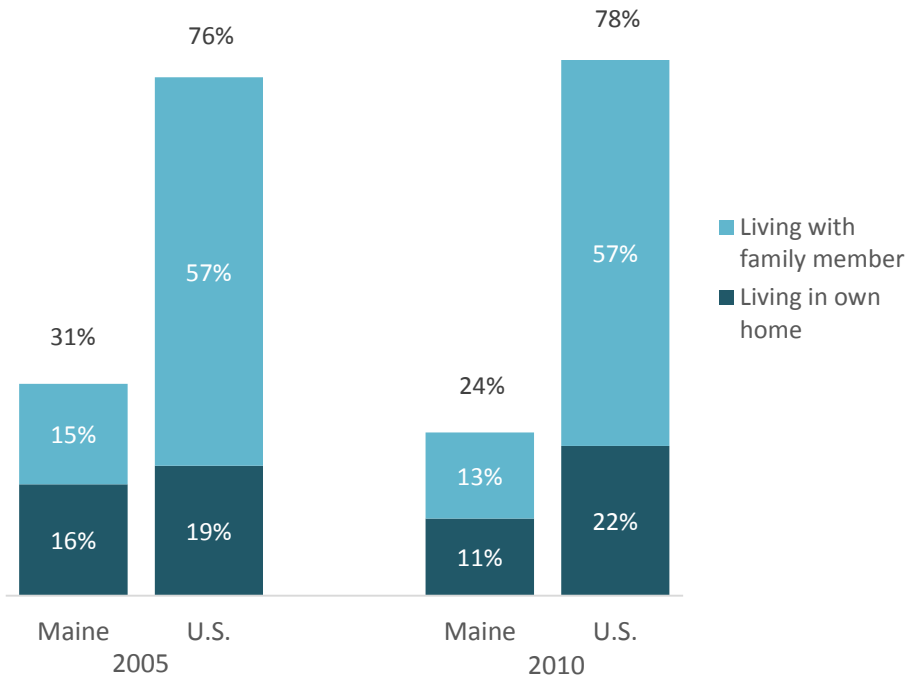


Chart 50 shows that Maine has had a much lower percentage of people receiving ID/ASD services who live either in their own homes or in the homes of family members, compared to the national average. In 2010 less than a quarter of Mainers with ID/ASD lived on their own or with family, compared to nearly 80% of people with ID/ASD nationwide.

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

Chart 51: Maine's 2014 Supply of ICF-IIDs and the Number of Residents Served*

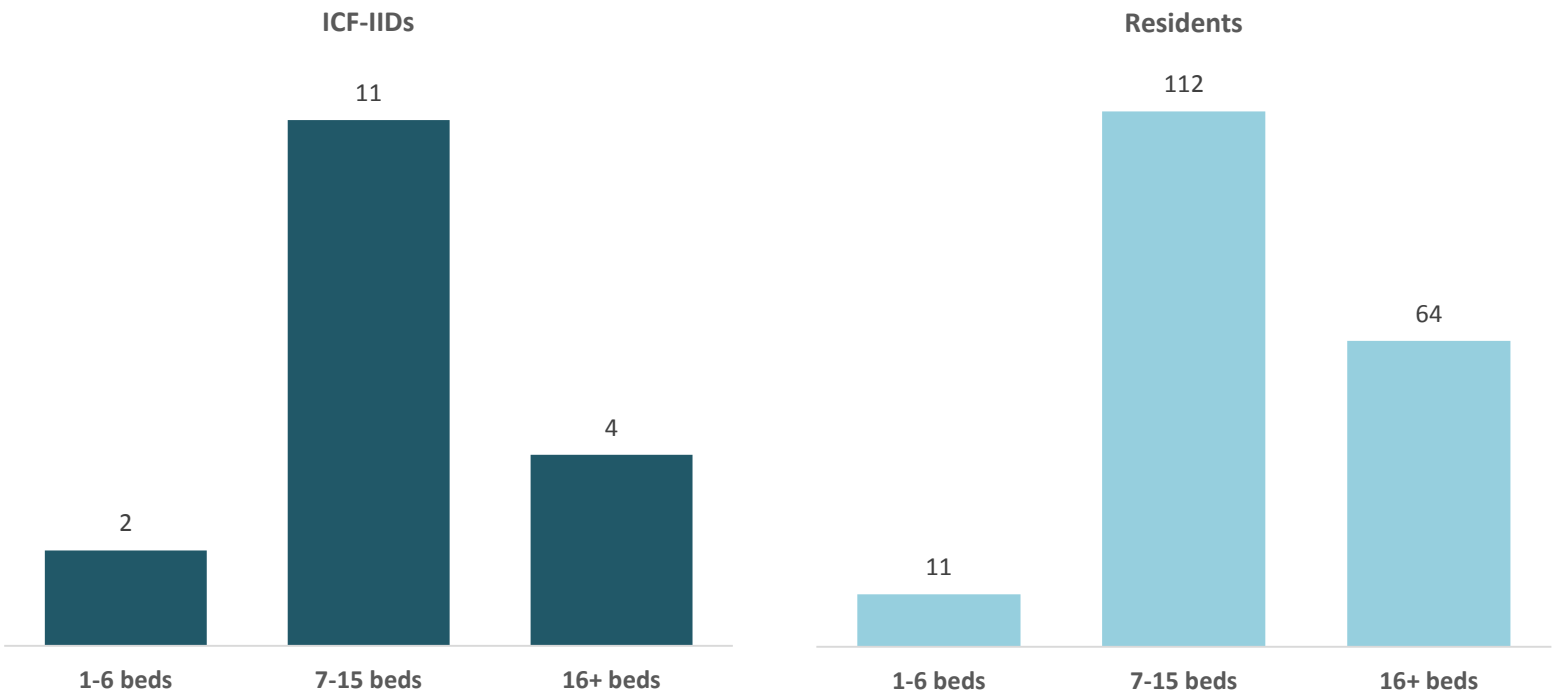


Chart 51 shows that the majority (11) of Maine's seventeen ICF-IIDs serve 7-15 residents. Of the 187 individuals living in an ICF-IID in March 2014, 60% were served in facilities with 7-15 beds, and 34% were served in facilities with 16 or more beds. Of the four large facilities, three were licensed to have 16 beds and one was licensed to have 17 beds.[27]

* 2014 data are from the Maine Office of Aging and Disability Services, Maine Department of Health and Human Services, e-mail communication received 2/19/2014.

Table 17: Providers Serving Individuals with ID/ASD by County, 2014*

	Community Support Providers	Shared Living Providers		Family Centered Providers (no new approved since 2007)					Agency Home Support Providers	PNMI-IIDs		ICF-IIDs	
										# of Facilities	Total # of PNMI-IID beds	# of Facilities	Total # of ICF-IID beds
County		One Person	Two Person	One Person	Two Person	Three Person	Four Person	Five Person					
Androscoggin	18	48		1					39	4	21	5	56
Aroostook	14	34	1	7	8	3	1	1	20	2	12	3	29
Cumberland	28	93		10	1				120	4	32	1	16
Franklin	13	12	1		1				14				
Hancock	7	12			1				7			1	15
Kennebec	20	33	1	5	4	1			29	6	42		
Knox	12	11	1	1	1				13	3	18	1	8
Lincoln	8	6	2		2				10				
Oxford	18	38		1	4				12	4	21		
Penobscot	15	84	1	16	5	1			103	2	10	2	31
Piscataquis	8	7							8				
Sagadahoc	12	8							14	1	6		
Somerset	15	20		1	3				18	5	30	2	30
Waldo	8	28		3	3				2				
Washington	7	23		3		1			5	2	12	1	7
York	18	80	1	6	3				69	1	6	1	5
Total	**206**	**537**	**8**	**54**	**36**	**6**	**1**	**1**	**483**	**34**	**210**	**17**	**197**

* Community Support Provider data are from the OADS Provider Directory at http://www.maine.gov/dhhs/oads/disability/ds/resource_directory/index.shtml accessed 5/22/2014; Shared Living, Family Centered, and Agency Home Support Providers are based on data from the Enterprise Information System received from the Office of Aging and Disability Services via e-mail communication on 5/1/2014; PNMI-IID data are from Office of Aging and Disability Services, e-mail communication received 5/20/2014; 2014 ICF-IID data are from the Office of Aging and Disability Services, e-mail communication received 2/19/2014.

Glossary

Terms Found in the Charts and Tables	
Boarding Home	This term appears in the 2013 MIHMS claims data and corresponds to the 2010 MeCMS provider specialty codes referring to either Appendix C PNMIs; Appendix F PNMIs or non-case-mixed medical and remedial facilities. They are private institutions that provide room, board, and services to residents. Room and board costs of residential care are paid for through state funds. https://mainecare.maine.gov/Provider%20Enrollment%20Guides/Special%20Tools/MIHMS_RG_0003_v7.0_20140605.pdf *retrieved 9/12/2014*
Case management for Children with Emotional Disturbance or Comprehensive Children's Case Management for Intellectual Disabilities-- available to adult members 18-20 years of age.	Services covered through Section 13 Targeted Case Management include "services provided by a social services or health professional, or other qualified staff, to identify the medical, social, educational and other needs (including housing and transportation) of the eligible member, identify the services necessary to meet those needs, and facilitate access to those services. Case management consists of intake/assessment, plan of care development, coordination/advocacy, monitoring, and evaluation." *MaineCare Benefits Manual Chapter II, Section 13*
Children's Community Rehabilitation -- available to adult members 18-20 years of age.	Treatment Services and Specialized Services for Children with Cognitive Impairments and Functional Limitations provided through Section 28 Rehabilitative and Community Support Services for Children with Cognitive Impairments and Functional Limitations: "medically necessary treatment services for members under the age of twenty one (21). Treatment services are designed to retain or improve functional abilities which have been negatively impacted by the effects of cognitive or functional impairment and are focused on behavior modification and management, social development, and acquisition and retention of developmentally appropriate skills. Services include problem solving activities in order to help the member develop and maintain skills and abilities necessary to manage his or her behavioral health treatment needs, learning the social skills and behaviors necessary to live with and interact with other community members and independently, and to build or maintain satisfactory relationships with peers or adults, learning the skills that will improve a member's self-awareness, environmental awareness, social appropriateness and support social integration, and learning awareness of and appropriate use of community services and resources." *MaineCare Benefits Manual Chapter II, Section 28*

Terms Found in the Charts and Tables	
Community Support	"Community Support is direct support provided by a Direct Support Professional in order to increase or maintain a member's ability to successfully engage in inclusive social and community relationship and to maintain and develop skills that support health and well-being. This is a habilitative service with a focus on community inclusion, personal development and support in areas of daily living skills if necessary." *MaineCare Benefits Manual, Chapter II, Section 29*.
DME/Supplies	Durable medical equipment and supplies are: "Equipment that can withstand repeated use; primarily used to serve a medical purpose and is medically necessary and reasonable for the treatment of the member's illness or injury or to improve an altered body function. Examples of items that are not primarily used for medical purposes include air conditioners, pools and exercise equipment, and equipment primarily used for the convenience of a caregiver; not generally useful to a person in the absence of illness or injury; and appropriate for use in the member's home or place of residence (excluding hospital settings) and is in safe and reasonably good condition and suitable for its intended use." *MaineCare Benefits Manual, Chapter II, Section 60.*
Free Standing Day Habilitation	Habilitation services provided to individuals with ID/ASD in nursing facilities or nursing level ICF-IIDs and others as required by the Preadmission Screening and Resident Review (PASRR) or Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) programs to assist the individuals attain the skills necessary to participate in the community. While this service provided through PASRR was called "Free Standing Day Habilitation" in 2010 (and referenced in the claims analysis section in this chartbook), it is currently known as "Specialized Services" when administered through PASRR. This type of service is also provided to participants of the Section 21 Comprehensive and Section 29 Supports waivers where it is known as Community Support.
Full Service Transport	Transportation to non-emergency medical appointments *MaineCare Benefits Manual, Chapter II, Section 113.*
Habilitation	Services that are "provided to assist a member to acquire a variety of skills, including self-help, socialization and adaptive skills. Habilitation is aimed at raising the level of physical, mental and social functioning of a member. Habilitation is contrasted to rehabilitation which involves the restoration of function that a person has lost." *MaineCare Benefits Manual, Chapter II, Section 29.*
Independent Laboratory	"An independent clinical laboratory is one which is not under direct jurisdiction of a hospital or the patient's attending physician." *MaineCare Benefits Manual, Chapter II, Section 55.*
Intermediate Care Facility for Individuals with Intellectual Disabilities ICF-IID	An ICF-IID "provides, under an agreement with the Department of Health and Human Services (DHHS), health-related care and a rehabilitative services program for members with mental retardation or members with related conditions who do not require the degree of care and treatment that a hospital or skilled nursing facility is designed to provide, but require care and services above the level of room and board." *MaineCare Benefits Manual, Chapter II, Section 50.*

Terms Found in the Charts and Tables	
Private Non-Medical Institution PNMI	"An agency or facility that is not, as a matter of regular business, a health insuring organization, hospital, nursing home, or a community health care center, that provides food, shelter, personal care, and treatment services to four or more residents in single or multiple facilities or scattered site facilities." *MaineCare Benefits Manual, Chapter II, Section 97.*
School Based Rehab-Certified Seed	Rehabilitation services provided by public schools and special purpose schools to children with ID/ASD through Rehabilitation and Community Support Services for Children with Cognitive Impairments and Functional Limitations, described in *MaineCare Benefits Manual, Chapter II, Section 28*.
Wheelchair Van	Transportation to non-emergency medical appointments *MaineCare Benefits Manual, Chapter II, Section 113.*

1. McGuire C, Gressani T, Bratesman S, Fralich J, Griffin E. *Members Dually Eligible for MaineCare and Medicare Benefits: MaineCare and Medicare Expenditures and Utilization, State Fiscal Year 2010.* Portland, ME: University of Southern Maine, Muskie School of Public Service; 2012. Chartbook; McGuire C, Bratesman S, Gressani T, Fralich J, Griffin E. *Children and Adults with Long Term Services and Support Needs: MaineCare and Medicare Expenditures and Utilization, State Fiscal Year 2010.* Portland, ME: University of Southern Maine, Muskie School of Public Service; 2012. Chartbook.
2. American Association on Intellectual and Developmental Disabilities. *Frequently Asked Questions on Intellectual Disability*. [Web Page]. 2013. Available at: http://aaidd.org/intellectual-disability/definition/faqs-on-intellectual-disability#..U39ZSBAsOSo. Accessed May 23, 2014.
3. The Arc. *Causes and Prevention of Intellectual Disabilities*. [Web Page]. 2011, March 1. Available at: http://www.thearc.org/page.aspx?pid=2453. Accessed May 23, 2014.
4. National Institute of Mental Health. *What Is Autism Spectrum Disorder?* [Web Page]. 2014. Available at: http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml. Accessed July 1, 2014.
5. Autism Speaks. *What Is Autism?* [Web Page]. 2014. Available at: http://www.autismspeaks.org/what-autism. Accessed May 23, 2014.
6. Centers for Disease Control and Prevention. *U.S. Surveillance of Health of People with Intellectual Disabilities: A White Paper.* Atlanta, GA: CDC, National Center on Birth Defects and Developmental Disabilities, Health Surveillance Work Group; 2009.
7. Cornell University. *Disability Statistics: Online Resource for US Disability Statistics*. [Web Page]. 2013. Available at: http://disabilitystatistics.org/reports/acs.cfm?statistic=1. Accessed May 27, 2014.
8. Larson, S. et al. Prevalence of Mental Retardation and Developmental Disabilities: Estimates from the 1994/1995 national Health Interview Survey Disability Supplements, *American Journal on Mental Retardation*, 2001, vol. 106, No. 3, 231-252.
9. CDC. *U.S. Surveillance of Health of People with Intellectual Disabilities…*2009; p. 4.
10. Bonardi A, Lauer E, Mitra M, Bershadsky J, Taub S, Noblett C. *Expanding Surveillance of Adults with Intellectual Disability in the US.* Boston, MA: Center for Developmental Disabilities Evaluation and Research, E.K. Shrive Center, University of Massachusetts Medical School; 2011.
11. Centers for Disease Control and Prevention. *Autism Spectrum Disorder (ASD): Data and Statistics*. [Web Page]. 2014, March 24. Available at: http://www.cdc.gov/ncbddd/autism/data.html. Accessed May 27, 2014.
12. Maine Department of Health and Human Services, Maine Department of Education. *Autism Spectrum Disorders Report: In Response to Legislative Directive, the Autism Act of 1984, 34-B M.R.S.A. §6001* Augusta, ME: Maine DHHS and Maine Department of Education; April, 2013.
13. Insel T, National Institute of Mental Health. *Director's Blog: Autism Prevalence: More Affected or More Detected?* [Web Page]. 2012. Available at: http://www.nimh.nih.gov/about/director/2012/autism-prevalence-more-affected-or-more-detected.shtml. Accessed May 27, 2014.

14. Maine DHHS. *Autism Spectrum Disorders Report*…2013; p. 9.

15. Griffin E, Fralich J, McGuire C, et al. *A Cross-System Profile of Maine's Long Term Support System: A New View of Maine's Long Term Services and Supports and the People Served.* Portland, ME: University of Southern Maine, Muskie School of Public Service and the Maine Department of Health and Human Services; 2009.

16. Office of Aging and Disability Services. *Olmstead Roadmap for Change: Update for Developmental Services.* Augusta, ME: Maine Department of Health and Human Services; March 18, 2014.

17. Office of Aging and Disability Services. Personal Communication with Muskie School of Public Service on October 14, 2014.

18. Office of Aging and Disability Services. Personal Communication with Muskie School of Public Service on October 17, 2014.

19. Pollack H, Kaiser Health News. *Social Security's Disabled Adult Child Program: A Key Option Often Below the Radar*. [Web Page]. 2010, September 6. Available at: http://www.kaiserhealthnews.org/Columns/2010/September/090610pollack.aspx. Accessed August 27, 2014.

20. Gilmer D. *Maine APSE Has Moved Employment First Forward: APSE Connections.* Rockville, MD: Association of People Supporting Employment First (APSE); September, 2013.

21. Harbour CK, Maulik PK. History of Intellectual Disability. In: Stone JH, Blouin M, eds. *International Encyclopedia of Rehabilitation*. Available at: http://cirrie.buffalo.edu/encyclopedia/en/article/143/. Accessed May 23, 2014.

22. Office of Aging and Disability Services. Personal Communication with Muskie School of Public Service on May 20, 2014.

23. Maine Department of Health and Human Services. *MaineCare Benefits Manual*. [Web Page]. 2014. Available at: http://www.maine.gov/sos/cec/rules/10/ch101.htm. Accessed May 27, 2014.

24. Tripp A, Folkemer D. *Model States' Supports Waivers*. Presented at the DDA Stakeholder Meeting. Hilltop Institute at the University of Maryland Baltimore County; May 30, 2012; Baltimore, MD.

25. American Association on Intellectual and Developmental Disabilities. *What Is SIS (Supports Intensity Scale)*. [Web Page]. 2013. Available at: http://aaidd.org/sis/product-information#.U4YHeBAsOSo. Accessed May 27, 2014.

26. National Residential Information Systems Project (RISP). *Tables 2.6, 2.7 and 3.1 in Residential Services for Persons with Intellectual and Developmental Disabilities: Status and Trends.* Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration; 2002, 2007, and 2013.

27. Office of Aging and Disability Services. 2014 ICF-IID Data. Personal Communication with Muskie School of Public Service on February 19, 2014.