3-11-2016

# Adults Using Long-term Services and Supports: Population and Service Use Trends in Maine, SFY 2014

Kimberly I. Snow MHSA, BA
*University of Southern Maine, Muskie School of Public Service*

Tina Gressani
*University of Southern Maine, Muskie School of Public Service*

Louise Olsen
*University of Southern Maine, Muskie School of Public Service*

Catherine McGuire BS
*University of Southern Maine, Muskie School of Public Service*

Stuart Bratesman MPP
*University of Southern Maine, Muskie School of Public Service*

*See next page for additional authors*

## Authors

Kimberly I. Snow MHSA, BA; Tina Gressani; Louise Olsen; Catherine McGuire BS; Stuart Bratesman MPP; Karen Mauney; and Jason Theriault

# CHARTBOOK

# Adults Using Long Term Services and Supports:

## *Population and Service Use Trends in Maine*

*State Fiscal Year 2014*

**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 Using Long Term Services and Supports: Population and Service Use Trends in Maine, SFY 2014


***Muskie School Project Staff***

Kimberly I. Snow, Project Director
Tina Gressani
Louise Olsen
Cathy McGuire
Stuart Bratesman
Karen Mauney
Jason Theriault

***DHHS Leads***

Gary F. Wolcott, Director, Office of Aging and Disability Services
Debra Halm
Kirsten Capeless
David Berry
Karen Mason
Jacqui Downing



*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 Using Long Term Services and Supports: Population and Service Use Trends in Maine, State Fiscal Year 2014. (Chartbook). Portland, ME: University of Southern Maine, Muskie School of Public Service; 2016. Available at http://muskie.usm.maine.edu/Publications/DA/Long-Term-Services-Supports-Use-Trends-Chartbook-SFY2014.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-15-9312.

# Foreword

The Maine Office of Aging and Disability Services is pleased to present this chartbook on Maine adults who use long term services and supports. This is the first chartbook to reflect all the populations served by our Office: older adults; adults with physical disabilities; adults with intellectual disabilities/autism spectrum disorder or other related conditions; and adults with acquired brain injury.

Long term services and supports are a vital lifeline for the thousands of Maine adults who need them, and they account for a significant portion of our MaineCare budget. In providing information about the demographic trends that impact our service system as well as data on the service utilization and expenditures, we hope to spur an exchange of ideas between policymakers, providers, consumers, and advocates so that we can continue to sustain our programs to ensure we meet the needs of Maine's vulnerable adults.

Gary F. Wolcott
Director, Office of Aging and Disability Services
Maine Department of Health and Human Services

# Notes on the Data

Many data sources were used to create this chartbook, and they are cited with the charts as they appear. Below is a summary of the different sources and where they appear in the document.

In general, the demographic data are from the U.S. Census Bureau; the Woods & Poole Economics, Inc. publication, "2015 New England State Profile: State and County Projections to 2050"[1]; and the Social Security Administration.

Information on the demographic and functional characteristics of Maine adults who used nursing facility, residential care, or home and community based services in state fiscal year 2014 are point-in-time counts of these users from the Minimum Data Set (MDS) and Medical Eligibility Determination (MED) assessments.

MaineCare claims data are from the Maine Integrated Health Management Solution (MIHMS), SFY 2014. The table in the Overview (table O.1) shows the total number of adult MaineCare members who used various long term services and supports (LTSS) and the expenditures on those services throughout the year.

We also created a hierarchy of LTSS users to conduct the claims analysis in Section 4. This analysis includes both LTSS expenditures as well as non-LTSS expenditures for users of long term services and supports. Thus, a direct comparison between the MIHMS data presented in the Overview and in Section 4 cannot be made.

A description of our process for identifying both LTSS expenditures as well as users in the MIHMS data for both the Overview and Section 4 can be found in Appendix A at the end of this chartbook.

## Table of Contents



## List of Figures

## List of Tables

# Overview

- Frailty that accompanies aging
- Chronic, disabling illness
- Physical disability
- Intellectual disability or autism spectrum disorder
- Acquired brain injury

These are factors associated with requiring long term services and supports. Thousands of adults with these conditions need help to accomplish activities of daily living (ADLs) such as getting out of bed, eating, bathing, dressing, or using the toilet. Many also need assistance with instrumental activities of daily living (IADLs) such as shopping, housework, paying bills, and preparing meals

**Older adults**, once they are 65 years old, have a 70% chance of requiring long term services and supports during their lives.[2]

**Younger adults with physical disabilities**, whether from chronic illnesses like diabetes, traumatic injury, or from congenital conditions such as muscular dystrophy, may require assistance from caregivers in their daily lives. While older adults comprise over half of the population needing long term services and supports, 42% are under 65 years old.[3]

***In Maine, 191,000 family caregivers provide daily assistance to adults with limitations in activities of daily living at an estimated annual value of $2.3 billion.***

While many **adults with intellectual disabilities**, **autism spectrum disorder** (ID/ASD) or **other related conditions** may live on their own with minimal support, others require constant supervision or more substantial help with everyday tasks.

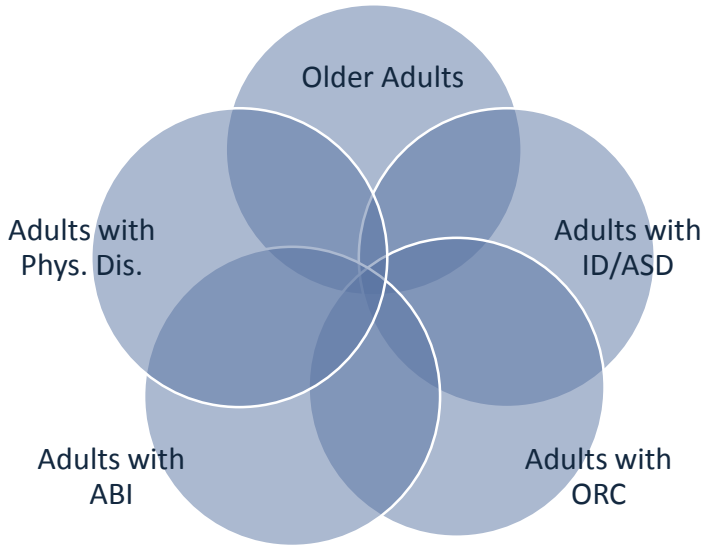
**Acquired brain injury** can affect a person's thinking, motor function, sensation, communication skills and emotional health to a degree requiring ongoing assistance and therapies in order to maintain independence and relationships with family and community. It can also cause epilepsy and increase the risk of developing other brain disorders such as Alzheimer's or Parkinson's disease.[4]

Informal, unpaid support from family and friends enables many adults with long term services and supports needs to stay in their own homes. In fact, the AARP estimates that in Maine, at any given time, there are 191,000 family caregivers providing assistance to adults with limitations in activities of daily living. This translates to an estimated annual value of $2.3 billion.[5]

However, there are times when formal support from professional caregivers either in the community or other residential setting is needed.

The Maine Office of Aging and Disability Services (OADS) manages services for many people who require LTSS. Eligibility for different services depends on a person's diagnosis, level of care need, and financial circumstance. Some adults may qualify for services from multiple programs within OADS. The diagram below shows how the different populations may overlap. The services available to these groups, most of which are covered by MaineCare, are also likely to overlap.

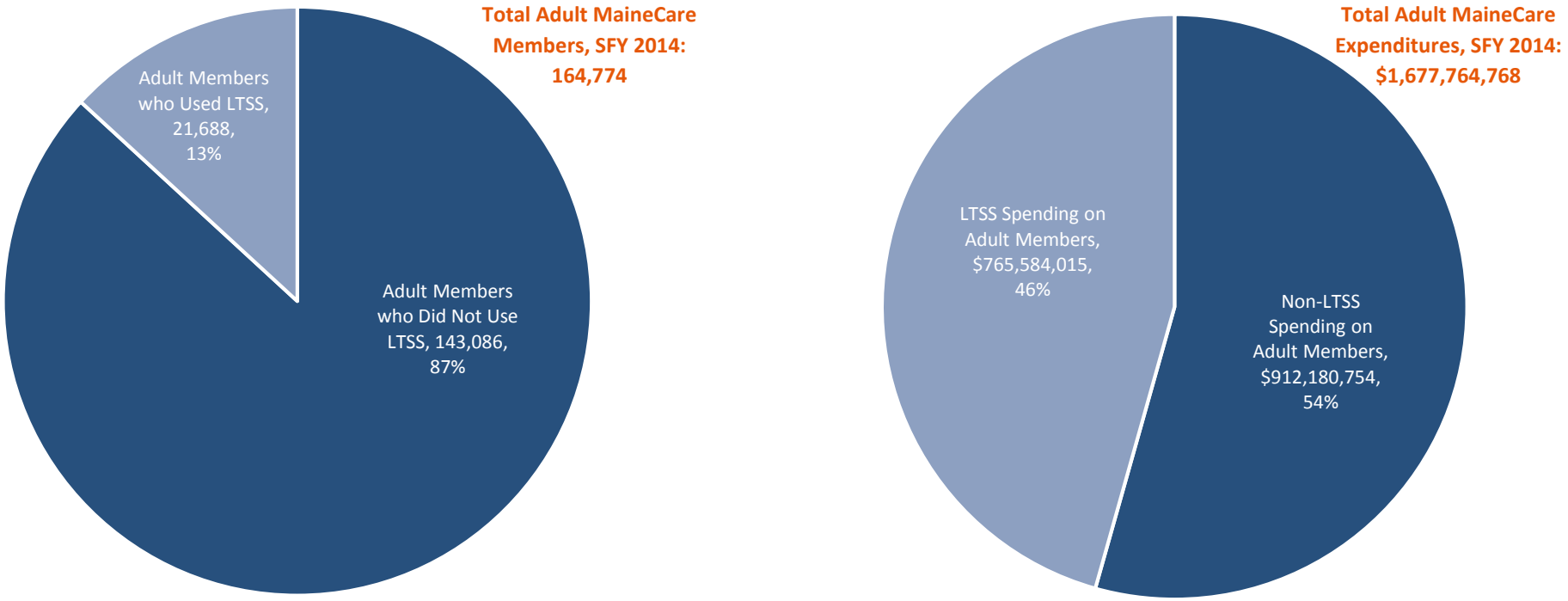
***Figure O.1 Office of Aging and Disability Services Populations, Programs and Services***




| Long Term Services and Supports Categories |
|---|
| Nursing facilities (NF) |
| Intermediate care facilities for individuals with intellectual disabilities (ICF-IID) |
| Residential care facilities serving older adults and adults with physical disabilities, intellectual disabilities or autism spectrum disorder (ID/ASD) or other related conditions (ORC), acquired brain injury (ABI), substance abuse, mental illness, or adults served by Adult Protective Services. |
| Adult family care homes |
| Assisted living facilities |
| Rehabilitation services for adults with acquired brain injury |
| MaineCare home and community based waivers for adults needing institutional level of care |
| MaineCare private duty nursing/personal care services |
| MaineCare consumer directed attendant services |
| MaineCare day health services |
| MaineCare case management for adults with intellectual disabilities |
| State funded consumer directed attendant services, adult day health, homebased care, homemaker services, respite, and others. |
| Meals on Wheels |

MaineCare is the dominant payer of LTSS, and the expenditures are a significant portion of all MaineCare spending on adults. In 2014, 13 percent of adult MaineCare members used LTSS, and spending on LTSS services accounted for 46% of all adult MaineCare expenditures.

***Figure O.2 Adult MaineCare LTSS Members and Expenditures as Proportions of all Adult MaineCare Members and Expenditures, SFY 2014****




Note: Adults using LTSS also account for some non-LTSS spending as well. But for most LTSS users, the majority of their MaineCare expenditures are for the LTSS services themselves. More information on MaineCare service utilization by LTSS users can be found in Section 4.

* Adult Members (age 18 as of 7/1/13) with Full MaineCare eligibility and expenditures identified in MIHMS, SFY 2014; expenditures on the Section 20 ORC waiver obtained from OADS via email communication, 11/10/2015.

*Table O.1 MaineCare Expenditures for LTSS, SFY 2014*[*]

| LTSS Settings and Programs | Distinct Members in Each Group | Total MaineCare LTSS Expenditures |
|---|---|---|
| Nursing Facility | 7,885 | $238,792,775 |
| Nursing Facility ABI | 27 | $1,466,241 |
| ICF-IID (Nursing) | 172 | $31,537,519 |
| ICF-IID (Group) | 29 | $4,809,899 |
| Residential Care Facility Appendix C | 4,387 | $86,707,619 |
| Residential Care Facility Appendix F, by population served: | | |
| • Acquired Brain Injury | • 119 | • $10,045,621 |
| • Adult Protective Services | • 57 | • $3,489,468 |
| • Developmental Disability | • 213 | • $9,376,980 |
| • Mental Health | • 27 | • $1,077,599 |
| Section 19 Elder and Adults with Disabilities Waiver | 1,594 | $30,078,029 |
| Section 20 Adults with Other Related Conditions Waiver[†] | NA | $282,268 |
| Section 21 Comprehensive ID/ASD Waiver | 3,070 | $279,669,485 |
| Section 22 Physically Disabled Waiver | 156 | $4,986,843 |
| Section 29 Supports ID/ASD Waiver | 1,772 | $28,539,203 |
| Consumer Directed Attendant Services | 602 | $4,738,152 |
| Adult Family Care Home | 317 | $4,810,366 |
| Private Duty Nursing | 2,770 | $15,657,480 |
| Home Health Services | 1,992 | $3,004,427 |
| Hospice | 736 | $2,302,230 |
| Adult Day Health | 66 | $245,177 |
| Case Management-ID/ASD[‡] | 2,131 | $3,635,438 |
| Money Follows the Person | 21 | $331,195 |
| **Total** **Distinct LTSS Users** | **21,688** | **$765,451,217** |

The table on the left shows the MaineCare expenditures for predominant LTSS settings and programs in SFY 2014 for adult members. Note that members may have used multiple types of LTSS during the year; the total Distinct LTSS Users is a unique count of users during the year and not a sum of the middle column.

Long term services and supports are critical to the well-being and independence of many adults in Maine, and it is important that Maine's LTSS system continues to evolve to meet their needs. This chartbook describes

- Maine's aging population and other disability-related demographics
- Characteristics of the populations using LTSS programs in Maine
- The MaineCare expenditures and utilization rates of MaineCare services among users in different LTSS settings, and
- Quality of care indicators among users of different LTSS settings

It is our hope that this chartbook informs the discussion among policymakers, providers, consumers, and advocates as they work together to ensure that Maine's system of LTSS meets the needs of all its citizens.

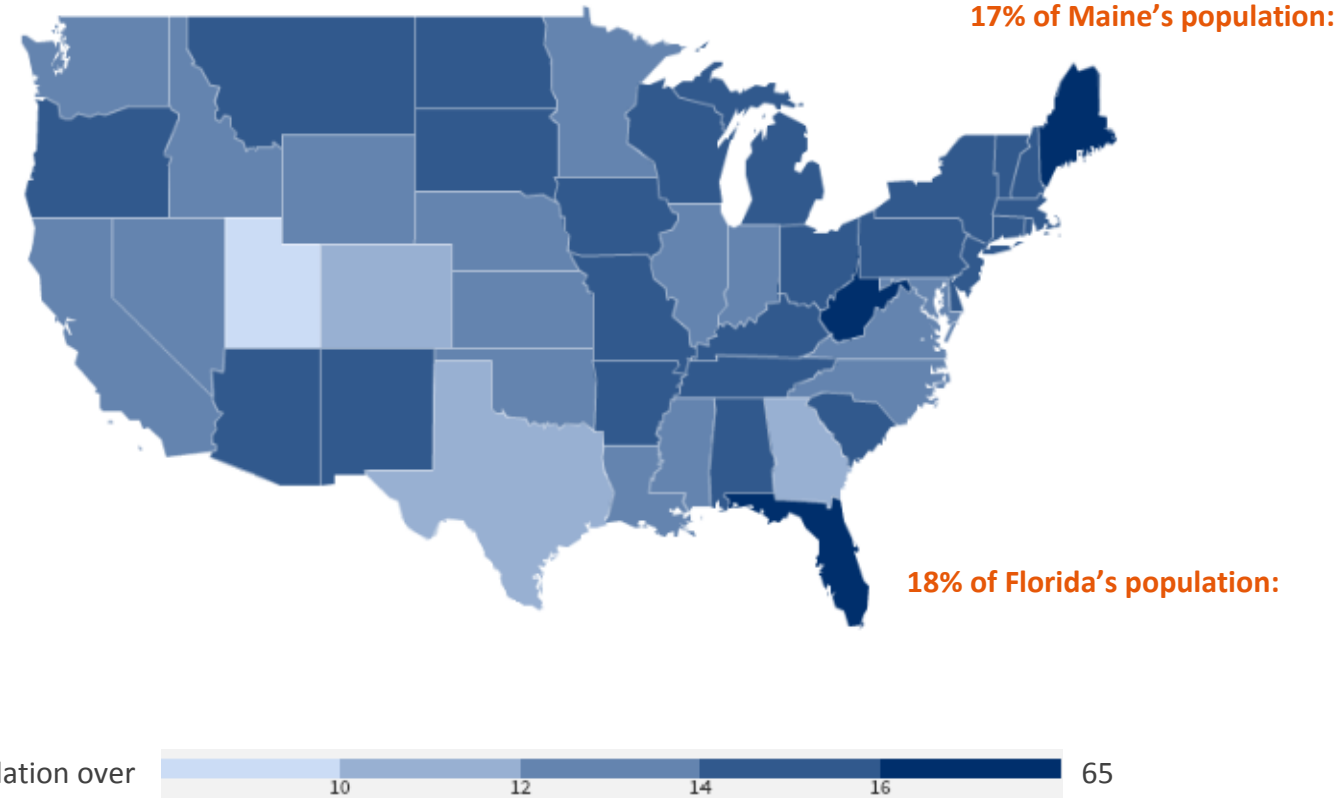
[*] Adult Members (age 18 as of 7/1/13) with Full MaineCare eligibility and expenditures identified in MIHMS, SFY 2014.

[†] Fewer than 11 people received LTSS services paid for through the ORC waiver; privacy regulations prohibit us from publishing the number. Total expenditures for this waiver were obtained from OADS via email communication, 11/10/2015; this does not include expenditures for members with ORC that were paid for through the Money Follows the Person program as they transitioned to the waiver.

[‡] Case management ID/ASD services are also provided to all adults on the ID/ASD waivers; they are counted in the waiver cells on this table, and not in the case management line.

# Section 1: Demographic Trends in Aging Affecting the LTSS System

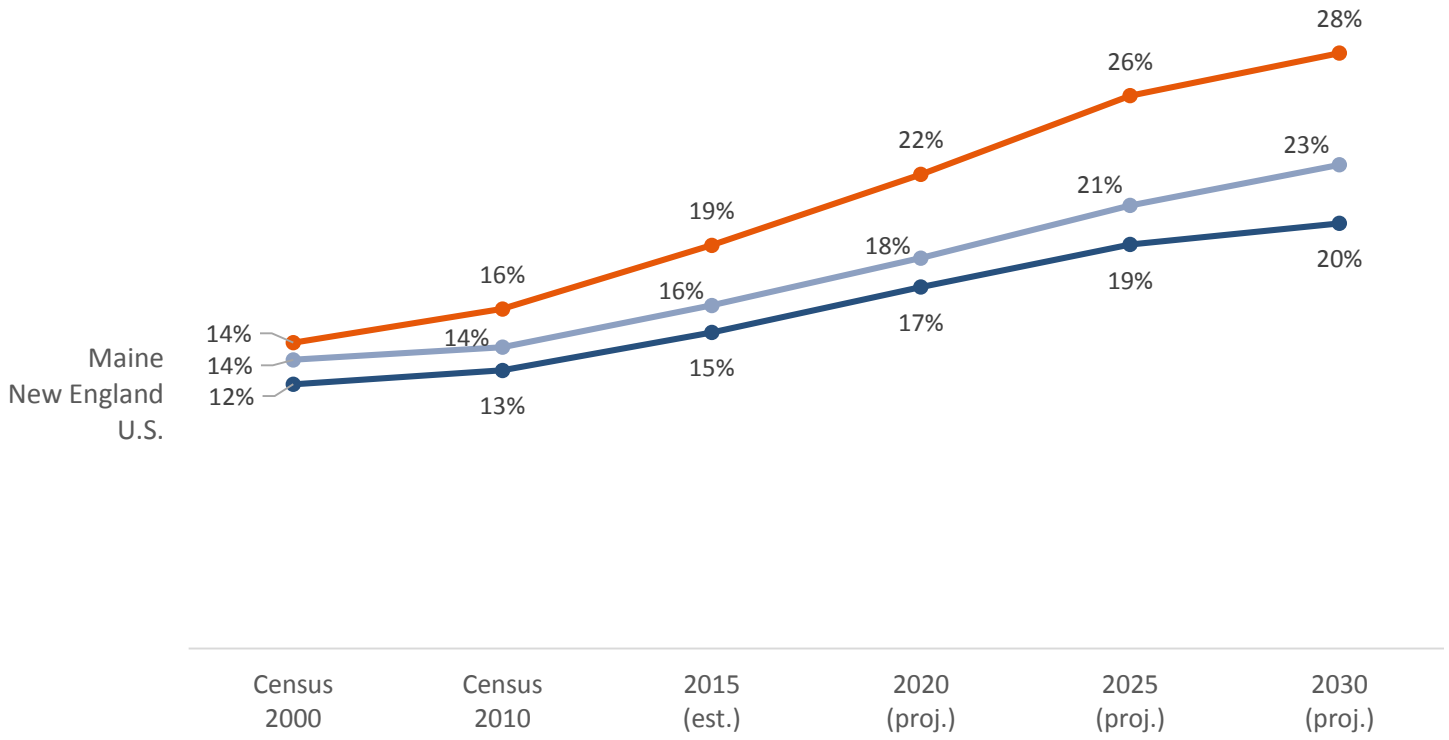
***Figure 1.1 Percentage of United States Population over 65 in 2013*** [*]




In 2013, Maine was the second oldest state with 17% of the population over 65. Florida was the oldest state with 18% of the population over 65.

[*] "More than 65 Years, 2011-2013." Map. Social Explorer, 2014. Website. Retrieved from http://www.socialexplorer.com November 6, 2014.

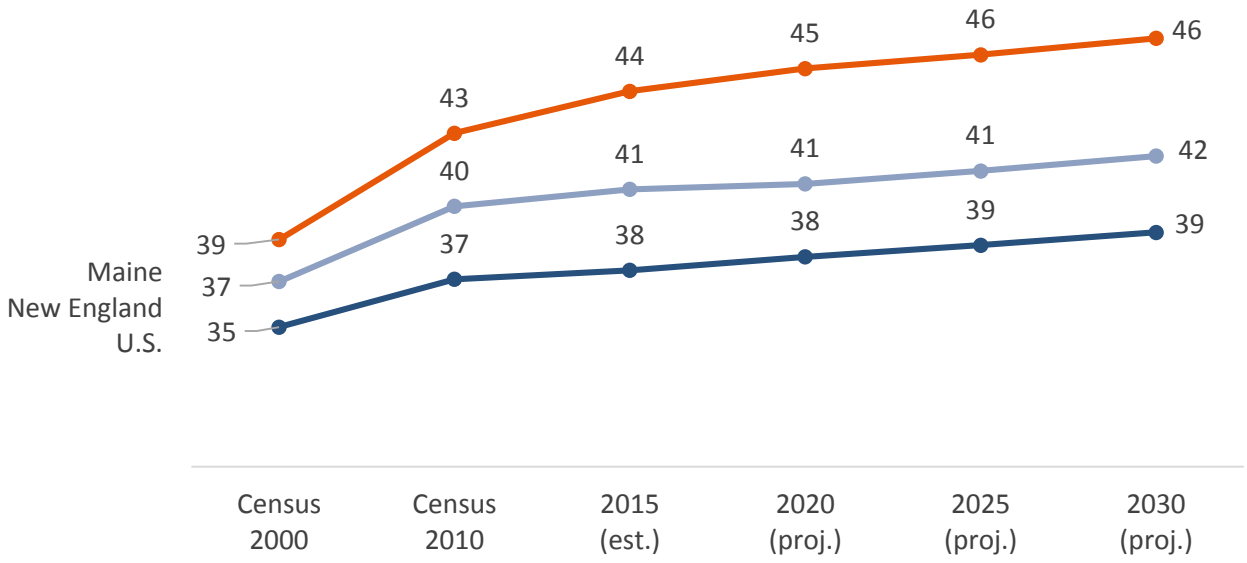
***Figure 1.2 Historical and Projected Trends in the Percentage of Population 65 and Older, Maine, New England, and the United States, 2000-2030 [*]***




The population of adults age 65 and over is expected to rise significantly in the future. The 2015 estimate of the percentage of Maine's population 65 and older is 19%. This population is projected to grow at a faster rate than either the New England region or the national average over the next fifteen years, reaching 28% of the state's population by 2030.

[*] 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

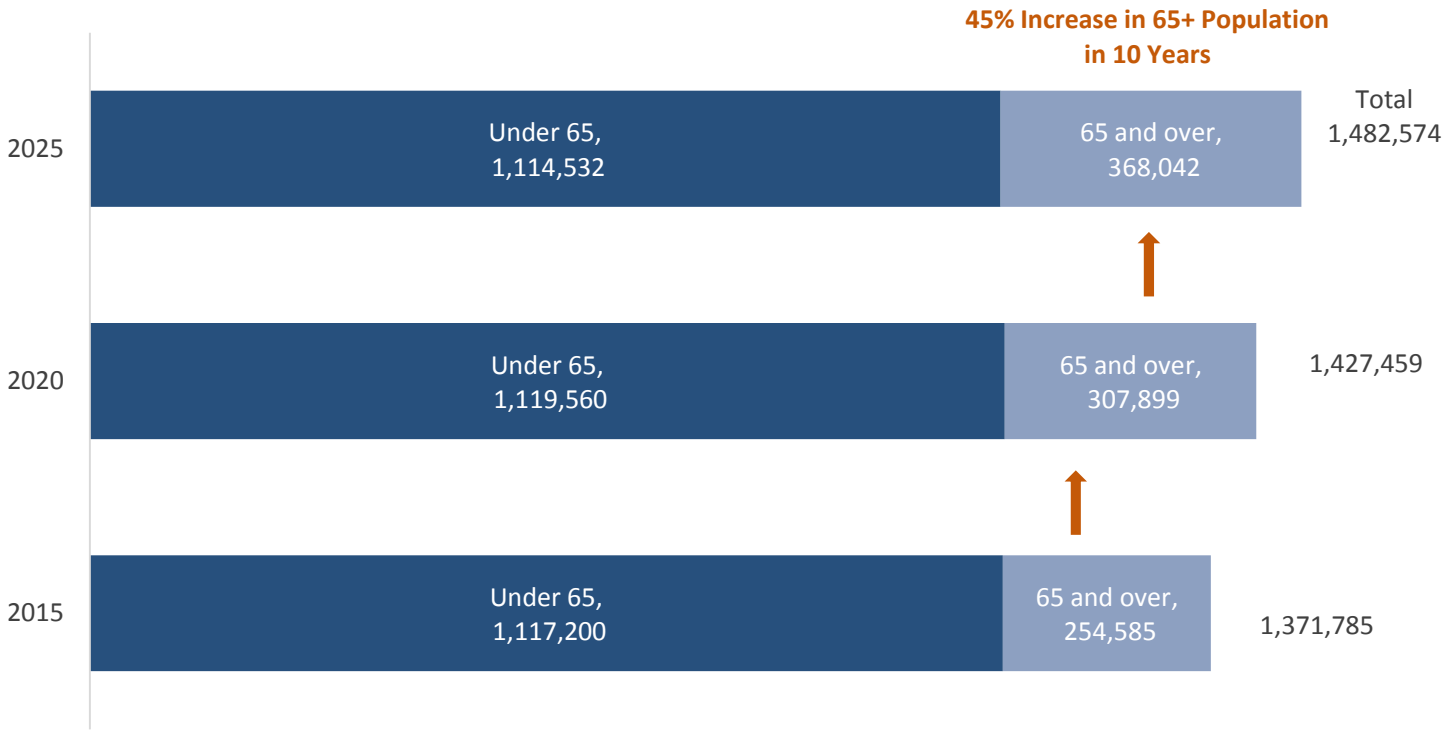
***Figure 1.3 Historical and Projected Trends in the Median Age, Maine, New England, and the United States, 2000-2030****




The 2010 Census showed Maine to have the highest median age in the country at 43 years old. In comparing Maine to New England and the nation, between the 2000 Census and the 2010 Census, Maine aged faster than either the New England or national average; Maine's median age rose by over 4 years compared to just under 3 years in New England and just under 2 years nationwide. By 2030, Maine's median age is projected to be 46 years compared to 39 nationwide.

* 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

*Figure 1.4 Projected Maine Population under and over 65, 2015, 2020, and 2025* [*]




Maine's population age 65 and over is expected to grow by more than 110,000 (a 45% increase) over the next 10 years. In contrast, Maine's population under 65 is expected to decrease slightly (-2.6%).

[*] 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

***Figure 1.5 Projected Maine Population by Age Group in 2015, 2020, and 2025****

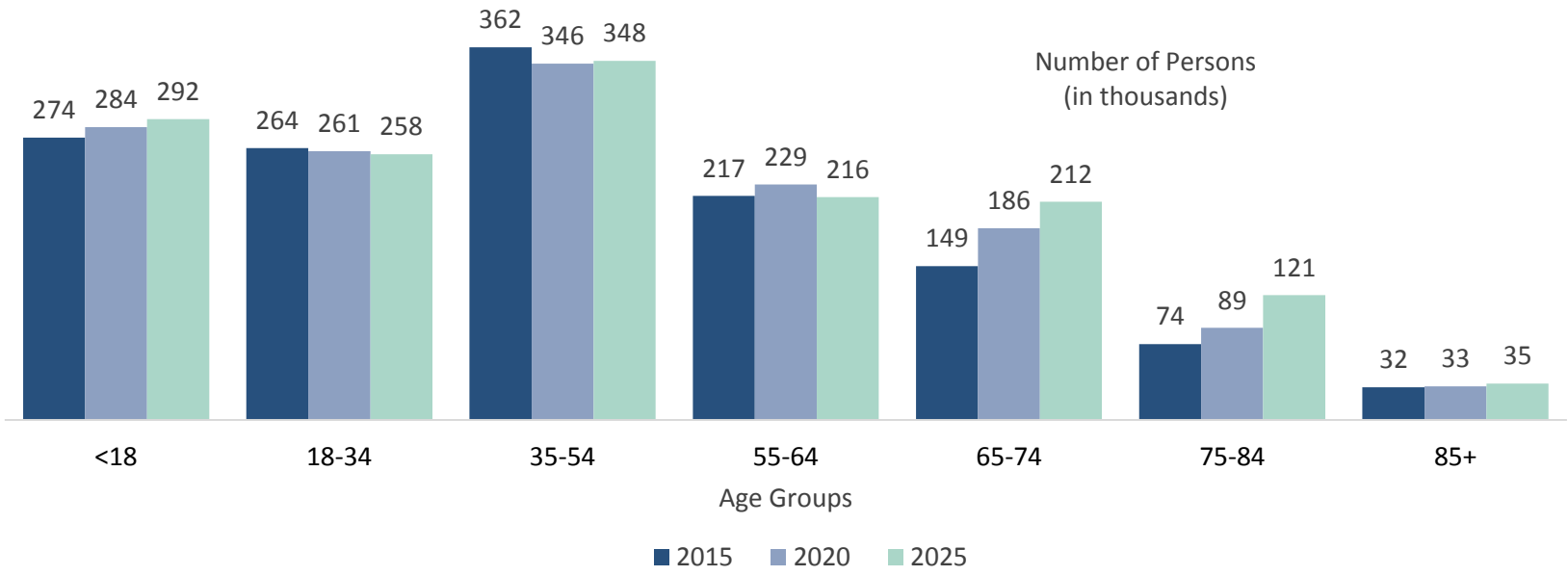
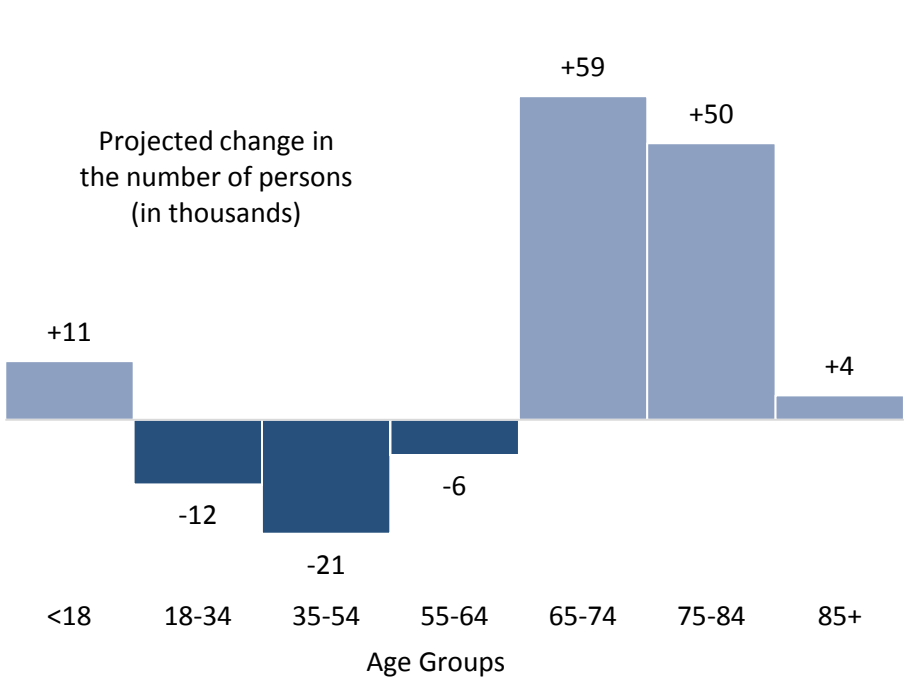
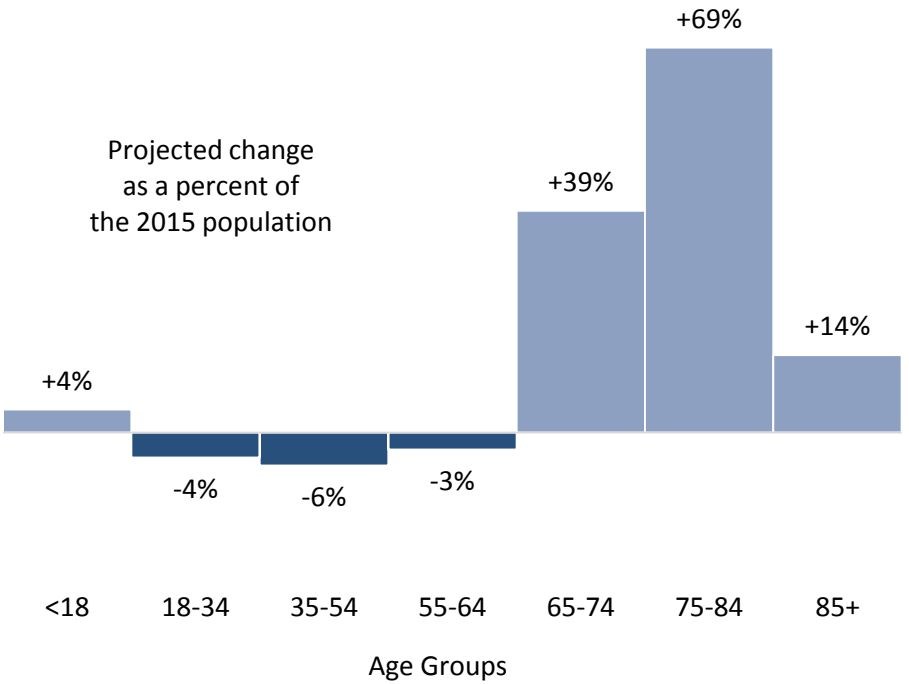



Figure 1.5 shows projected changes in Maine's population over the next 10 years by age group. The population age 65 through 84 is projected to experience the most growth over the time period, while the younger adult population is expected to decrease.

* 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

***Figure 1.6 Projected Change in the Number and Percentage of Maine's Population by Age Group, 2015 to 2025****

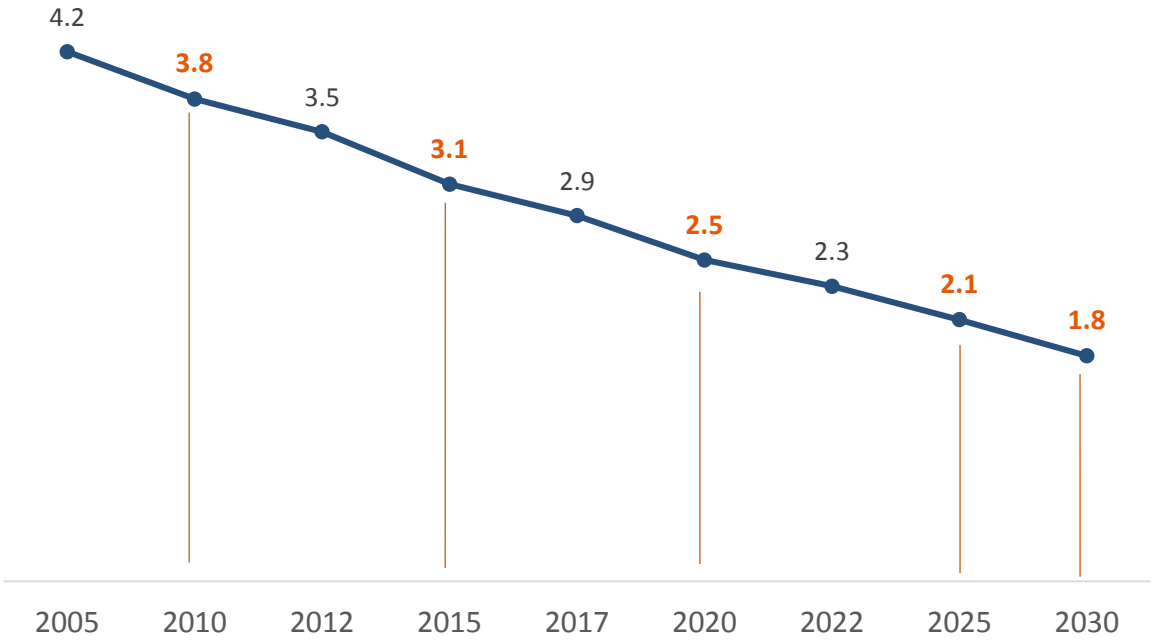



Over the ten year period from 2015 to 2025, the 65 to 74 year old age group is projected to grow the most, increasing by 59,000 (a 39% increase in that population). And the population in the 75 to 84 year old age group will increase by 50,000 (a 69% increase). The number of Mainers age 85 and over, the age group with the highest demand for long term services and supports will grow by 4,000 persons (a 14% increase).

* 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

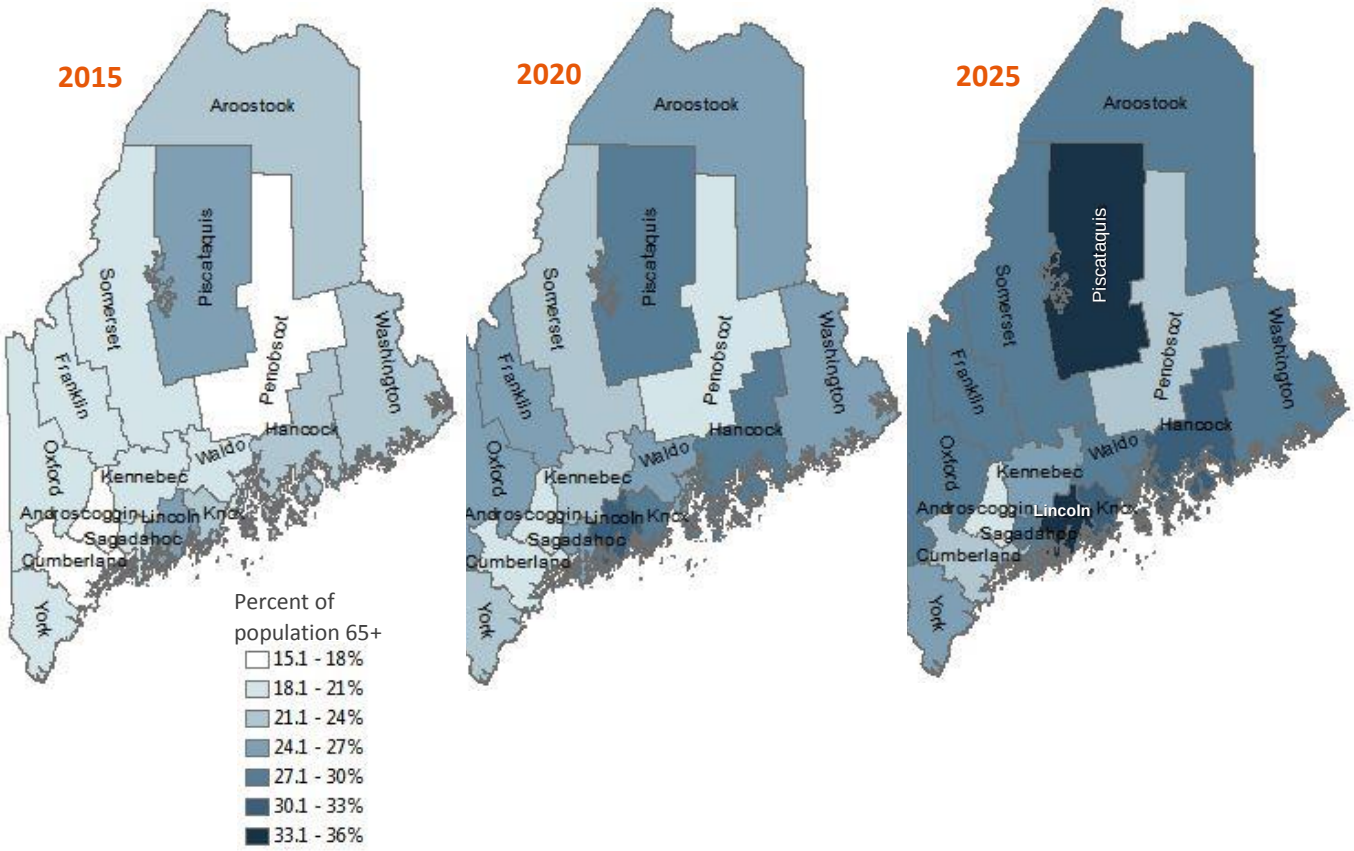
***Figure 1.7 Maine's Historical and Projected Dependency Ratio– Number of Working Age (20-64) per One Person Age 65+, 2005 to 2030 [*]***




The number of working age (20-64) people per one person age 65 and over is also expected to continue its downward trend as the number of people over 65 outpaces the younger population. By 2030, the ratio is expected to reach 1.8 working age people per one person 65 and over, less than half of what it was in 2010.

[*] 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

*Figure 1.8 Projected Percent of Maine's Population 65+ in 2015, 2020, and 2025, by County**




| County | 2015 | 2020 | 2025 |
|---|---|---|---|
| **Maine** | **19%** | **22%** | **26%** |
| Androscoggin | 16% | 18% | 21% |
| Aroostook | 22% | 26% | 30% |
| Cumberland | 17% | 20% | 23% |
| Franklin | 20% | 25% | 29% |
| Hancock | 23% | 27% | 31% |
| Kennebec | 18% | 22% | 25% |
| Knox | 23% | 27% | 31% |
| Lincoln | 26% | 31% | 35% |
| Oxford | 20% | 24% | 28% |
| Penobscot | 17% | 20% | 23% |
| Piscataquis | 25% | 29% | 35% |
| Sagadahoc | 20% | 24% | 29% |
| Somerset | 20% | 23% | 27% |
| Waldo | 20% | 24% | 27% |
| Washington | 23% | 26% | 30% |
| York | 19% | 22% | 26% |

Maine counties vary in their current and projected proportion of older residents. The maps and table above show that in 2025, Lincoln and Piscataquis counties are projected to have the highest proportion of seniors at 35% of their populations, while Androscoggin County will remain the youngest with 21% of its population over 65.

* 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

# Section 2: Demographic Trends in Disability: Data from the American Community Survey, Medicare, and Social Security

The American Community Survey (ACS) provides estimates of the percentage of people with different types of disabilities. In the early 2000's, the ACS questions on disability focused on the presence of certain conditions in the population such as "sensory" disabilities, including blindness or deafness, or a "go-outside-home" disability that resulted in a person having difficulty going out to shop. In 2008, the ACS questions on disability began to reflect more current models of understanding disability.[6] Rather than simply reflecting the presence of a disability, the questions now reflect how different conditions may impact basic functioning. The current ACS covers the following six disability types:

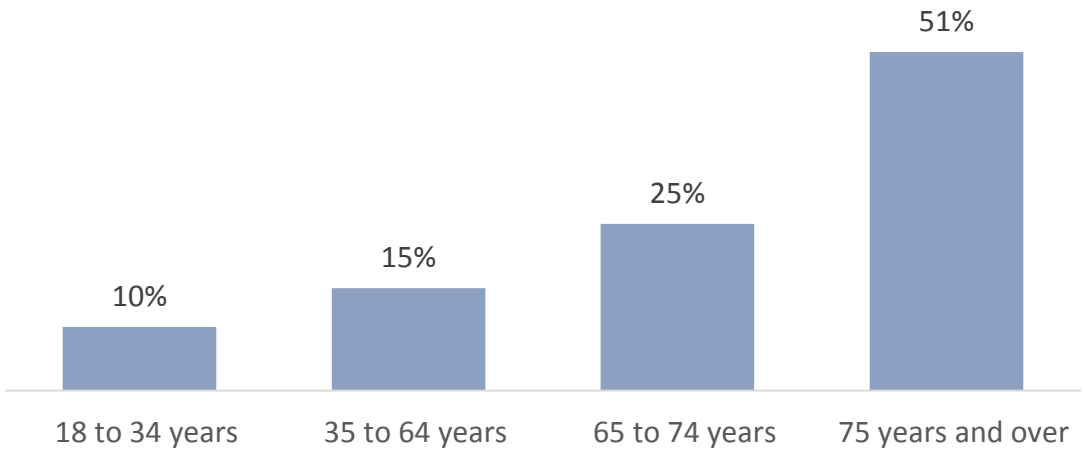
- **Hearing difficulty**: deaf or having serious difficulty hearing
- **Vision difficulty**: blind or having serious difficulty seeing, even when wearing glasses
- **Cognitive difficulty**: because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions
- **Ambulatory difficulty**: having serious difficulty walking or climbing stairs
- **Self-care difficulty**: having difficulty bathing or dressing
- **Independent living difficulty**: because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping

A person who responds affirmatively to having any one of the above disability types is considered to have a disability. The cognitive difficulty category captures a broad group of people and may include those with mental illness as well as those with ID/ASD or other related condition, Alzheimer's disease or other dementias.

While the ACS does not provide details on the level of disability or the service needs of the population, it is a useful tool for estimating the percentage of the population that may have needs for long term services and supports. This information, combined with aging, poverty, employment, and housing data, provides a helpful context as we look at the service use and cost patterns of those who are served by Maine's LTSS system.

Note: Most of the following charts use ACS 3-Year Estimates to describe Maine's population. However, due to the small populations of some of Maine's more rural counties, ACS 5-Year Estimates are used when providing county-level data.

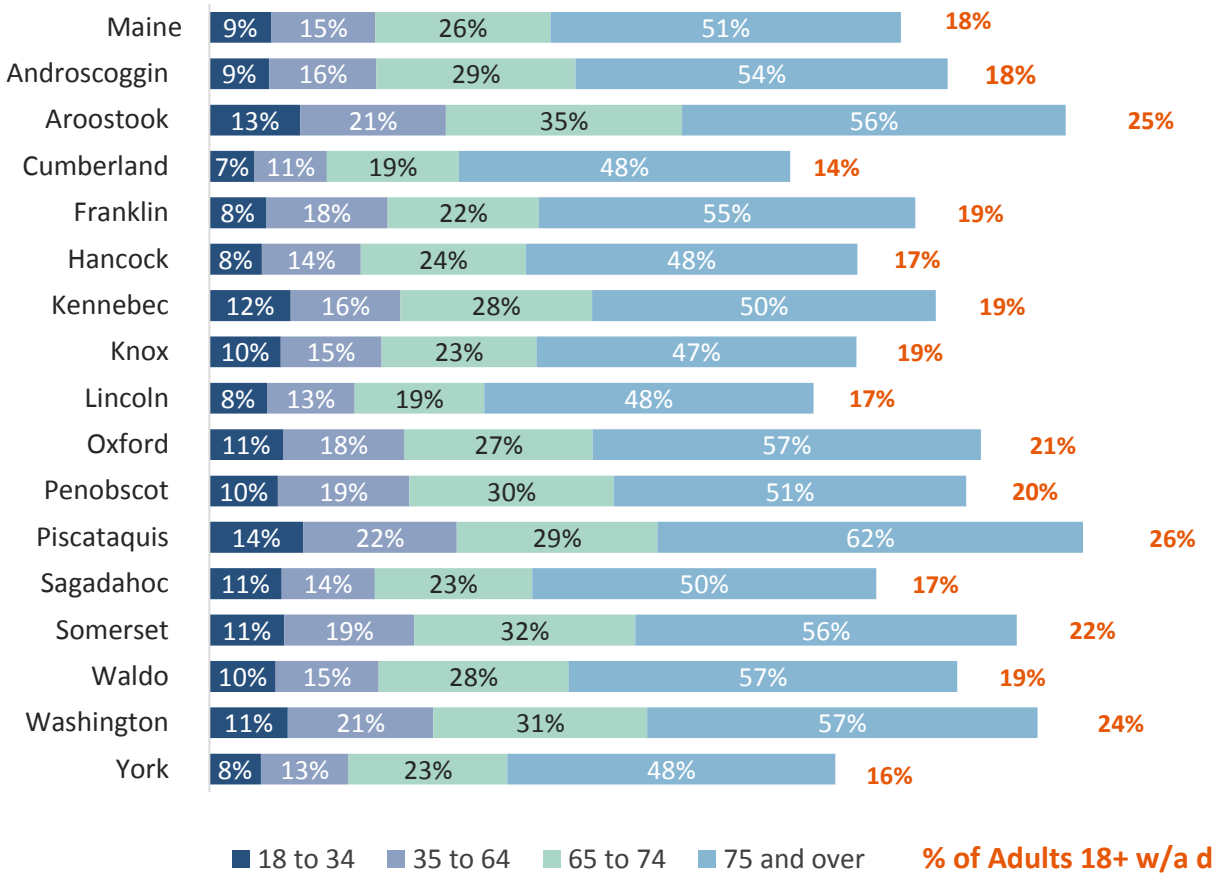
***Figure 2.1 Percentage of Population with a Disability by Age, Maine, 2013 ACS 3-Year Estimate*** [*]




The percentage of people having a disability increases with age. The 2013 ACS 3-Year Estimate of the percentage of population with any type of disability was highest (51%) among those Mainers 75 years and older.

[*] U.S. Census Bureau, 2011-2013 American Community Survey, B18101, "Sex by Age by Disability", aggregated estimates.

***Figure 2.2 Percentage of Population with any Disability in Maine by Age Group and Percent of Total Adult Population with a Disability, by County, 2013 ACS 5-Year Estimates****




Maine's more rural counties have higher rates of disability across different age groups than the state average. Piscataquis, Aroostook, and Washington counties have the highest percentage of their adult population who have a disability.

* U.S. Census Bureau, 2009-2013 American Community Survey, B18101, "Sex by Age by Disability", aggregated estimates.

***Figure 2.3 Percentage of Maine Younger and Older Adults with a Disability by Type, ACS 2013 3-Year Estimates****

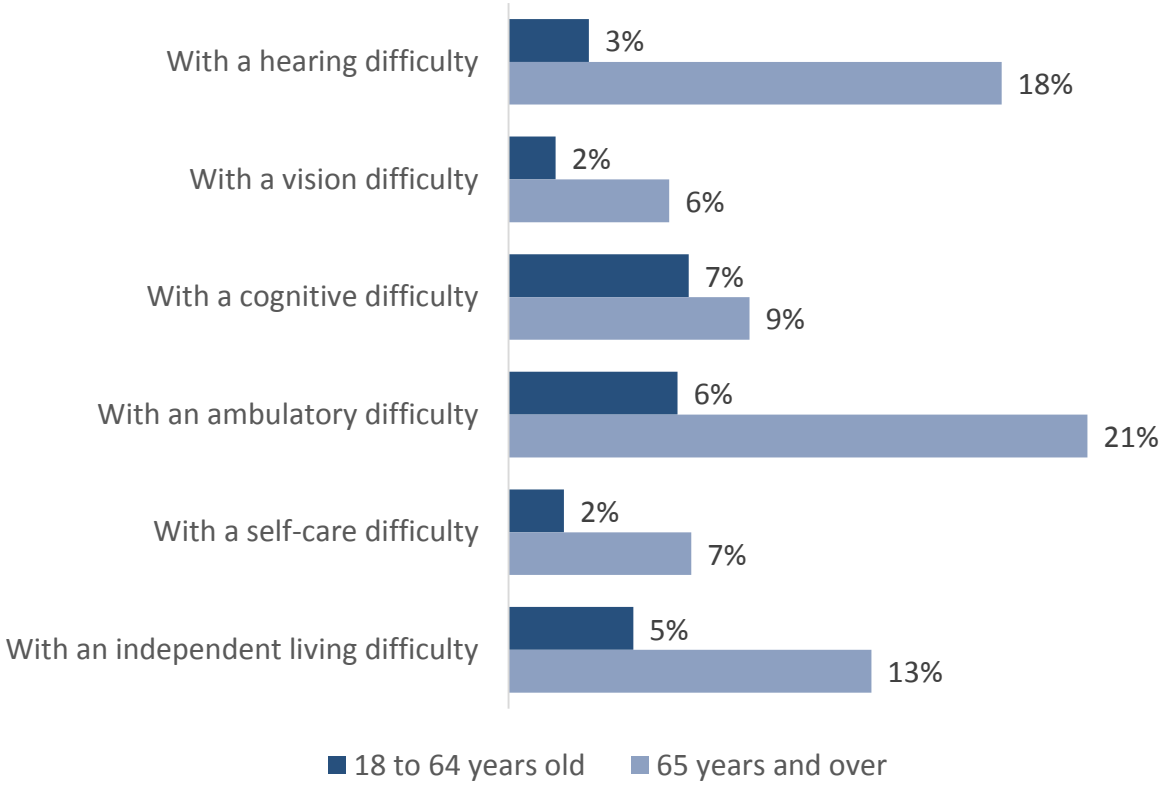
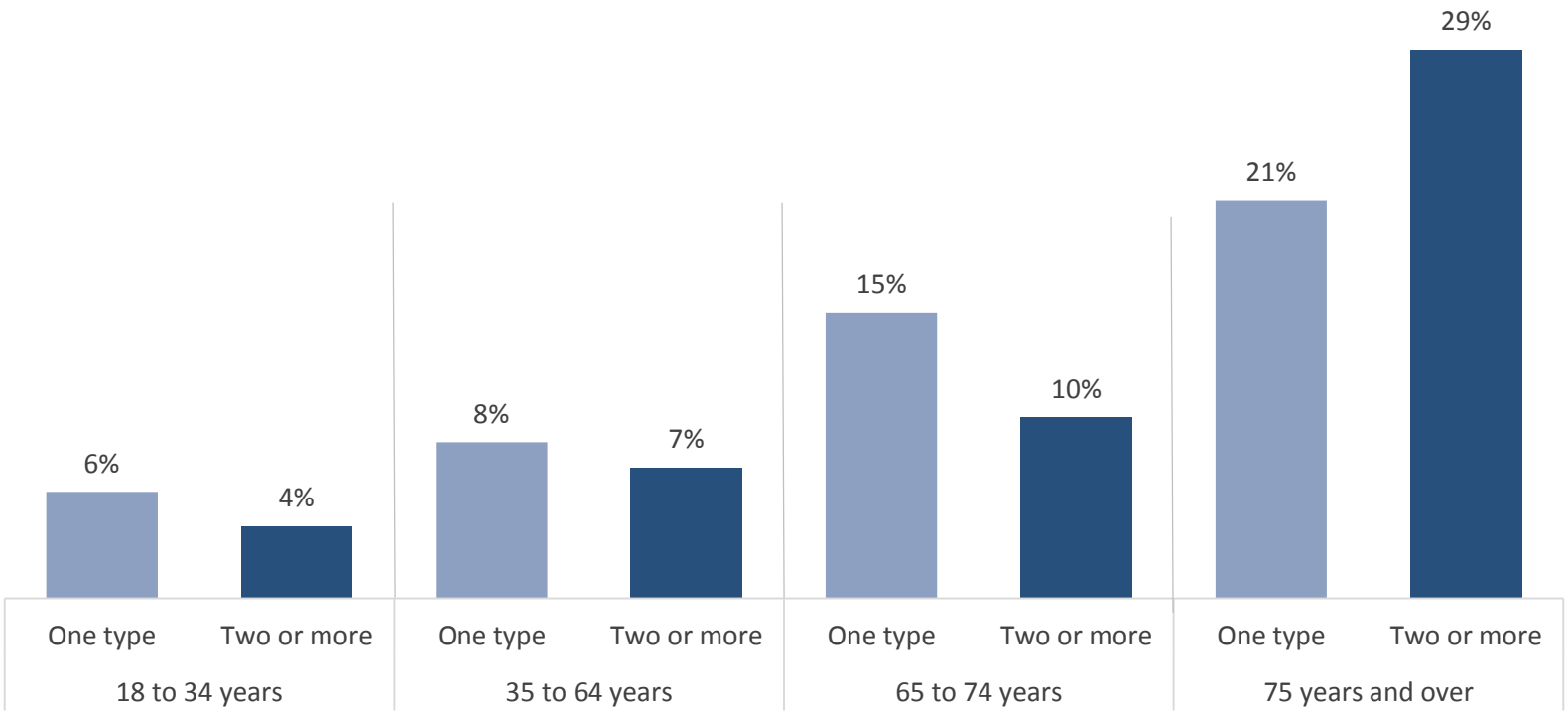



Figure 2.3 shows higher percentages of older adults having each of the disability types identified by the American Community Survey, with older adults having much higher rates of hearing, ambulatory, and independent living disabilities than their younger counterparts. Note that the question on "self-care difficulty" on the ACS asked respondents only about the bathing and/or dressing. Therefore, this measure is not a proxy for measuring the level of limitation in other ADLs such as eating or using the toilet.

* U.S. Census Bureau, 2011-2013 American Community Survey, S1810, "Disability Characteristics".

***Figure 2.4 Percentage of Maine Adults with One Type Only or Two or More Types of Disabilities, ACS 2013 3-Year Estimates****




The percentage of population having more than one type of disability also increases with advanced age. The ACS 2013 3-Year Estimates indicate that the percentage of people having two or more types of disabilities increases markedly for the population over 75 compared to the younger adults.

* U.S. Census Bureau, 2011-2013 American Community Survey, B18108, "Age by Number of Disabilities".

***Figure 2.5 Percentage of Maine Adults with Disability, by Age Group and Type, ACS 2013 3-Year Estimates****

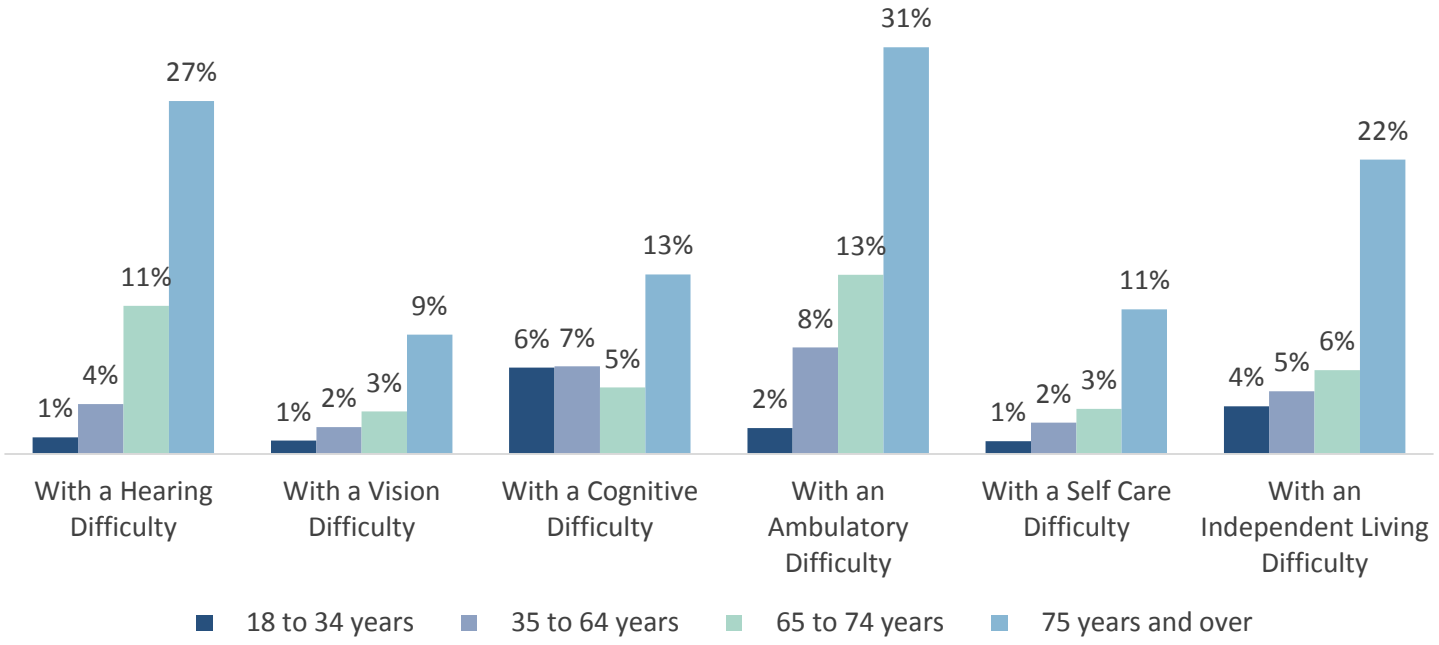


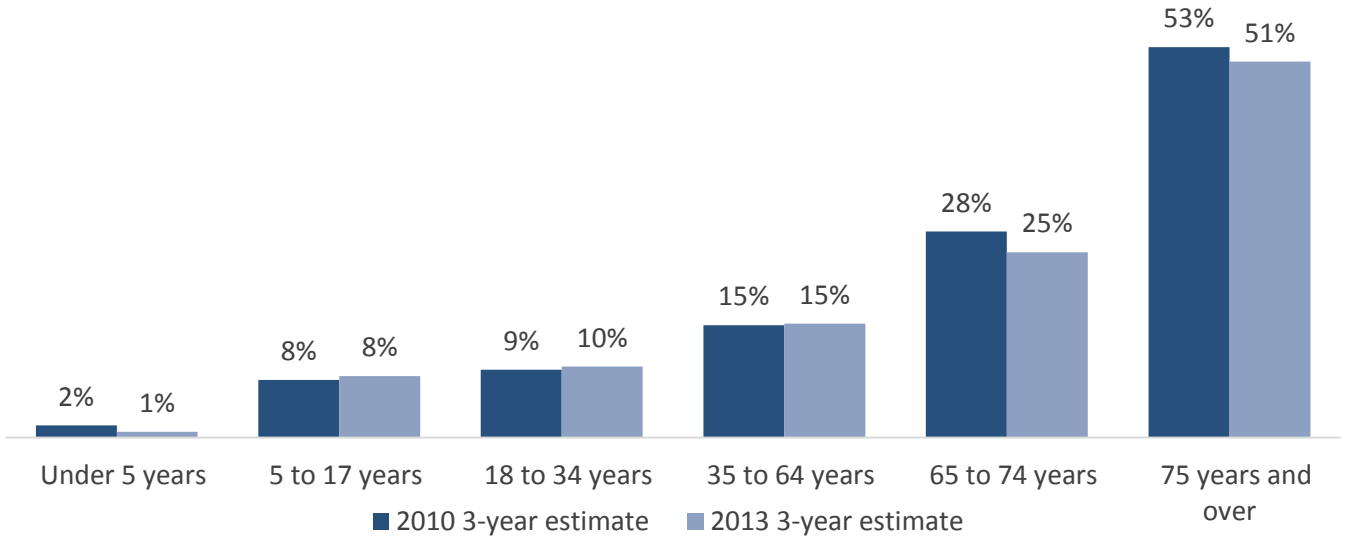

Figure 2.5 shows the different types of disability by age group. A higher percentage of older adults have each of the disability types identified by the American Community Survey, with adults 75 and older having much higher rates of hearing, ambulatory, and independent living disabilities than their younger counterparts

* U.S. Census Bureau, 2011-2013 American Community Survey, B18102 through B18107, Sex by Age by Disability Type.

# Changes in Disability Rates over Time: Maine and National Trends

## Maine Trends

***Figure 2.6 Changes in Rates of Disability in Maine Adults over Time, by Age, 2010 and 2013 ACS 3-Year Estimates****




While the previous charts have shown how disability tends to increase with age, today's seniors may be a little less disabled than those of the past. From 2010 to 2013, the disability rate among adults 65 to 74 years old decreased from 28% to 25%. This decrease was statistically significant at the 99% confidence level (z=-2.966); the population age 65 to 74 increased by 15,000 between 2010 and 2013, but the proportion of those with disabilities decreased. However, the decrease in the disability rate from 53% to 51% in the 75 years and over population was not statistically significant (z=-1.38).

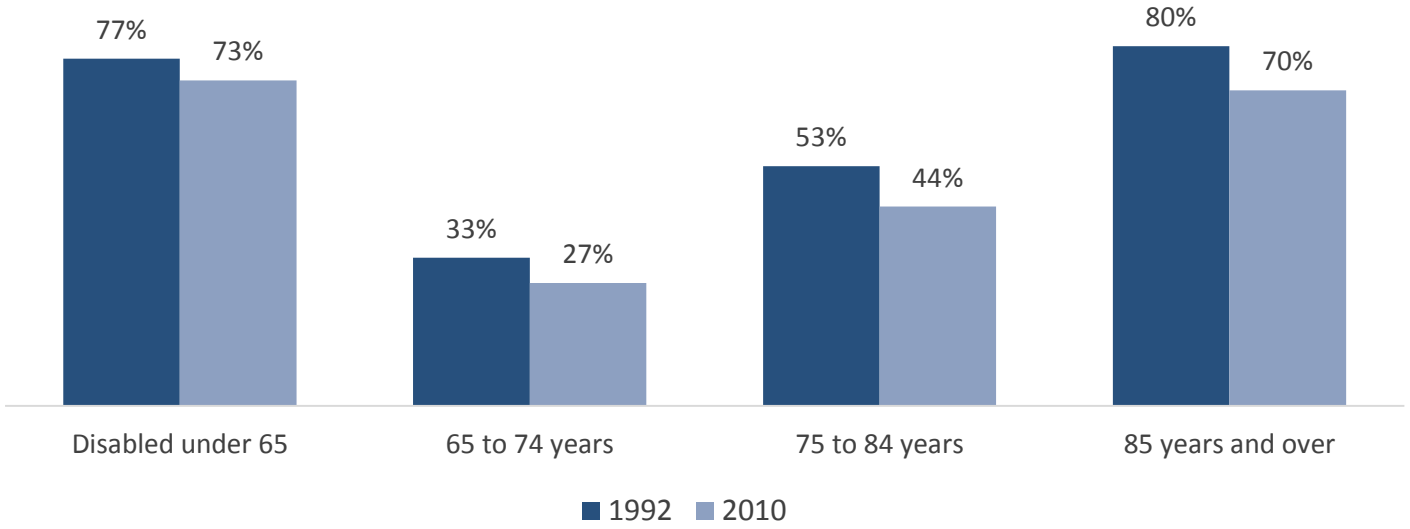
Changes in the disability questions that were asked by the ACS beginning in 2008 prevent comparisons between ACS surveys using data earlier than 2008.

* U.S. Census Bureau, 2008-2010 and 2011-2013 American Community Survey, B18108, "Age by Number of Disabilities".

## National Trends

Decreases in disability rates among older adults is not unique to Maine. National Medicare beneficiary survey data also show that the level of disability, as measured by needs for assistance in Instrumental Activities of Daily Living (IADLs) such as shopping, cooking, and housework, and Activities of Daily Living (ADLs) such as bathing, dressing, and eating, has also decreased over time, even as the population has been aging.

***Figure 2.7 Percentage of National Medicare Beneficiaries with Limitations in either IADLs or ADLs, 1992 and 2010****

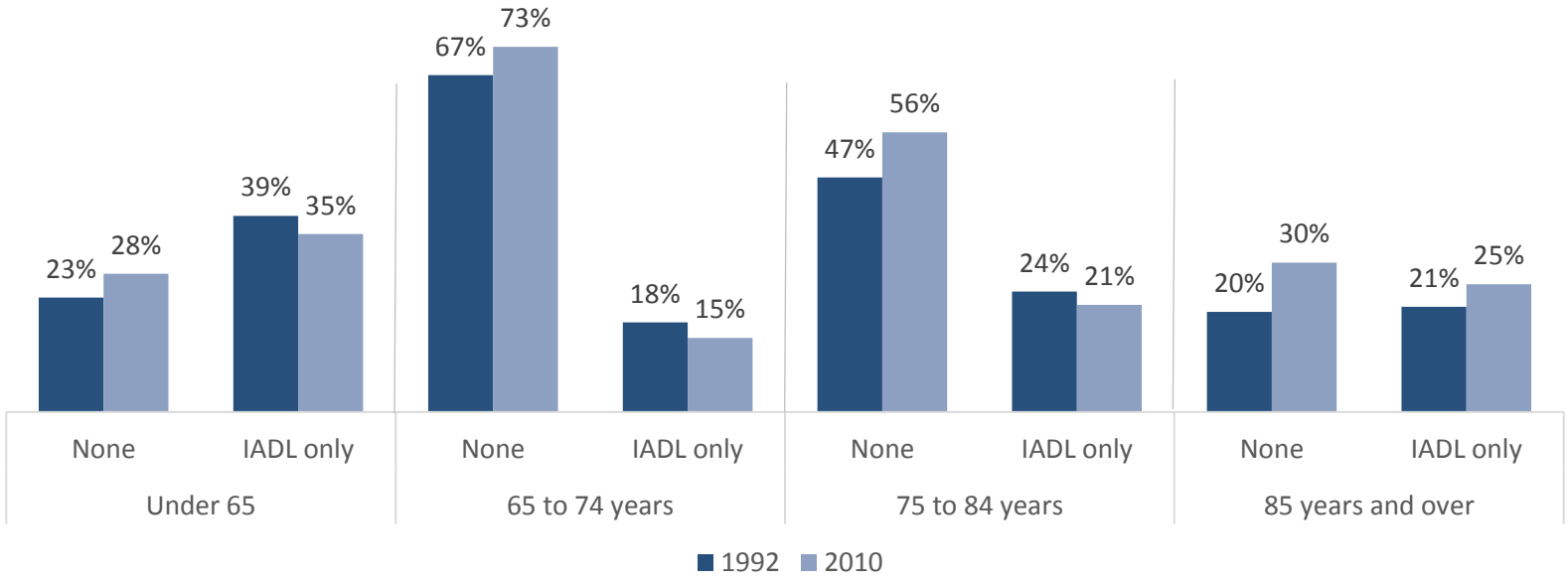



Some of the decrease can be explained by advances in assistive technology that allow individuals to remain more independent for greater portions of their lives. Other contributing factors are increases in health and wellness of the population, such as better diabetes and heart disease care and lower rates of smoking.

* Centers for Medicare & Medicaid Services, Medicare Current Beneficiary Survey, Cost and Use File, Health and Health Care of the Medicare Population, 2013. Table 129. Retrieved from http://www.cdc.gov/nchs/data/hus/2013/129.pdf February 4, 2015.

## National Trends

***Figure 2.8 National Percentage of Medicare Beneficiaries with either No Limitations or with Limitations in IADLs Only, 1992 and 2010****

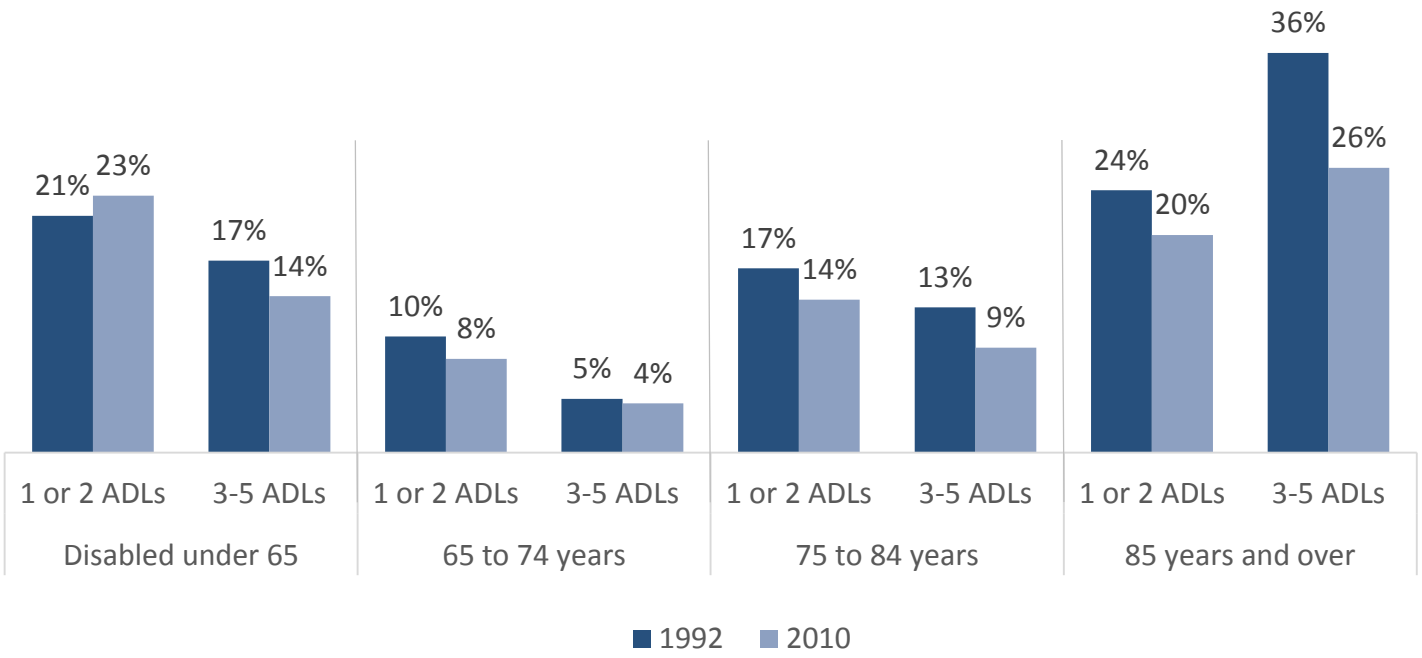



Nationally, the percentage of Medicare beneficiaries with no disabilities increased across all age groups between 1992 and 2010. The percentage of Medicare beneficiaries with limitations only in IADLs decreased between 1992 and 2010 for all age groups except those age 85 years and over. While this older population is increasing in number, over half (55%) has either no limitations or limitations in IADLS only compared to 41% in 1992.

* Centers for Medicare & Medicaid Services, Medicare Current Beneficiary Survey, Cost and Use File, Health and Health Care of the Medicare Population, 2013. Table 129. Retrieved from http://www.cdc.gov/nchs/data/hus/2013/129.pdf February 4, 2015.

## National Trends

***Figure 2.9 National Percentage of Medicare Beneficiaries with either 1-2 or 3-5 ADL Limitations, by Age Group, 1992 and 2010****

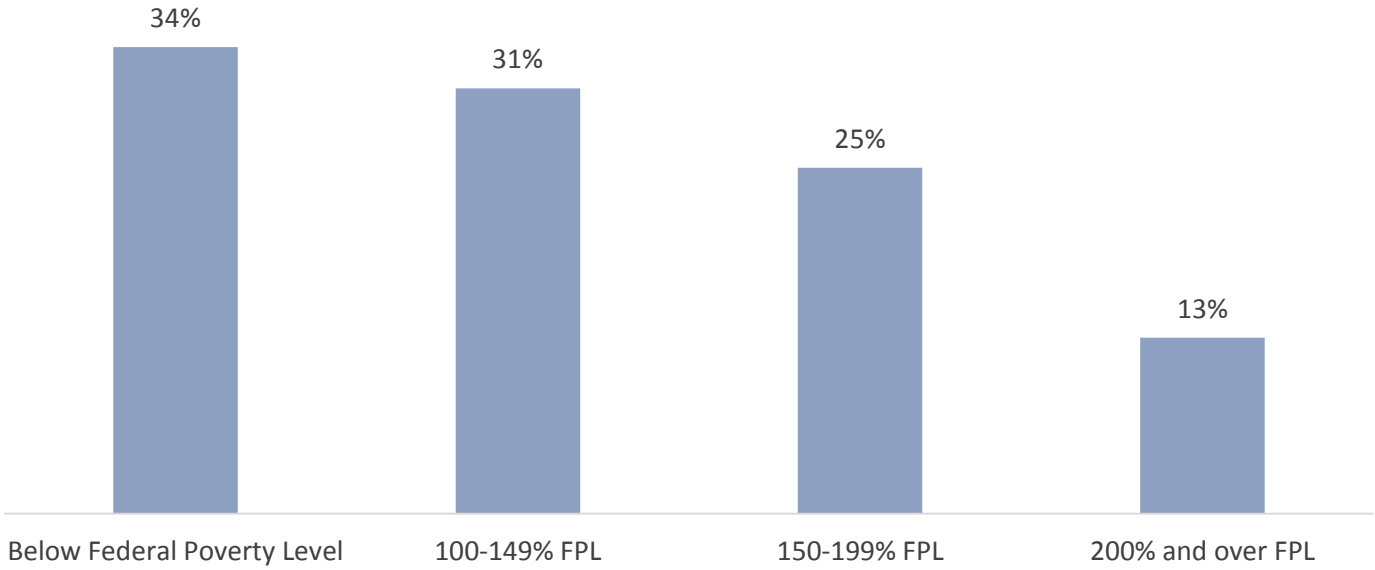



Nationally, between 1992 and 2010, the percentage of Medicare beneficiaries over 65 years old needing assistance in one or two ADLs decreased. And across all age groups, the percentage of Medicare beneficiaries with limitations in three to five ADLs decreased. Coupling the information on this figure with that in figure 2.8, we see that in 1992, 41% of Medicare beneficiaries 85 and older and no limitations or only IADL limitations and 60% had ADL limitations; but in 2010, 55% had no limits or only IADL limits and 46% had ADL limitations. Percentages may not add to 100% due to rounding.

* Centers for Medicare & Medicaid Services, Medicare Current Beneficiary Survey, Cost and Use File, Health and Health Care of the Medicare Population, 2013. Table 129. Retrieved from http://www.cdc.gov/nchs/data/hus/2013/129.pdf February 4, 2015.

## Poverty and Disability in Maine

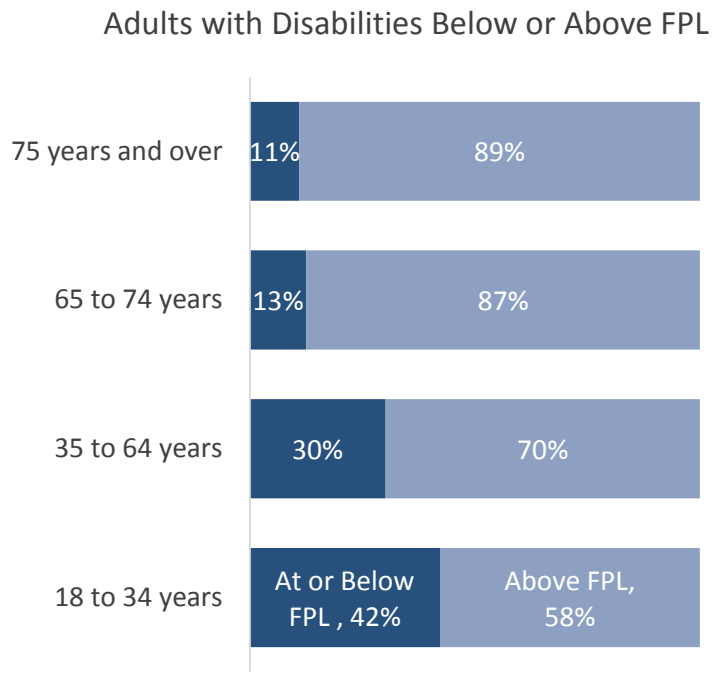
***Figure 2.10 Disability Rate in Maine Adults 18 and Over, By Income Relative to the Federal Poverty Level, ACS 2013 3-Year Estimates****



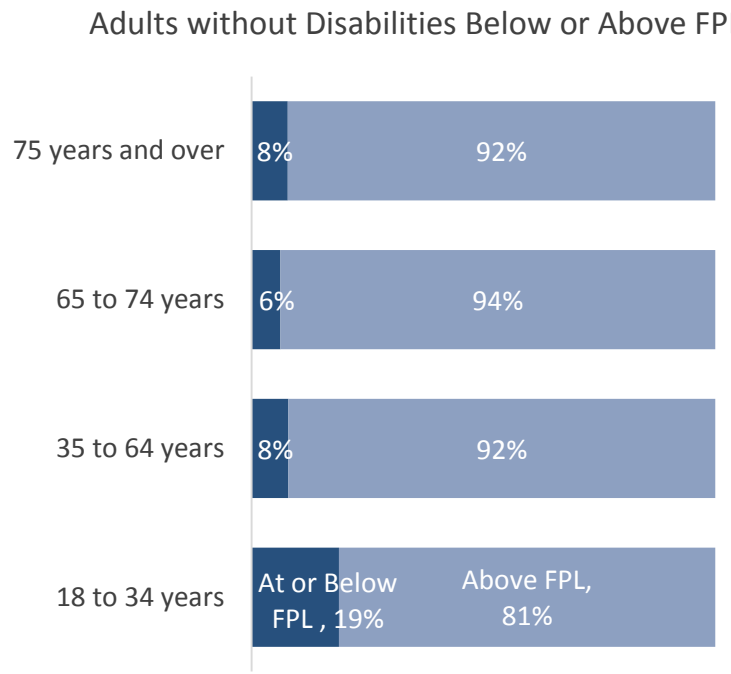

A higher proportion of adults living in or close to poverty also have disabilities, compared to adults who have incomes at least 200% of the federal poverty level (FPL). In Maine, 34% of adults 18 and over with income below the FPL reported having a disability, while 13% of those with income at least 200% of the FPL reported having a disability. The FPL for a single person in 2014 was $11,670.

* U.S. Census Bureau, 2011-2013 American Community Survey, B18131, "Age by Ratio of Income to Poverty Level in the Past 12 Months by Disability Status and Type".

***Figure 2.11 Percentage of Maine Adults with and without Disabilities by Age Group who are At, Below, or Above the Federal Poverty Level (FPL), 2013 ACS 3-Year Estimates****




Across all age groups, a higher percentage of Maine adults with disabilities live in poverty than those without disabilities across age groups.

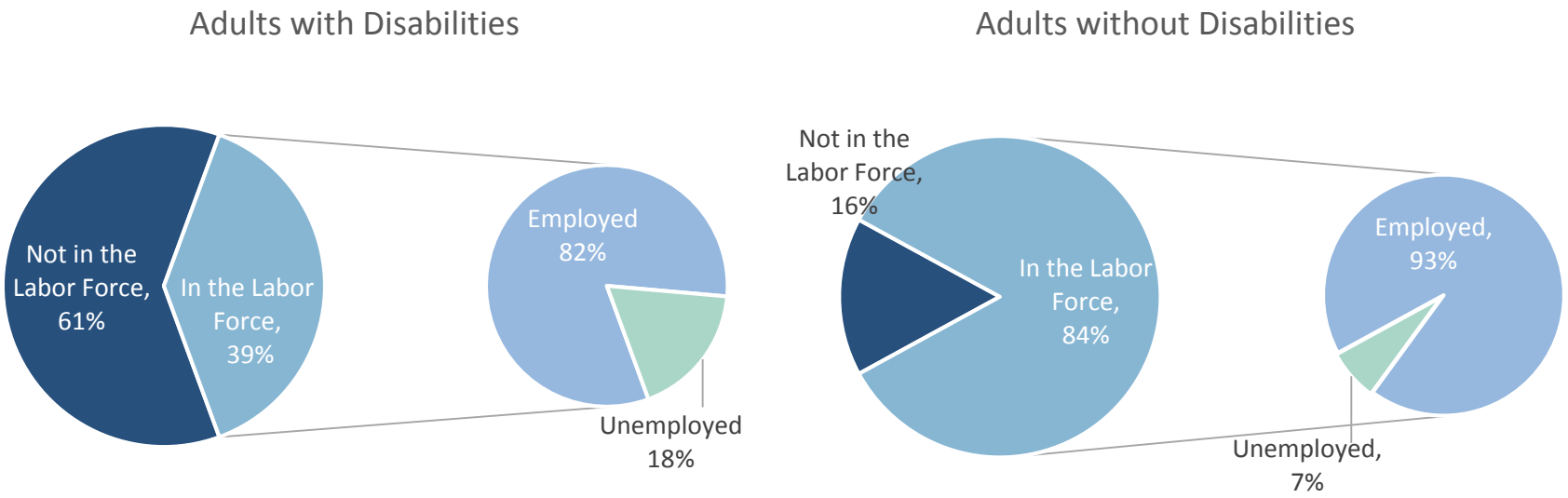



A much higher percentage of younger adults with disabilities (42%) live in poverty than younger adults without disabilities (19%).

* U.S. Census Bureau, 2011-2013 American Community Survey, B18131, "Age by Ratio of Income to Poverty Level in the Past 12 Months by Disability Status and Type".

## Work Status and Disability in Maine

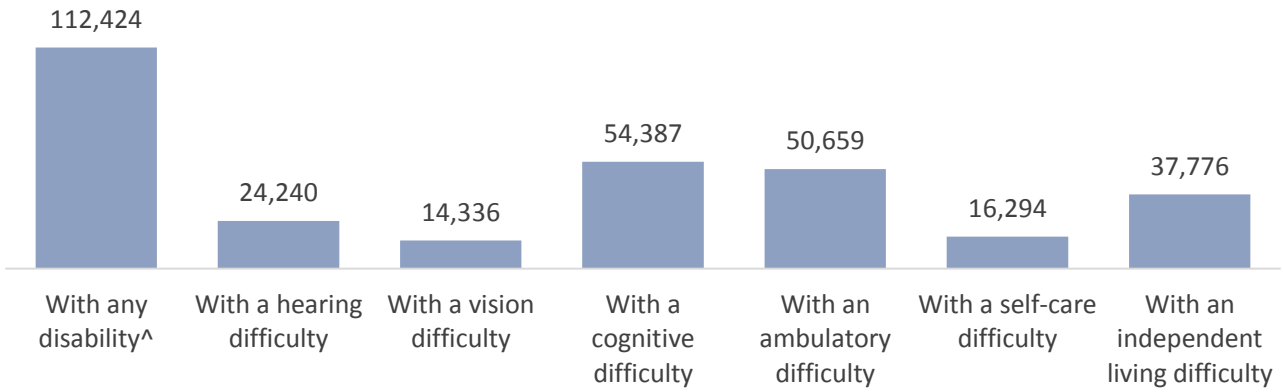
***Figure 2.12 Percentage of Employment among Maine Adults 18-64 in the Labor Force, with and without Disabilities, 2013 ACS 3-Year Estimates****




According to the American Community Survey, Maine adults with disabilities are less likely to participate in the labor force than adults without disabilities. Among adults with disabilities, 39% are in the labor force, either employed or looking for work; 61% were not in the labor force. Adults without disabilities were over twice as likely to report that they were in the labor force. Among Maine adults with disabilities who were in the labor force, a higher percentage were unemployed compared to Maine adults without disabilities who were in the labor force, 18% vs. 7%.

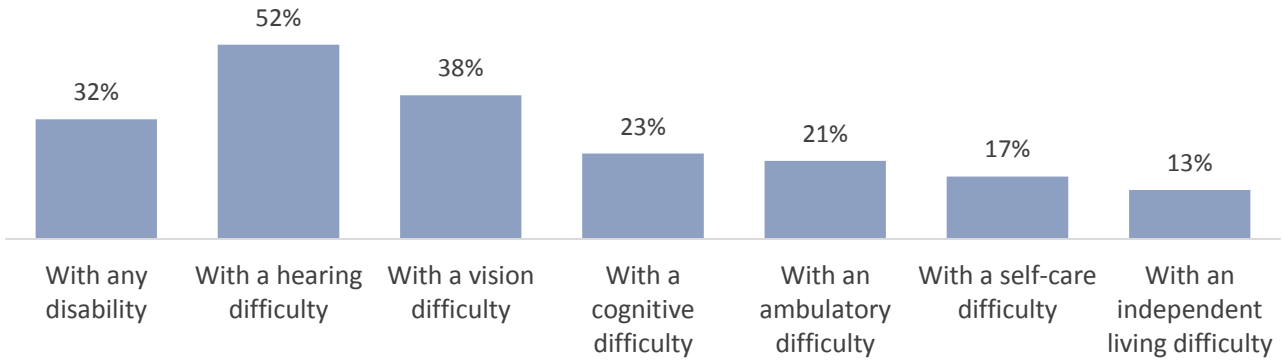
* U.S. Census Bureau, 2011-2013 American Community Survey, B18120, "Employment Status by Disability Status and Type".

***Figure 2.13 Total Population of Working Age Maine Adults with Disabilities by Type of Disability, ACS 2013 3-Year Estimates[*]***




^ Total population with any disability is smaller than the sum of persons by type of disability due to some respondents having more than one type of disability.

***Figure 2.14 Percentage of Employment by Type of Disability, among Working Age Maine Adults with Disabilities, ACS 2013 3-Year Estimates[†]***




Adults with hearing or vision impairments had higher employment rates that those with other disabilities; 52% of adults reporting hearing difficulties and 38% of adults with vision difficulties were employed. The percentage of employment was the lowest (13%) among adults with independent living difficulties.

[*] U.S. Census Bureau, 2011-2013 American Community Survey, B18120, "Employment Status by Disability Status and Type".
[†] Ibid.

## Maine Housing Statistics

Housing may impact a person's need for assistance and ability to pay for care. For example, older homes with many stairs are more difficult to move around in for adults with mobility impairments. And the cost of housing can impact one's ability to pay for needed services. The following charts describe homeownership statistics in Maine.

***Figure 2.15 Percentage of Maine Adults by Age Group who Rent or Own their Home, 2013 ACS 3-year Estimates****

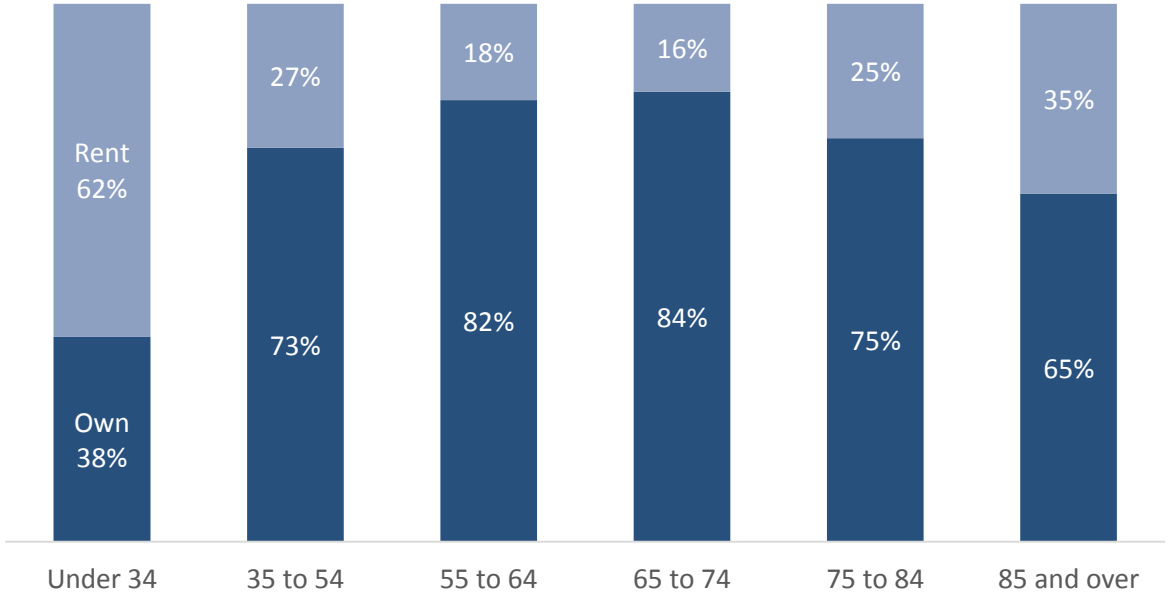
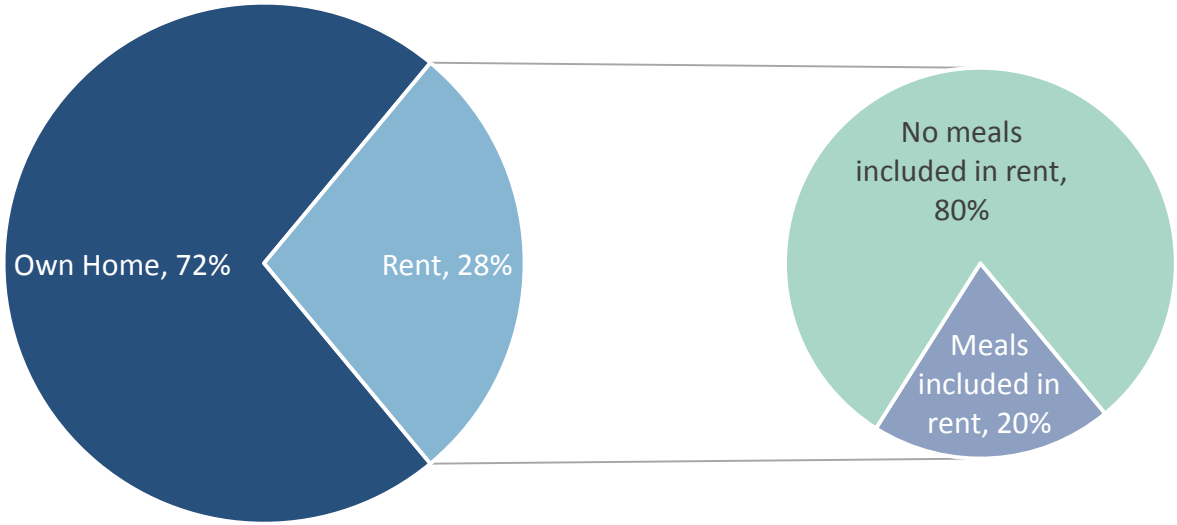



Figure 2.15 shows the percentage of Maine adults who own their home tends to increase with age. Younger adults are more likely to rent. However, the trend begins to decrease for adults over age 75 years old. For adults 85 and over, the percentage of adults who rent their home increases to 35% up from 16% among 65 to 74 year olds.

* U.S. Census Bureau, 2011-2013 American Community Survey, B25007, "Tenure by Age of Householder".

***Figure 2.16 Percentage of Maine Adults 75 Years and Over who Rent their Homes, and the Percentage of the Rental Arrangements that Include Meals, 2013 ACS 3-Year Estimates****




Among Maine adults who are 75 years or over, 28% rent their homes. Of this group of renters, 20% live in apartments or congregate housing arrangements where meals are provided as part of the rent. The ACS includes continuing care facilities in this data if the contracts cover meal services. The ACS considers congregate housing to be housing units where the rent includes meals and other services. While some older adults may live in rental properties where meals are included as part of the rent, the majority, 80%, do not have meals included in their rental fees.

* U.S. Census Bureau, 2011-2013 American Community Survey, B25055, "Age of Householder by Meals Included in Rent".

***Figure 2.17 Year of Construction of Owner-Occupied Housing Units in Maine and the United States, ACS 2013 3-Year Estimates[*]***

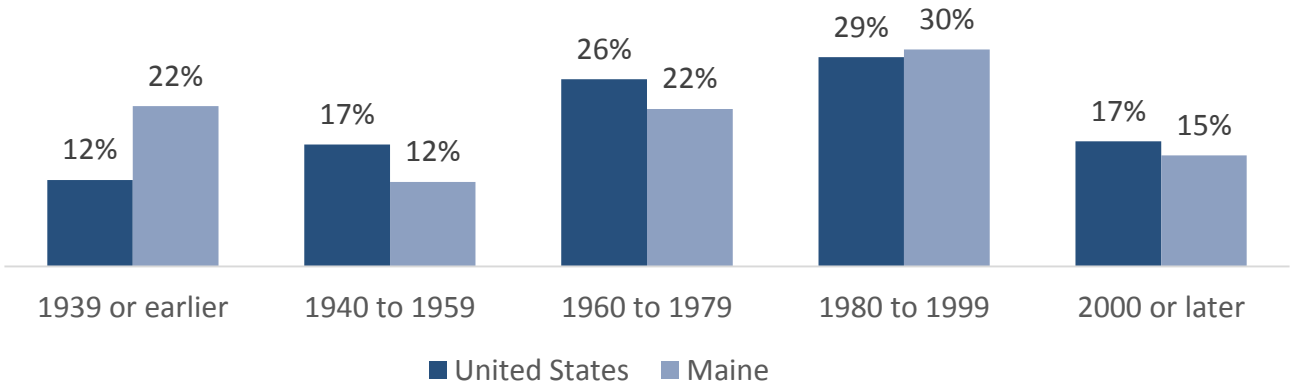
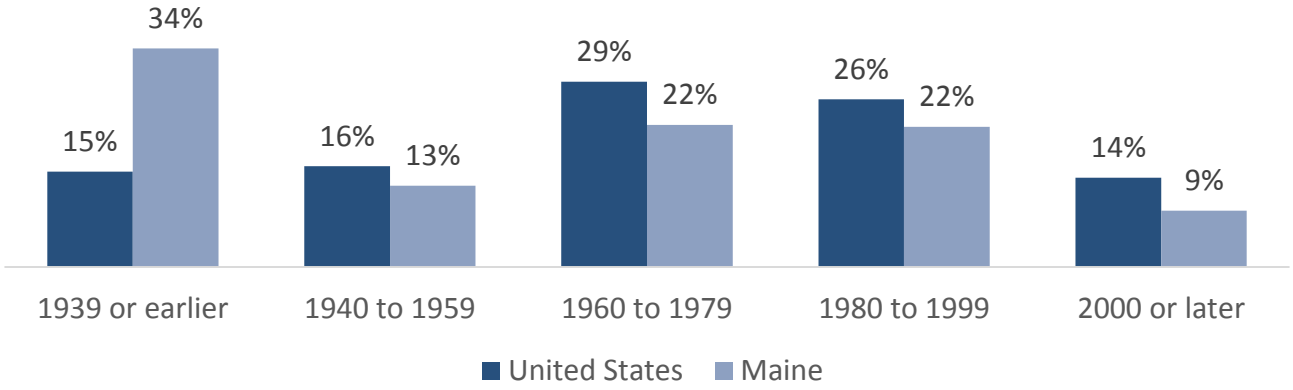


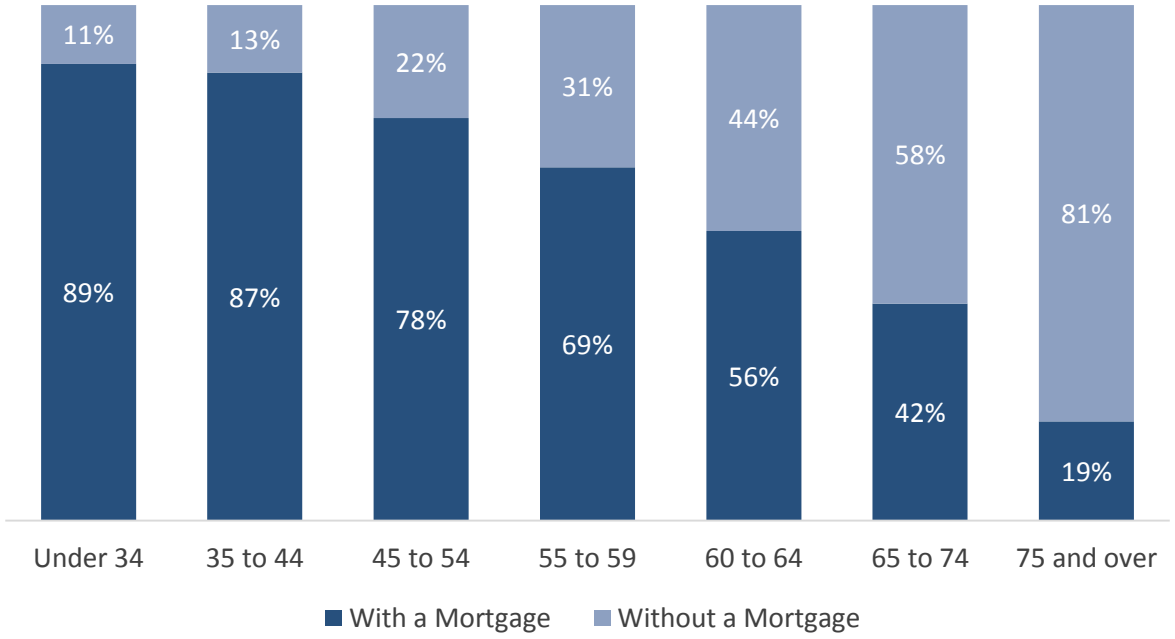

***Figure 2.18 Year of Construction of Renter-Occupied Housing Units in Maine and the United States, ACS 2013 3-Year Estimates[†]***




Maine's housing stock is older than the national average with 22% of owner-occupied and 34% of renter-occupied housing units in Maine being over 75 years old. And the construction of newer homes built in 2000 or later also lags behind the national average.

[*] U.S. Census Bureau, 2011-2013 American Community Survey, B25036, "Tenure by Year Built".
[†] Ibid.

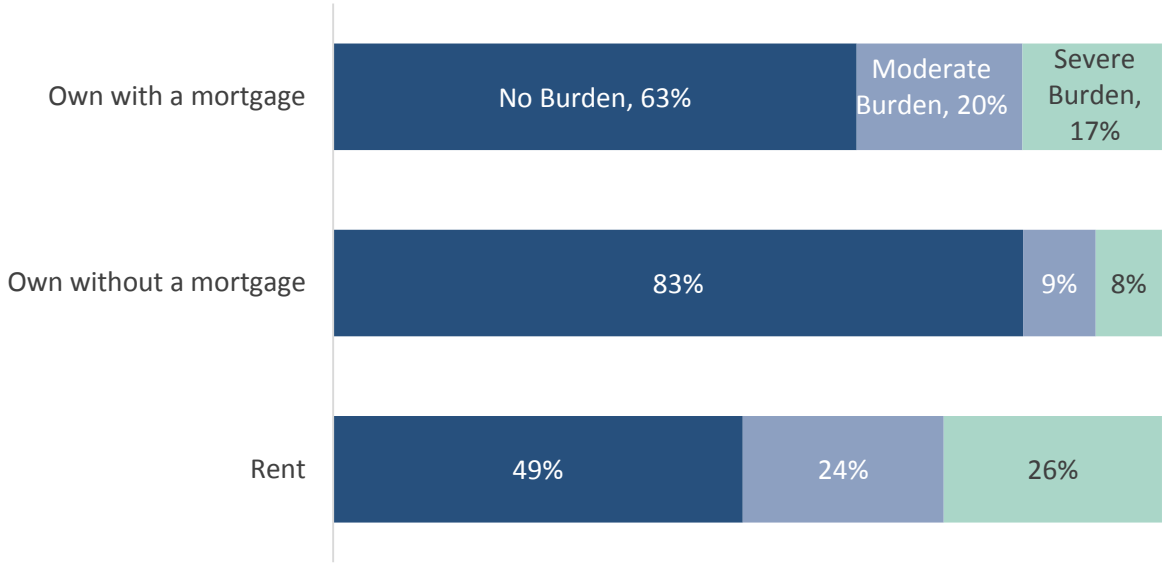
***Figure 2.19 Mortgage Status among Maine Adults who Own their Homes, by Age Group, ACS 2013 3-Year Estimates****




According to the ACS 3-Year Estimates, older adults in Maine are more likely to own their own home without a mortgage; however, it should be noted that nearly one-fifth of adults 75 years and older had a mortgage. Some of these mortgages may be reverse mortgages in which a person can withdraw some of the equity in one's home. State specific data is unavailable on how many older adults in Maine may have a reverse mortgage, but nationally, approximately 5% of mortgages held by adults 65 and older are reverse mortgages.†

* U.S. Census Bureau, 2011-2013 American Community Survey, B25027, "Mortgage Status by Age of Householder".
† U.S Census Bureau, 2013 American Housing Survey, C-14A-OO, "Mortgage Characteristics – Owner Occupied Units (National).

***Figure 2.20 Share of Maine Households Aged 50 and Over with Housing Cost Burdens, by Ownership Status, 2012****

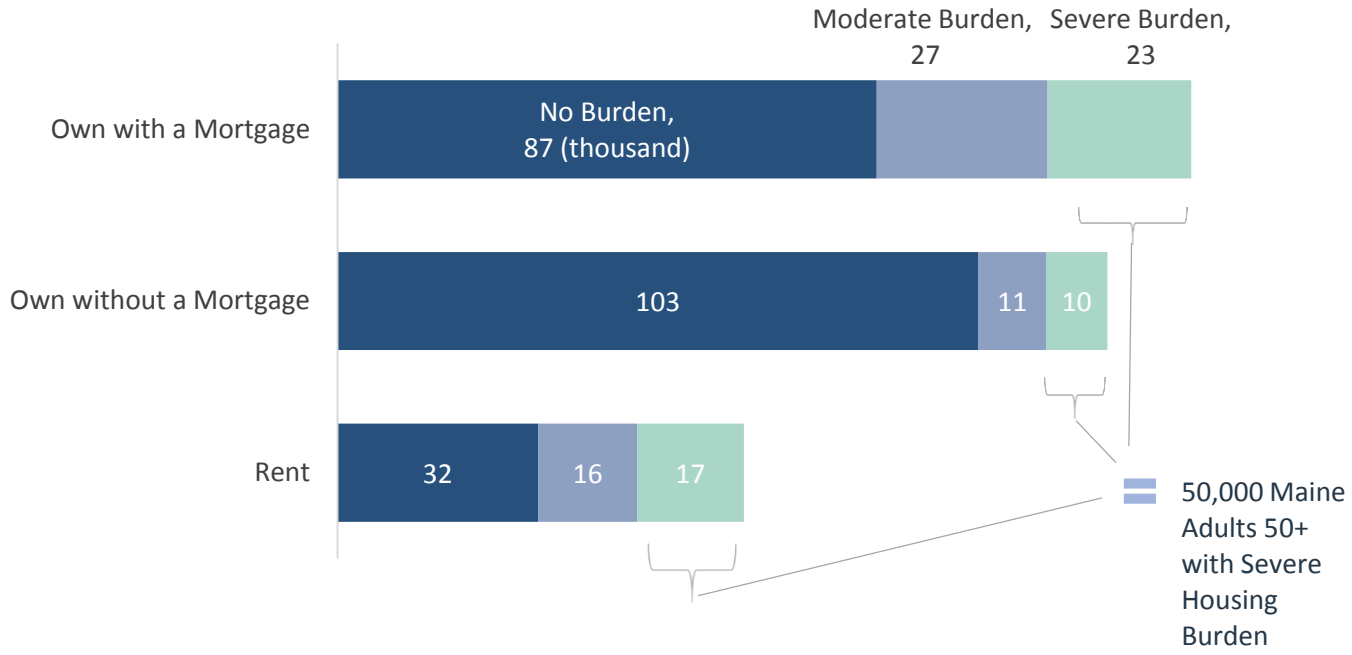



Researchers at the Joint Center for Housing Studies at Harvard University calculated "housing burden" for adults age 50 and older in 2012 using data from the ACS. Housing burden was defined as "moderate" if annual housing costs were 30-50% of household income and "severe" if housing costs were more than 50% of household income. Housing costs included mortgages, fees, rent, property taxes, insurance, and utilities.

In 2012, 37% of Maine adults age 50 and over who own their homes with a mortgage experienced moderate to severe housing burden. Among renters, 50% experienced moderate to severe burden. This has implications for how much seniors may be able to pay for outside help if they begin to require assistance with ADLs or IADLs.

* *Housing America's Older Adults—Meeting the Needs of an Aging Population*. Fernald, M., editor. Cambridge, MA: Joint Center for Housing Studies of Harvard University; 2014. http://www.jchs.harvard.edu/research/housing_americas_older_adults retrieved on January 22, 2015.

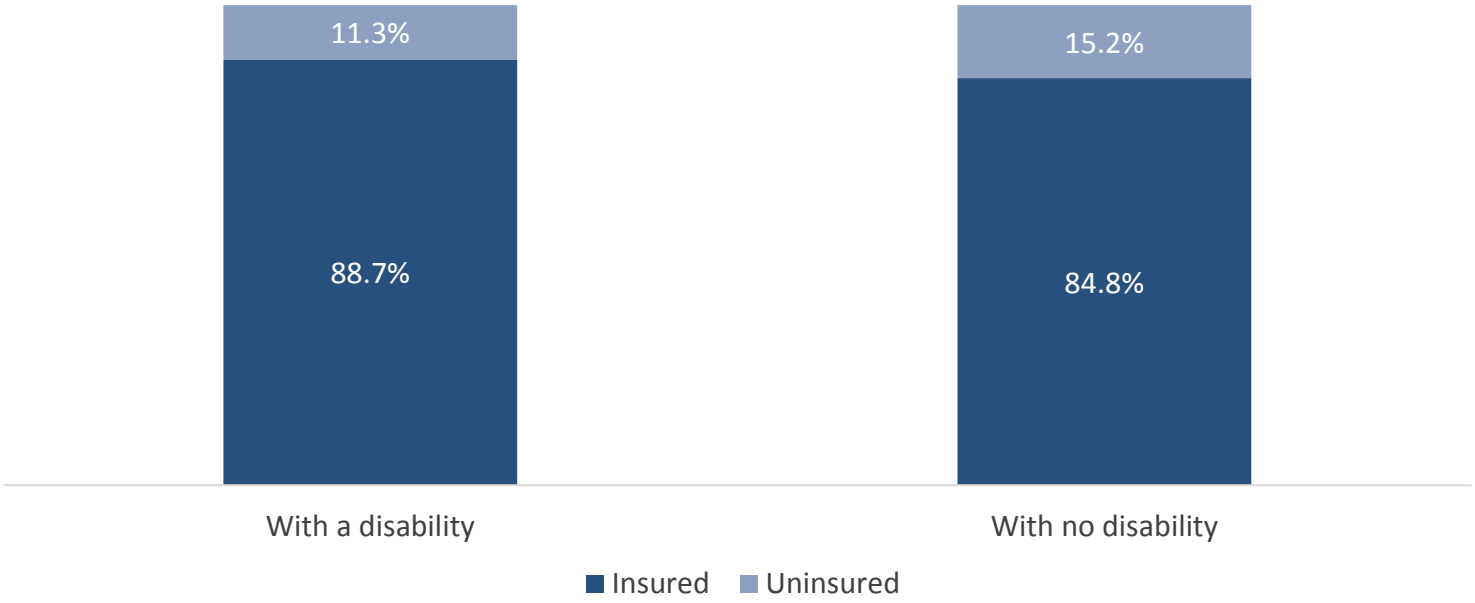
***Figure 2.21 Number (in Thousands) of Maine Adults over Age 50 with Housing Cost Burdens, by Ownership Status, 2012****




Among Maine adults over age 50 and across all ownership categories, there are an estimated 50,000 people with severe housing burden. This means that their housing costs account for more than 50% of their household income.

* *Housing America's Older Adults—Meeting the Needs of an Aging Population*. Fernald, M., editor. Cambridge, MA: Joint Center for Housing Studies of Harvard University; 2014. http://www.jchs.harvard.edu/research/housing_americas_older_adults retrieved on January 22, 2015.

***Figure 2.22 Rate of Health Insurance Coverage by Disability Status among Maine Adults 18 to 64 Years Old, ACS 2013 5 Year Estimates****




Insurance coverage varies by disability status. In Maine, working age adults 18-64 years old with disabilities were more likely to have insurance coverage (either Medicaid, Medicare, or private coverage) than those without disabilities. Among adults over 65, insurance coverage is close to 100% for both adults with and without disabilities, likely due to Medicare eligibility.

* U.S. Census Bureau, 2011-2013 American Community Survey, B18135, "Age by Disability Status by Health Insurance Status".

# Social Security Disability Insurance and Supplemental Security Income

## Social Security Disability Insurance

Social Security Disability Insurance (SSDI) provides monthly cash payments to several different groups of disabled workers and/or their families. It is an earned benefit tied to a person's history of employment under Social Security. Under SSDI, a person must be unable to engage in substantial gainful activity due to any medically determinable physical or mental impairment which has lasted or is expected to last at least a year or more. It is also available to blind individuals who are at least 55 and are also unable to engage in gainful activity.

After a five month waiting period, funds are available through the Social Security Administration for a disabled worker and family; disabled widow(er) or a disabled surviving divorced spouse who is aged 50 to full retirement age; and disabled adult children of disabled, retired, or deceased workers (provided the adult children are 18 or older and have been disabled prior to age 22). After a two year waiting period, SSDI beneficiaries become eligible for Medicare benefits. And vocational rehabilitation services are available to disabled workers who can return to work with assistance.[*]

In 2013, Maine had 64,021 adults age 18-64 with disabilities who received SSDI benefits. This number is 7.7% of Maine's total population age 18-64, the sixth highest percentage nationwide.

***Table 2.1 States with the Highest and Lowest Percentage of their Adult Population Age 18-64 Receiving SSDI, 2013[†]***

| United States Average | | 4.8% | |
|---|---|---|---|
| **Ten Highest States** | | **Ten Lowest States** | |
| West Virginia | 8.9% | Texas | 3.8% |
| Alabama | 8.5% | Wyoming | 3.8% |
| Arkansas | 8.4% | Maryland | 3.7% |
| Kentucky | 8.2% | Nevada | 3.7% |
| Mississippi | 7.9% | North Dakota | 3.4% |
| **Maine** | **7.7%** | Colorado | 3.3% |
| Tennessee | 6.7% | California | 3.2% |
| South Carolina | 6.5% | Utah | 3.0% |
| Missouri | 6.4% | Hawaii | 2.9% |
| Michigan | 6.3% | Alaska | 2.8% |

[*] *Annual Statistical Report on the Social Security Disability Insurance Program, 2013*. Retrieved from http://www.socialsecurity.gov/policy/docs/statcomps/di_asr/2013/background.pdf January 15, 2015.

[†] Data are from *Annual Statistical Report on the Social Security Disability Insurance Program, 2013*. Retrieved from http://www.socialsecurity.gov/policy/docs/statcomps/di_asr/2013/ November 24, 2014.

In 2013, Maine had 67,404 SSDI beneficiaries of all ages:[*]

- 59,274 were disabled workers
- 1,455 were disabled widow(er)s
- 6,675 were disabled adult children

### *Table 2.2 Distribution of all Maine SSDI Beneficiaries by Diagnostic Group, 2013[†]*

| Total Number of Maine SSDI Beneficiaries, all Ages | 67,404 |
|---|---|
| **Diagnostic Group** | **Percentage of Beneficiaries** |
| Mental disorders | 42.8% |
| Musculoskeletal system and connective tissue disease | 26.8% |
| Nervous system and sense organ disease | 8.6% |
| Circulatory system disease | 5.5% |
| Injuries | 3.2% |
| Endocrine, nutritional, and metabolic diseases | 2.6% |
| Respiratory system disease | 2.5% |
| Neoplasms | 2.3% |
| Digestive system disease | 1.6% |
| Genitourinary system disease | 0.7% |
| Infectious and parasitic diseases | 0.6% |
| Congenital anomalies | 0.3% |
| Skin and subcutaneous tissue disease | 0.3% |
| Blood and blood-forming organ diseases | 0.1% |
| Other | 0.2% |
| Unknown | 1.9% |

Of the Maine adults receiving SSDI, mental disorders was the most common diagnostic group, followed by diseases of the musculoskeletal system and connective tissues (table 2.2). The mental disorders diagnostic group includes developmental and autistic disorders as well as organic brain disease and psychotic disorders. The distribution of these different mental disorder diagnoses are detailed in table 2.3.

### *Table 2.3 Maine's SSDI Beneficiary Distribution of Diagnoses within the Mental Disorders Diagnostic Group, 2013[‡]*

| Diagnosis | Percent Distribution |
|---|---|
| Mood disorders | 16.7% |
| Other | 9.5% |
| Intellectual disability | 8.0% |
| Schizophrenic and other psychotic disorders | 4.0% |
| Organic mental disorders | 3.6% |
| Autistic disorders | 0.7% |
| Childhood and adolescent disorders not elsewhere classified | 0.2% |
| Developmental Disorders | 0.1% |
| Total Percentage distribution in the Mental Disorders Diagnostic Group | 42.8% |

Nearly 9%, (approximately 6,000 people), of Maine's SSDI beneficiaries had diagnoses relating to autism or intellectual disability in 2013.

[*] Data are from *Annual Statistical Report on the Social Security Disability Insurance Program, 2013*. Retrieved from http://www.socialsecurity.gov/policy/docs/statcomps/di_asr/2013/ November 24, 2014.

[†] Ibid.

[‡] Ibid.

***Table 2.4 States with the Highest and Lowest Percentage of SSDI Beneficiaries in the Diagnostic Group "Mental Disorders", 2013****

| U.S. Average Percentage of SSDI Beneficiaries in the Diagnostic Group "Mental Disorders" | | 35.2% | |
|---|---|---|---|
| **Ten Highest States** | | **Ten Lowest States** | |
| Massachusetts | 49.9% | Tennessee | 31.3% |
| New Hampshire | 49.9% | North Carolina | 31.1% |
| Rhode Island | 47.1% | Nevada | 30.8% |
| Hawaii | 46.8% | Florida | 30.3% |
| Minnesota | 46.6% | West Virginia | 30.3% |
| Vermont | 45.2% | Arkansas | 30.2% |
| Connecticut | 43.8% | Louisiana | 30.2% |
| District of Columbia | 42.9% | South Carolina | 29.7% |
| **Maine** | **42.8%** | Georgia | 29.1% |
| Washington | 39.7% | Alabama | 28.8% |

Interestingly, all six New England states are in the top ten states that have the highest distribution of SSDI beneficiaries in the diagnostic group "Mental Disorders", with Maine having the ninth highest distribution in this category (table 2.4). States with the lowest distribution of the "Mental Disorders" diagnostic group tended to be southern states. There may be geographic variation in how disability determinations are made.

The average monthly and median monthly benefit received by Maine's SSDI population tends to be lower than the national average across all three eligibility groups, disabled workers, disabled widow(er)s, and disabled adult children. The table below shows these amounts for the different groups.

***Table 2.5 Average and Median Monthly SSDI Benefit Amount in the United States and Maine, 2013†***

| | Average Benefit | Median Benefit |
|---|---|---|
| **Disabled Workers** | | |
| United States | $1,146 | $1,056 |
| Maine | $1,066 | $989 |
| **Disabled Widow(er)s** | | |
| United States | $717 | $670 |
| Maine | $658 | $613 |
| **Adult Disabled Children** | | |
| United States | $735 | $721 |
| Maine | $668 | $655 |

* Data are from *Annual Statistical Report on the Social Security Disability Insurance Program, 2013*. Retrieved from http://www.socialsecurity.gov/policy/docs/statcomps/di_asr/2013/ November 24, 2014.

† Ibid.

## Supplemental Security Income

Supplemental Security Income (SSI) is available to people with low-incomes who are 65 or older; blind; or disabled. Most recipients are adults, but children with disabilities may qualify as well, as long as they meet income and resource limits. In 2013, there were 4,270 children in Maine under age 18 who received SSI. In Maine's adult population, 27,838 adults age 18-64 and 5,320 adults age 65 and older received SSI payments.

Using population estimates for 2013, the following table shows the percentage of the adult population who received SSI by county. Piscataquis County had the highest proportion (5.2%) of its adult population age 18-64 receiving SSI; Washington County had the highest proportion (4.2%) of its adult population over 65 receiving SSI. York County had the lowest proportion of both adult populations receiving SSI.

Thirty-two states, including Maine, provide automatic Medicaid eligibility to people who receive SSI.

***Table 2.6 Percentage of Maine Adults Receiving SSI, by County, 2013****

| | Percentage of Adults 18-64 Receiving SSI, 2013 | Percentage of Adults age 65+ Receiving SSI, 2013 |
|---|---|---|
| **Maine** | **3.3%** | **2.3%** |
| Androscoggin | 4.4% | 2.9% |
| Aroostook | 4.6% | 3.7% |
| Cumberland | 2.2% | 2.1% |
| Franklin | 3.7% | 1.8% |
| Hancock | 2.3% | 1.4% |
| Kennebec | 4.4% | 2.3% |
| Knox | 2.7% | 1.7% |
| Lincoln | 2.5% | 1.5% |
| Oxford | 4.2% | 2.5% |
| Penobscot | 4.3% | 2.5% |
| Piscataquis | 5.2% | 2.6% |
| Sagadahoc | 2.5% | 1.4% |
| Somerset | 4.5% | 3.3% |
| Waldo | 3.7% | 2.9% |
| Washington | 5.1% | 4.2% |
| York | 2.2% | 1.4% |

* SSI data are from *SSI Recipients by State and County.* Retrieved from http://www.socialsecurity.gov/policy/docs/statcomps/ssi_sc/2013/me.pdf April 16, 2014. Population estimates are from 2014 Woods and Poole Economics, Inc., "2015 New England State Profile: State and county Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

### *Table 2.7 Distribution of all Maine SSI Beneficiaries under Age 65, by Diagnostic Group, 2013**

| Total number of Maine SSI beneficiaries under 65 | 32,138 |
|---|---|
| **Diagnostic Group** | **Percent of Beneficiaries** |
| Mental disorders | 67.9% |
| Musculoskeletal system and connective tissue | 11.8% |
| Nervous system and sense organs | 5.8% |
| Unknown | 2.4% |
| Circulatory system | 2.1% |
| Endocrine, nutritional, and metabolic diseases | 2.0% |
| Injuries | 1.7% |
| Respiratory system | 1.5% |
| Congenital anomalies | 1.2% |
| Neoplasms | 1.0% |
| Digestive system | 0.9% |
| Other | 0.7% |
| Infectious and parasitic diseases | 0.3% |
| Genitourinary system | 0.3% |
| Skin and subcutaneous tissue | 0.2% |
| Blood and blood-forming organs | 0.1% |

Table 2.7 shows the distribution of Maine SSI beneficiaries under age 65 by diagnostic group; note that this includes nearly 4,300 Maine children under age 18 who also receive SSI. Diagnostic group data was not available for the separate age groups of adults, children, and adults over age 65.

Mental disorders was the most common diagnostic group among Maine's SSI beneficiaries under 65, with nearly 70% falling into this category. Table 2.8 shows the distribution of the different types of mental disorders within this diagnostic group.

### *Table 2.8 Distribution of Diagnoses within the Mental Disorders Diagnostic Group among Maine's SSI Beneficiaries under Age 65, 2013†*

| Diagnosis | Percent Distribution |
|---|---|
| Mood disorders | 25.0% |
| Intellectual disability | 24.0% |
| Other | 21.7% |
| Autistic disorders | 10.1% |
| Schizophrenic and other psychotic disorders | 6.6% |
| Organic mental disorders | 6.4% |
| Childhood and adolescent disorders not elsewhere classified | 3.8% |
| Developmental disorders | 2.4% |
| Total Distribution in the Mental Disorders Diagnostic Group | 67.9% |

Note again, that the table above includes children under age 18. Intellectual disability and autistic disorders are more common diagnoses in the SSI population than the SSDI population.

* Data are from SSI Annual Statistical Report, Table 38. Retrieved from https://www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/2013/ November 17, 2015.

† Ibid, Table 38A.

***Table 2.9 States with the Highest and Lowest Percentage of SSI Beneficiaries in the Diagnostic Group "Mental Disorders", 2013***

| U.S. Average Percentage of SSI Beneficiaries in the Diagnostic Group "Mental Disorders" | | 59.7% | |
|---|---|---|---|
| **Ten Highest States** | | **Ten Lowest States** | |
| New Hampshire | 72.9% | Montana | 56.7% |
| Rhode Island | 70.1% | Louisiana | 56.6% |
| Vermont | 69.0% | Nevada | 56.6% |
| Massachusetts | 68.3% | Alaska | 56.5% |
| **Maine** | **67.9%** | Mississippi | 56.2% |
| Minnesota | 66.7% | Tennessee | 55.5% |
| Hawaii | 66.3% | South Carolina | 53.6% |
| Arkansas | 65.6% | Colorado | 53.5% |
| Pennsylvania | 65.4% | Alabama | 53.1% |
| Wisconsin | 65.3% | Georgia | 50.7% |

Table 2.9 above shows a somewhat similar pattern of states with higher and lower percentages of beneficiaries qualifying for SSI due to mental disorders as those who qualify for SSDI in this diagnostic group (table 2.4). Note that this diagnostic group accounts for much higher percentages of SSI beneficiaries in all states than it does for the SSDI population. Additionally, this data includes children under 18.

Comparing the average monthly SSI benefit paid to Maine adults to the national average shows that Maine beneficiaries receive lower SSI payments, as seen in table 2.10.

***Table 2.10 Average Monthly SSI Benefit for Adults in the United States and Maine by Age Group, 2013[*]***

| | Average Benefit | |
|---|---|---|
| | 18-64 | 65 or Older |
| United States | $546 | $425 |
| Maine | $496 | $301 |

Likewise, monthly payments by eligibility category are lower in Maine compared to the national average, shown in table 2.11. This data includes children under 18.

***Table 2.11 Average Monthly SSI Benefit in the United States and Maine by Eligibility Category, 2013[†]***

| | Average Benefit | | |
|---|---|---|---|
| | Aged | Blind | Disabled |
| United States | $529 | $417 | $547 |
| Maine | $480 | $258 | $477 |

Income from SSI payments is used to offset room and board costs for MaineCare members living in nursing facilities and other institutional settings.

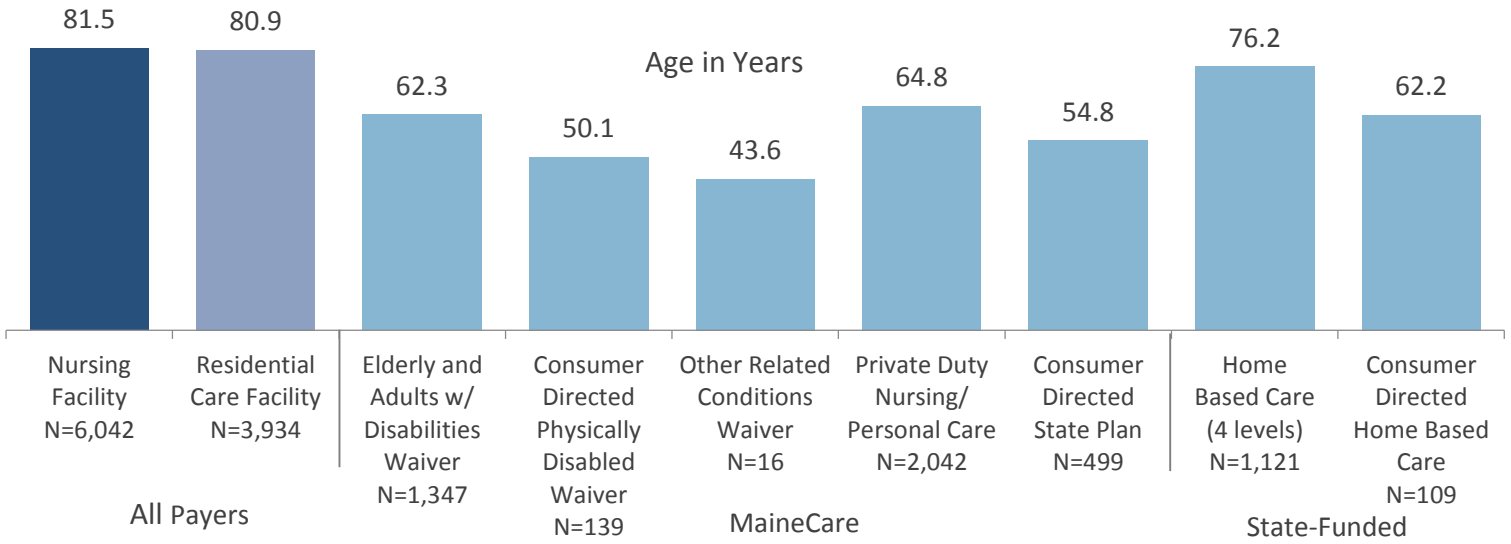
[*] Data are from SSI Annual Statistical Report, Table 11. Retrieved from https://www.socialsecurity.gov/policy/docs/statcomps/ssi_asr/2013/ November 20, 2015.

[†] Ibid.

# Section 3: Characteristics of Maine Adults who Use LTSS

## Maine's Elders and Adults with Disabilities: Data from the MDS and MED

***Figure 3.1 Average Age of Maine Long Term Services and Supports (LTSS) Users, Elders and Adults with Disabilities, 2014****

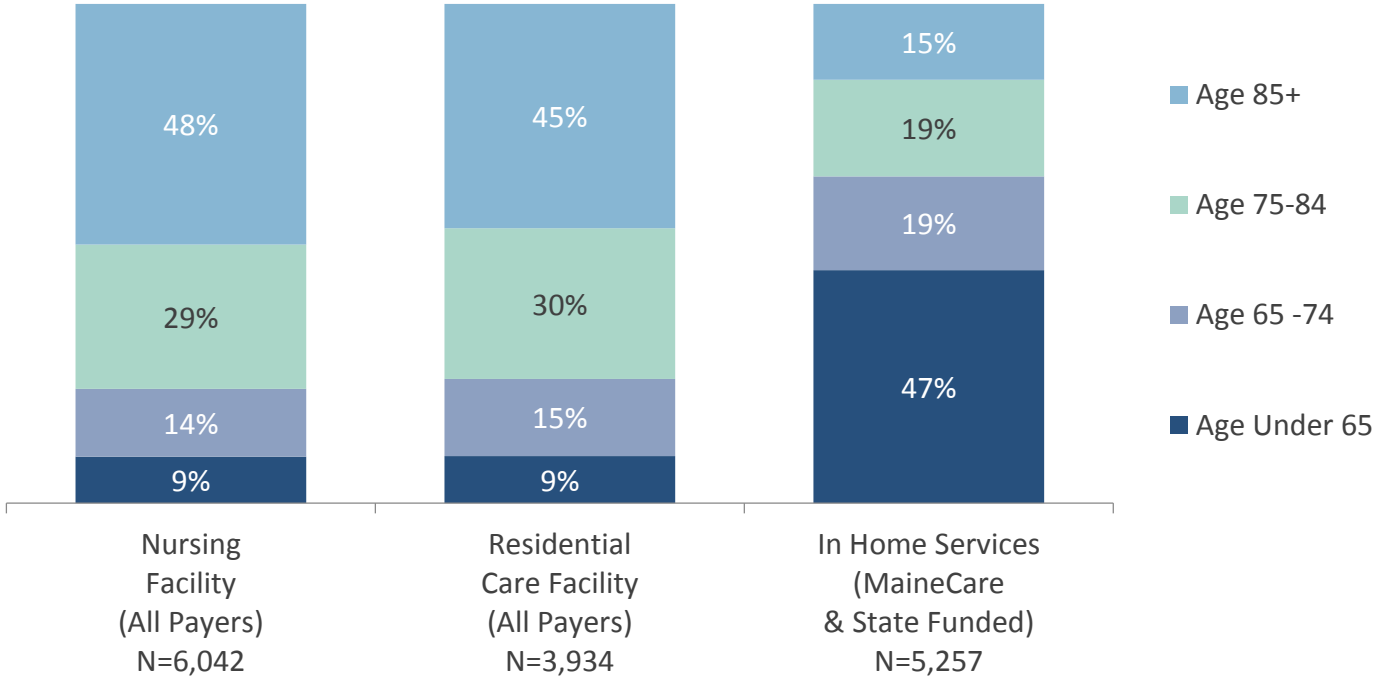



In 2014, the residents of Maine nursing facilities and case-mix reimbursed residential care facilities (Appendix C) had a similar average age of 81.5 and 80.9 respectively. Users of home and community based care tended to be younger. The average age across the four levels of Home Based Care program was 76.2. The youngest population was that served by the Other Related Conditions Waiver at 43.6. These age patterns are similar to those reported in SFY 2010, with the exception of the Elderly and Adults with Disabilities Waiver and Private Duty Nursing; the average age of these groups dropped from 63.9 to 62.3 for the waiver and from 67.0 to 64.8 for Private Duty Nursing from 2010 to 2014.†

* Point-in-time count of nursing facility and residential care residents as of 3/15/2014. All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only. ORC data from the MED

† See *Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine—2012 Edition*, University Of Southern Maine, Muskie School of Public Service. Available at http://muskie.usm.maine.edu/Publications/DA/Adults-Disabilities-Maine-Service-Use-Trends-chartbook-2012.pdf.

***Figure 3.2 Age Distribution of Maine LTSS Users by Setting, Elders and Adults with Disabilities, 2014****



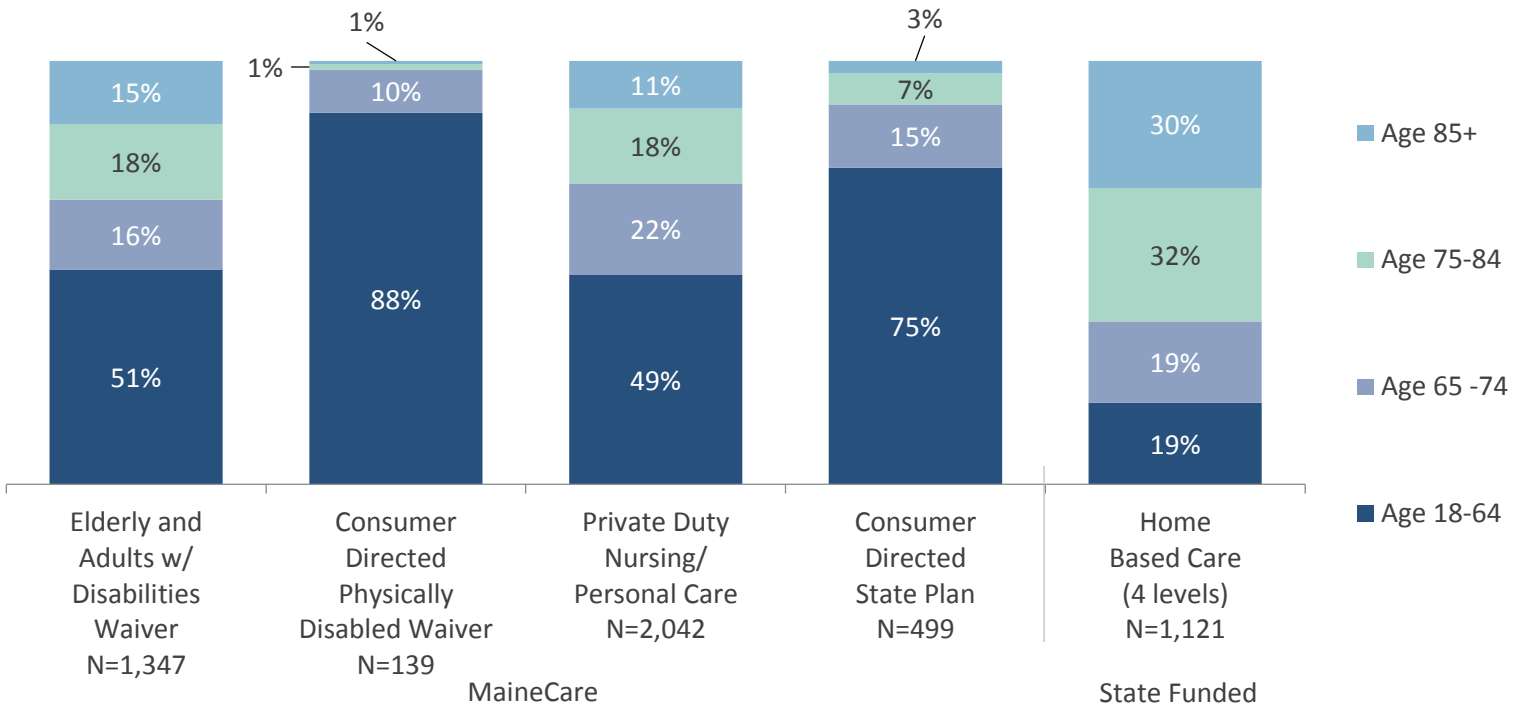

In SFY 2014, close to half of all Maine nursing facility residents and case mix residential care residents were age 85 or older. MaineCare and State funded home care services tended to be younger with only 15% of users age 85 or older. Nearly half of the home care population was under 65; this percentage increased between 2010 and 2014 from 44% to 47%†.

* Point-in-time count of nursing facility and residential care residents as of 3/15/2014. All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only.

+ In Home Services includes Personal Care Services, Private Duty Nursing, Elderly and Adult Waiver, Waiver for the Physically Disabled, and Consumer Directed Attendant Services.

† *Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine—2012 Edition*, University Of Southern Maine, Muskie School of Public Service. Available at https://usm.maine.edu/muskie/cutler/older-adults-and-adults-disabilities-population-and-service-use-trends-maine-2012-edit.

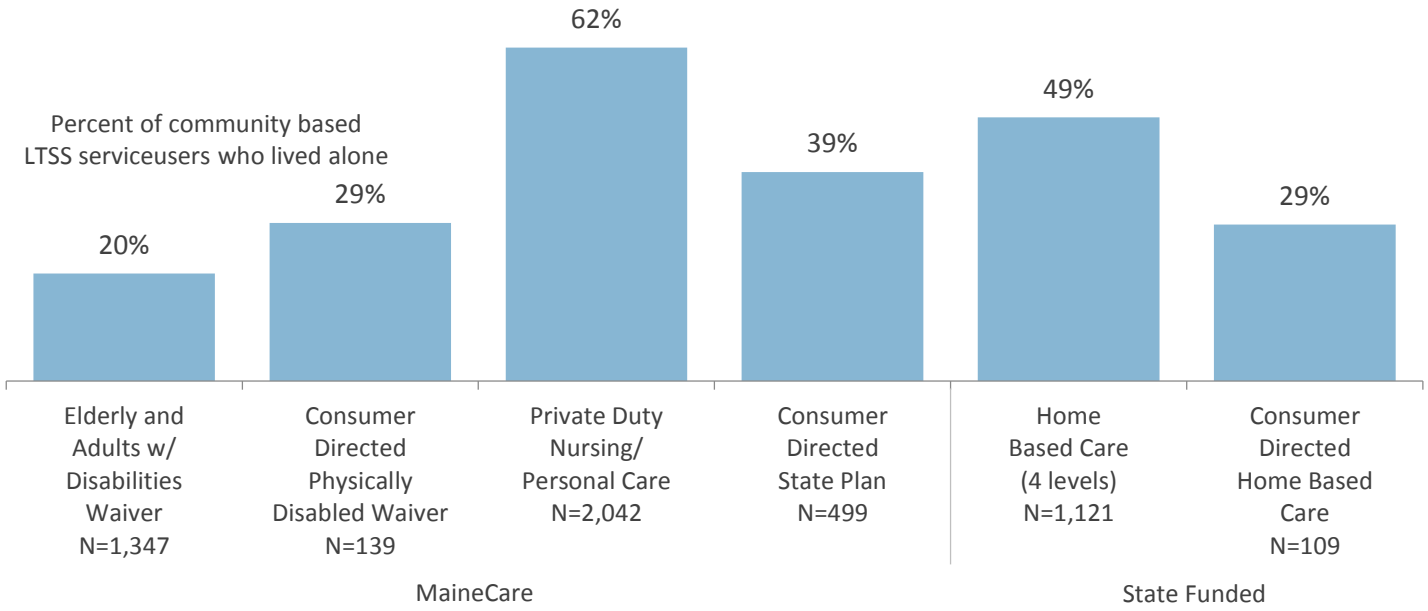
***Figure 3.3 Age Distribution of MaineCare and State-Funded LTSS Users by Program, Elders and Adults with Disabilities, 2014****




There is variation in the age distribution across the different home and community based LTSS settings serving elders and adults with physical disabilities. In SFY 2014, the four levels of state funded Home Based Care had the highest proportion of users who were 75 or older. The Physically Disabled Waiver and Consumer Directed State Plan programs serve a younger population; 88% of those on the Consumer Directed Physically Disabled Waiver and 75% of those served by the Consumer Directed State Plan were between age 18 and 65. Due to privacy regulations, we cannot show the detailed age distribution of the state funded Consumer Directed Home Based Care program on this chart. However, we can note that 64% were under age 64.

* All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only.

***Figure 3.4 Percentage of Maine Community Based LTSS Users who Lived Alone, by Program, Elders and Adults with Disabilities, 2014****

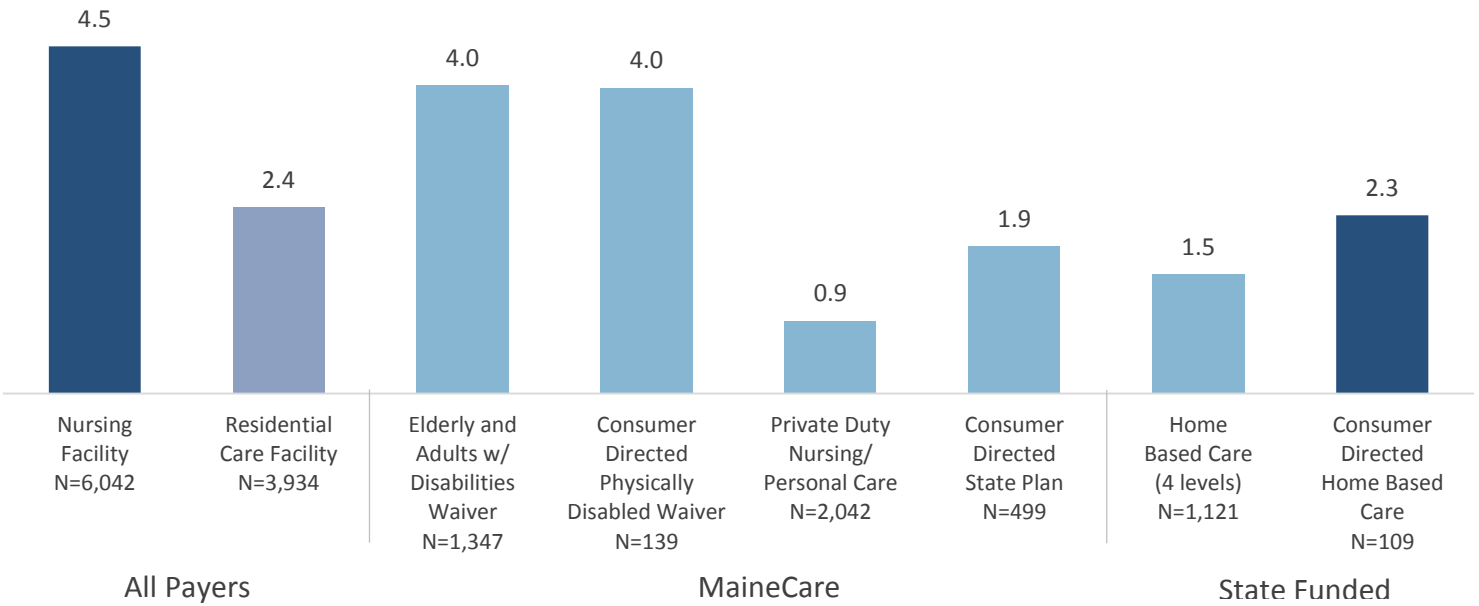



The proportion of MaineCare and state funded home and community based LTSS users who lived alone varied widely by program in SFY 2014. Users of Private Duty Nursing were the most likely to live alone, at 62%. Users of the Elderly and Adults with Disabilities Waiver were least likely to live alone, at 20%. The percentage of users of the state funded Home Based Care (across the four levels) who lived alone went down from 54% in 2010 to 49% in 2014†.

* All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only.

† *Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine—2012 Edition*, University Of Southern Maine, Muskie School of Public Service. Available at http://muskie.usm.maine.edu/Publications/DA/Adults-Disabilities-Maine-Service-Use-Trends-chartbook-2012.pdf

***Figure 3.5 Average Number out of Five Activities of Daily Living* (ADLs) Requiring Supervision or Greater Levels of Assistance, among Maine Adults Using LTSS, 2014†***



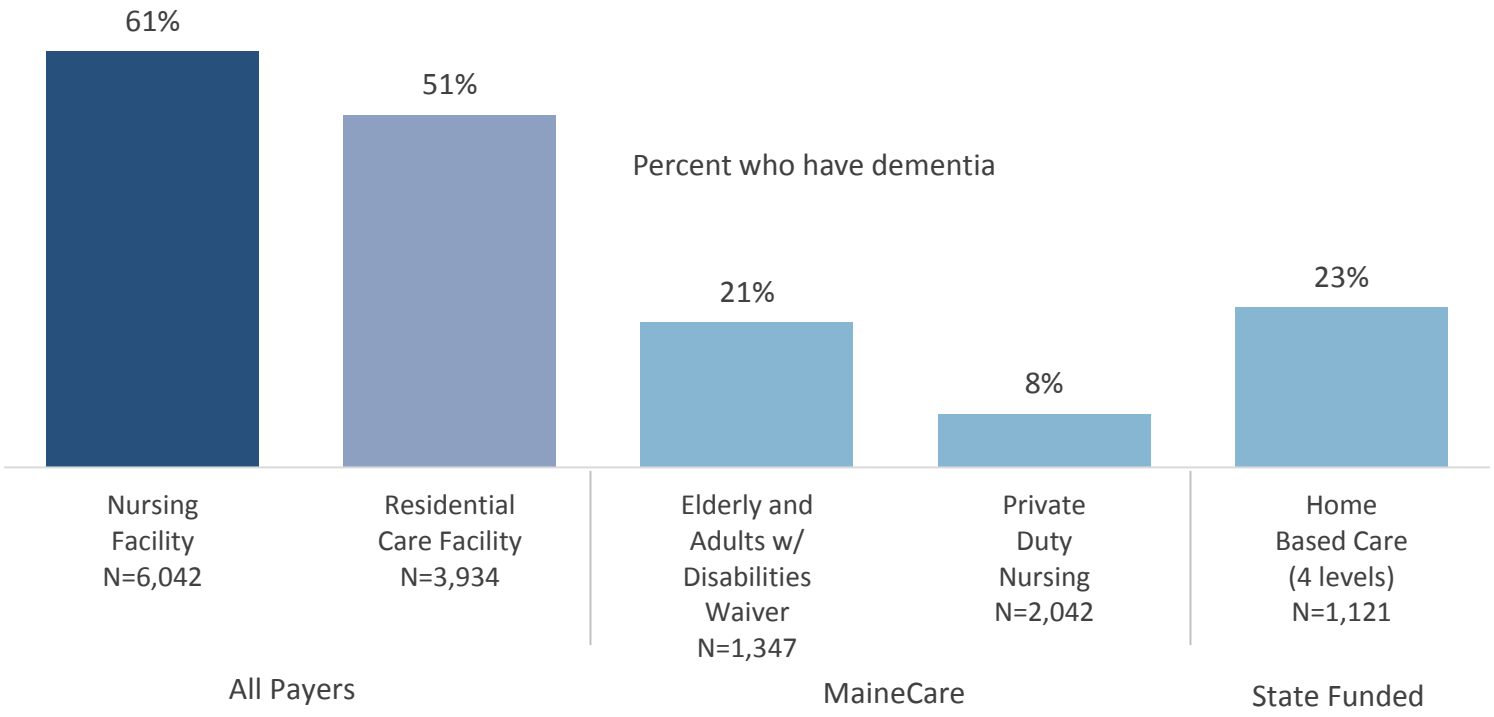

In SFY 2014, nursing facility residents required supervision or hands-on assistance with an average of 4.5 ADLs. Those in residential care facilities required supervision or hands-on assistance with an average of 2.4 ADLs; in SFY 2010, this population required such assistance in 2.0 ADLs. Users of State Plan Consumer Directed services required supervision or assistance with 1.9 ADLs, down from 2.3 in SFY 2010. Users of waiver services, Private Duty Nursing, and state funded Home Based Care did not experience changes in the average number of ADLS requiring supervision or assistance since 2010.‡

* The five ADLs measured include bed mobility, transferring, locomotion, eating, and toileting.

† Point-in-time count of nursing facility and residential care residents as of 3/15/2014. All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only.

‡ *Older Adults and Adults with Physical Disabilities: Population and Service Use Trends in Maine—2012 Edition*, University Of Southern Maine, Muskie School of Public Service. Available at http://muskie.usm.maine.edu/Publications/DA/Adults-Disabilities-Maine-Service-Use-Trends-chartbook-2012.pdf

***Figure 3.6 Percentage of Maine LTSS Users who have Dementia by Setting, Elders and Adults with Disabilities, 2014****




The proportion of Maine LTSS users who have dementia varies by program. Those using Private Duty Nursing had the lowest reportable percentage of dementia at 8%, while those using nursing facilities services had the highest at 61%. While there were users of both Consumer Directed State Plan and state funded services who had dementia, privacy regulations prohibit us from reporting the percentage when it would show fewer than 11 people. There were no users of the Consumer Directed Physically Disabled Waiver services with dementia.

* Point-in-time count of nursing facility and residential care residents as of 3/15/2014. All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only.

***Table 3.1 Prevalence of Selected Diagnoses among Maine LTSS Users by Program, Elders and Adults with Disabilities, 2014[*]***

| Diagnosis | Nursing Facility (All Payers) N=6,042 | Residential Care Facility (All Payers) N=3,934 | Elderly and Adults w/ Disabilities Waiver N=1,347 | Physically Disabled Waiver N=139 | Private Duty Nursing N=2,042 | Consumer Directed State Plan N=499 | Home Based Care (4 levels) N=1,121 | Consumer Directed Home Based Care State Funded N=109 |
|---|---|---|---|---|---|---|---|---|
| Hypertension | 67% | 72% | 51% | 30% | 65% | 51% | 72% | 51% |
| Depression | 55% | 45% | 48% | 40% | 54% | 57% | 47% | 44% |
| Any Dementia | 61% | 51% | 21% | 0% | 8% | NA | 23% | NA |
| Anemia | 25% | 21% | 15% | NA | 16% | 15% | 16% | 56% |
| Diabetes | 30% | 30% | 30% | 19% | 40% | 34% | 36% | 29% |
| Arthritis | 25%[†] | 23% | 40% | 37% | 57% | 59% | 62% | 22% |
| Osteoporosis | 15%[†] | 22% | 18% | 18% | 18% | 15% | 21% | 12% |

The MDS and MED collect information on different diagnoses among users of LTSS in different settings. Hypertension was one of the most common diagnoses across the different service settings, but this varied by setting from 30% of Physically Disabled Waiver users to 72% of Residential Care facility users. Depression also ranked high among LTSS users but with less variation across settings. Beginning in October 2010, the MDS collected diagnosis information on arthritis and osteoporosis only on the comprehensive assessment, not on the quarterly assessment, for those in nursing facilities. This change in data collection prevents comparisons of the prevalence rates of these two diagnoses with those reported in earlier chartbooks. The table shows NA when there were fewer than 11 members identified.

[*] Point-in-time count of nursing facility and residential care residents as of 3/15/2014. All home care data are based on the latest SFY 2014 MED assessment for each person who had an assessment for any home care service during the fiscal year. Private Duty Nursing includes Levels I, II, III for adults only.

[†] Data on "Arthritis" and "Osteoporosis" for the NF population are from the most current comprehensive assessment available for each resident, as it is the only assessment that collects this information.

## Maine Adults with ID/ASD: Data from the Supports Intensity Scale

The Supports Intensity Scale (SIS) is a nationally recognized and normed tool designed to assess the actual supports needed by an individual with intellectual disability or autism spectrum disorder in order 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. Support needs in 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 Maine Office of Aging and Disability Services has been using the SIS to assess the practical support requirements of adults with intellectual disabilities who are served by the Section 21 Comprehensive ID/ASD waiver with the following goals:[†]

- To use the same tool for everyone.
- To find out what each person's needs are for support.
- To be flexible when a person's needs change.
- To make sure that each person gets the resources they need.
- To increase person-centeredness, self-direction, employment and community inclusion.
- To have case managers use the SIS results in Person Centered Planning.
- To look at interview results and review the cost of services provided.
- To complete a SIS interview once every three years for each consumer.

[*] From "Product Information" web page, at http://aaidd.org/sis/product-information#.VS_ikmOZj7X retrieved April 16, 2015.

[†] From "Supporting Individual Success" web page at http://www.maine.gov/dhhs/oads/trainings-resources/initiatives/sis.html retrieved October 18, 2015.

*Table 3.2 Distribution of Assessed Adults on the Section 21 Comprehensive ID/ASD Waiver by SIS Level*[*]

| Level | Number of Individuals | Percent |
|---|---|---|
| **1** | 620 | **20%** |
| **2** | 1,009 | **32%** |
| **3** | 849 | **27%** |
| **4** | 326 | **10%** |
| **5** | 332 | **11%** |
| **Total** | 3,136 | **100%** |

Table 2.3 shows the distribution of users of the Section 21 Comprehensive ID/ASD waiver according to their assessed level on the Supports Intensity Scale, as of October 30, 2015. Over half (52%) of the users of these waiver services were assessed to have low to moderate supports needs. The table on the following pages describes the support needs of people assessed at these different levels.

[*] Email communication from Maine Office of Aging and Disability Services, received November 2, 2015.

*Table 3.3 Expanded Descriptions of Maine SIS Support Levels*[*]

| Level | Description of Supports Needs |
|---|---|
| 1 | Adults in this level have low support needs, including little to no support need for medical and behavioral challenges. They can manage many aspects of their lives independently or with little assistance. This includes instrumental activities like eating or dressing, as well as daily living activities such as shopping or going out into the community. Supports are typically intermittent rather than 24 hours a day, 7 days a week (24/7).<br><br>Someone in this level may need supports with clothing care, preparing meals, and dressing. Often support needed involves some monitoring or prompting instead of partial to full physical support. They may need intermittent help participating in leisure activities, gaining and maintaining employment, visiting family and friends, or assistance with shopping. They may be able to ambulate or need little to no help moving about, but need help with health practices that include maintaining a nutritious diet and/or taking medications. |
| 2 | Adults in this level have moderate support needs and little to no support need for medical and behavioral challenges. Although they need more support than those in Level 1, their support needs are minimal in a number of life areas. They may also receive intermittent daily support rather than 24/7.<br><br>An individual in this level may need some assistance preparing and eating meals, they might need monitoring or prompting with daily dressing, and daily assistance with housekeeping and laundry. They may need support getting from place to place, gaining and maintaining employment, accessing public services or interacting with community members. In this level, they most likely will need partial physical assistance taking medications, avoiding health and safety concerns and maintaining a healthy diet. |
| 3 | Adults in this level have either:<br>• Low to moderate support needs as in Levels 1 & 2 but also above average, non-extensive support need due to behavioral challenges; or<br>• Above average support needs and up to above average, non-extensive support need due to behavioral challenges.<br><br>Adults in this level may need 24/7 supports due to their daily support needs and/or behavioral challenges. In this level, an individual will most likely need daily assistance preparing food, eating meals, dressing, and bathing. This could range from monitoring, but will most likely include partial to full physical assistance for some supports including gaining and maintaining employment, accessing community activities; such as, visiting friends and family members, or participating in preferred community activities. They will most likely need at least partial physical assistance obtaining health care. They may also have behavioral support needs that lie outside of overall living activity supports. This could include support with prevention of outbursts, or monitoring for wandering. |

[*] From http://www.maine.gov/dhhs/oads/disability/ds/sis/documents/MaineLevelExpandedLevelDescriptions20140718.pdf retrieved on April 16, 2015.

| | |
|---|---|
| **4** | Adults in this level have either:<br>• High to maximum support needs; or<br>• Significant need for support due to medical conditions.<br><br>They have behavioral support needs that are not significant but can range from none to above average. Adults in this level may need additional 24/7 supports due to their daily support needs and/or medical conditions.<br><br>Support needs may include partial to full physical assistance with eating and preparation of meals, dressing, and all household activities. An individual in this level may have difficulty ambulating, and therefore needs full physical help accessing the community. In order to maintain health and safety, an individual in this level will likely need full support in meal planning, obtaining health care and taking medications. Support for medical issues may also be required to ensure people in this level are able to participate in employment activities. |
| **5** | All adults in this level have significant behavioral challenges, regardless of their support need to complete daily activities or for medical conditions. Adults in this level may need enhanced 24/7 supports due to their behavioral challenges.<br><br>• Individuals that meet Level 5 criteria due to behavioral challenges, and have significant medical need (Section 3A score higher than 7) may require additional review to ensure their medical and behavioral needs are addressed appropriately.<br><br>In this level, an individual has behavioral support needs that are exceptional and require a great amount of assistance. They may have lower support needs in daily living activities but require full physical assistance of support staff to prevent harm to themselves or others. Support needs in this domain include prevention of pica, sexually aggressive behavior, wandering and tantrums, or other forms of self-harm. Given the behavioral challenges experienced by people in this level, employment supports will need to be highly specialized. |

# Section Four: MaineCare Claims Analysis of Adults Who Use LTSS, by Category, SFY 2014

Adults who use LTSS in Maine vary in their use of MaineCare services and the expenditures associated with them. Some use a wide range of MaineCare services whereas others use fewer. While the total number of adult MaineCare members who used LTSS in SFY 2014 and the expenditures on LTSS programs is shown on table O.1 in the Overview, this next section describes a subset of LTSS users in different service settings and their use of all types of MaineCare services.

*This section aims to provide a broad picture of how adults needing LTSS use the variety of available MaineCare services, including primary, acute, and other non-LTSS services. It does not provide an analysis of a particular LTSS program's expenditures. Therefore, the numbers reported here may not match those in other program-level analyses.*

In order to conduct this focused analysis of the claims experience of members using different MaineCare LTSS programs, we established a hierarchy of adult MaineCare LTSS users based on the intensity of the services provided by setting, and the members' eligibility for MaineCare for at least eleven months during the SFY 2014. Members were placed in the hierarchy according to either the length of time they used a particular LTSS service, such as nursing facility care for 6 or more months, or through identification by OADS as belonging to a specific category, as in the case of members with acquired brain injury and members with other related conditions.

The members in higher intensity categories were then excluded from the categories of lesser intensity for the purposes of tracking the service use and expenditures associated with being a member of a particular category. Members of any one category may have used the services of one of the other programs during the year, but their placement in a particular category signifies that they were members of that category for a majority of the fiscal year. Utilization rates are presented for services used by at least 10% of members of an LTSS category except when doing so would identify fewer than 11 people. A more detailed description of how we determined the hierarchy groupings can be found in Appendix A at the end of this chartbook. Descriptions of many of the services noted on these charts can be found in the Glossary in Appendix C.

An additional analysis of quality indicators at the end of this section shows how the different categories of LTSS users fare on select quality measures including emergency department use, re-hospitalizations, and access to primary care.

Table 4.1 shows the 13 hierarchical categories we established for this analysis, the distinct number of members in each category, and the total MaineCare dollars spent on the members in each category. Again, the total expenditures are not just for the LTSS, but also for the non-LTSS MaineCare services used by these members throughout the year. It includes medical and pharmacy costs.

*Table 4.1 Hierarchical Categories of MaineCare LTSS Users, SFY 2014*[*]

| Hierarchy Categories | Distinct Members Assigned to Category | Total Cost |
|---|---|---|
| Acquired Brain Injury | 1,450 | $60,043,040 |
| ICF-IID (Nursing) | 136 | $29,937,084 |
| NF Excluding Residents with ID/ASD | 3,638 | $195,170,015 |
| NF Residents with ID/ASD | 55 | $3,724,679 |
| ICF-IID (Group) | 35 | $5,728,106 |
| Residential Care Facility (Appendix C) | 2,746 | $83,946,956 |
| Residential Care Facility (Appendix F) | 293 | $20,648,713 |
| Section 21 Comprehensive ID/ASD | 2,743 | $294,751,199 |
| Section 29 Supports ID/ASD | 1,112 | $25,976,378 |
| Section 19 Elder / Section 22 PDW | 1,009 | $38,983,191 |
| Adult Family Care Home | 184 | $4,905,892 |
| Non-Waiver MaineCare Home Care Services | 2,611 | $51,074,410 |
| Case Management-ID/ASD | 673 | $12,704,058 |
| **Totals:** | **16,685** | **$827,593,720** |

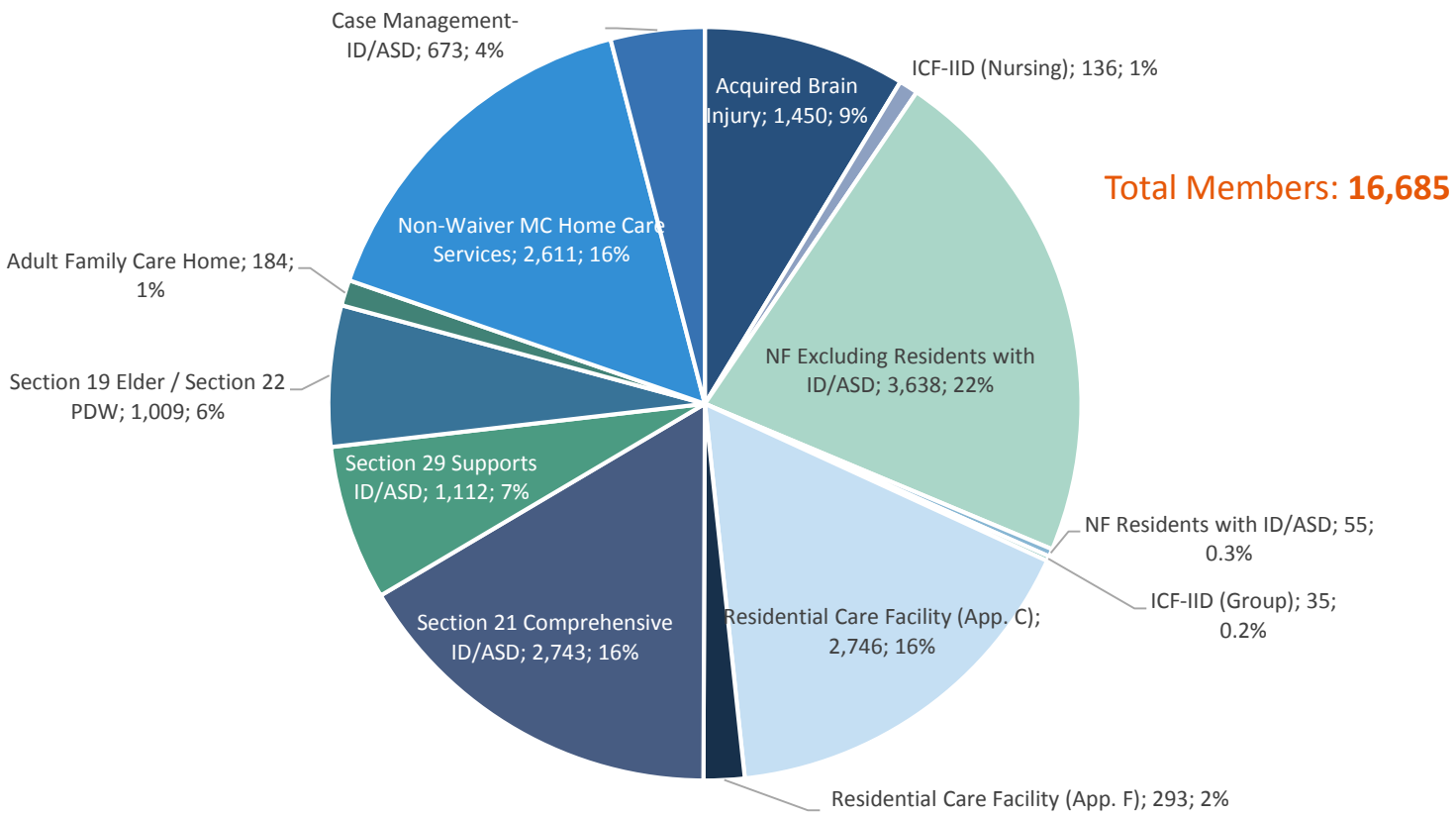
We placed ABI at the top of the hierarchy in order to isolate expenditures for this population which might have been otherwise grouped into a lower level such as Residential Care Facility (Appendix F). We placed ICF-IID (Nursing) above the nursing facility categories due to the intensity of developmental services available to members in these ICFs; and we placed the ICF-IID (Group) below the nursing facility categories due to the lower level of nursing care required these residents. Nursing Facility residents with ID/ASD were identified through MDS assessment data. The Section 19 and Section 22 waivers were combined in this analysis as these two waivers were combined beginning in December 2014. Non-waiver Home Care includes a wide range of care from consumer directed attendant services and assistance with ADLs to higher intensity personal care and nursing services.

The Section 20 waiver for Adults with Other Related Conditions was in a transition period during SFY 2014, with some members' costs paid for through the Money Follows the Person program. Therefore, we did not include ORC waiver members in this analysis. Expenditures paid under the ORC Waiver totaled $282,268 in SFY 2014[†]; waiver expenditures in SFY 2015 will be higher as more participants are fully paid for under the waiver.

[*] Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS. Expenditures identified in MIHMS for SFY 2014. Members in the ABI category were identified through **any** use of brain injury service during the year, not six months of use as in the other categories; therefore, this group may include members with just a few months of brain injury service. Further explanation of how we established the hierarchy groups can be found in Appendix A of this chartbook.

[†] Data received via email communication from OADS on November 10, 2015.

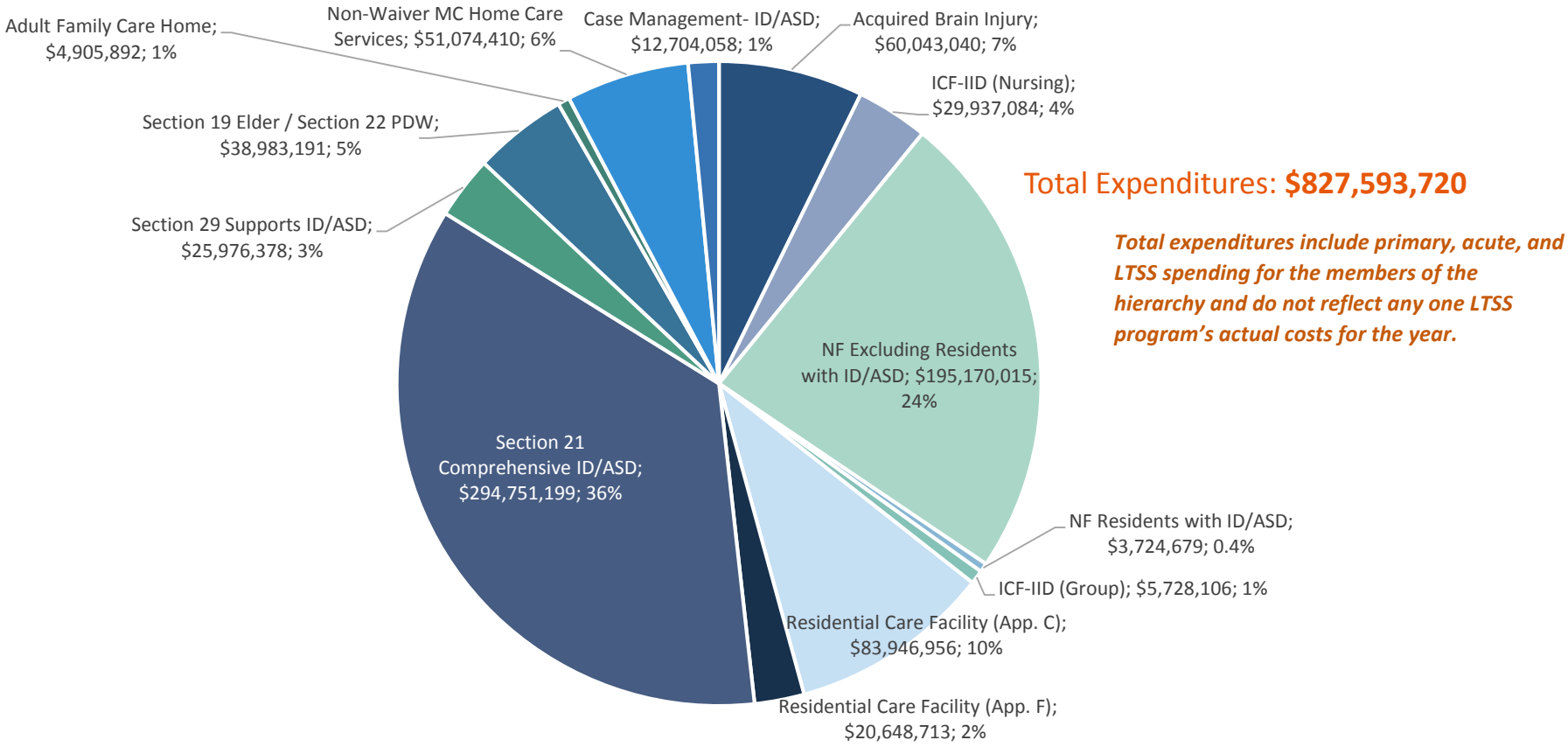
***Figure 4.1 Distribution of Adult MaineCare Members Using LTSS, by Category, SFY 2014****




Adult members served in nursing facilities, residential care facilities (App. C), and by the elder and physically disabled waivers accounted for 44% of adults identified in the LTSS hierarchy. Adults served by the residential care facilities (App. F) and the HCBS waivers for ID/ASD accounted for 25% of adults in the LTSS hierarchy.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS. Expenditures identified in MIHMS for SFY 2014. Members in the ABI category were identified through MaineCare ID with **any** use of brain injury service during the year, not six months of use as in the other categories; therefore, this group may include members with just a few months of brain injury service. Further explanation of how we established the hierarchy groups can be found in Appendix A of this chartbook. Residential care facilities described in this chartbook are authorized under either Appendix C or Appendix F of the MaineCare Benefits Manual. Appendix C facilities primarily serve older adults and adults with physical disabilities, and Appendix F facilities serve a variety of special populations including adults with acquired brain injury, ID/ASD, substance abuse or mental illness, or who are served by Maine Adult Protective Services.

***Figure 4.2 Distribution of Total MaineCare Expenditures for Adults using LTSS, by Category, SFY 2014****




Total Expenditures: **$827,593,720**

***Total expenditures include primary, acute, and LTSS spending for the members of the hierarchy and do not reflect any one LTSS program's actual costs for the year.***

The categories with the highest expenditures in SFY 2014 in the hierarchy were the Nursing Facility (excluding residents with ID/ASD) and the Section 21 Comprehensive ID/ASD waiver. Nursing Facility (excluding residents with ID/ASD) accounted for 22% of the LTSS population and 24% of expenditures. Section 21 Comprehensive ID/ASD accounted for 16% of the LTSS population and 36% of expenditures.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS. Expenditures identified in MIHMS for SFY 2014. Members in the ABI category were identified through MaineCare ID with **any** use of brain injury service during the year, not six months of use as in the other categories; therefore, this group may include members with just a few months of brain injury service. Further explanation of how we established the hierarchy groups can be found in Appendix A of this chartbook.

***Figure 4.3 Average Annual per Person Total MaineCare Expenditure for Adults Using LTSS, by Category, SFY 2014****

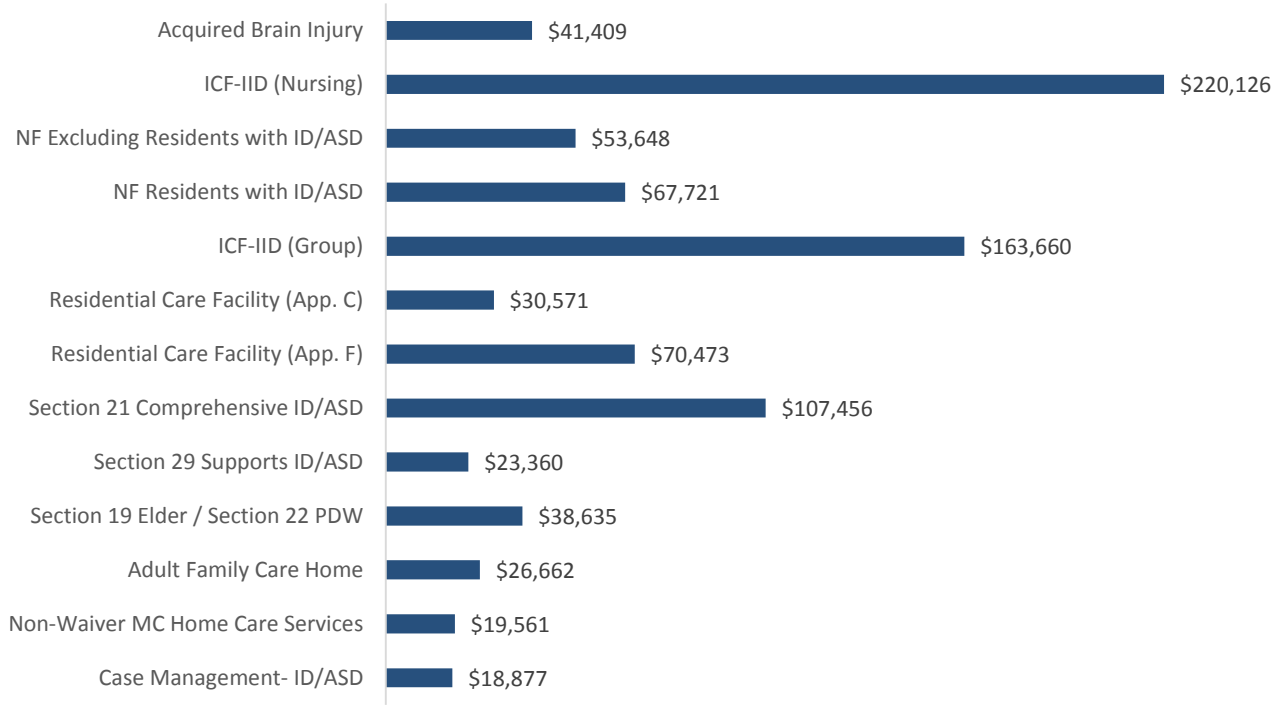
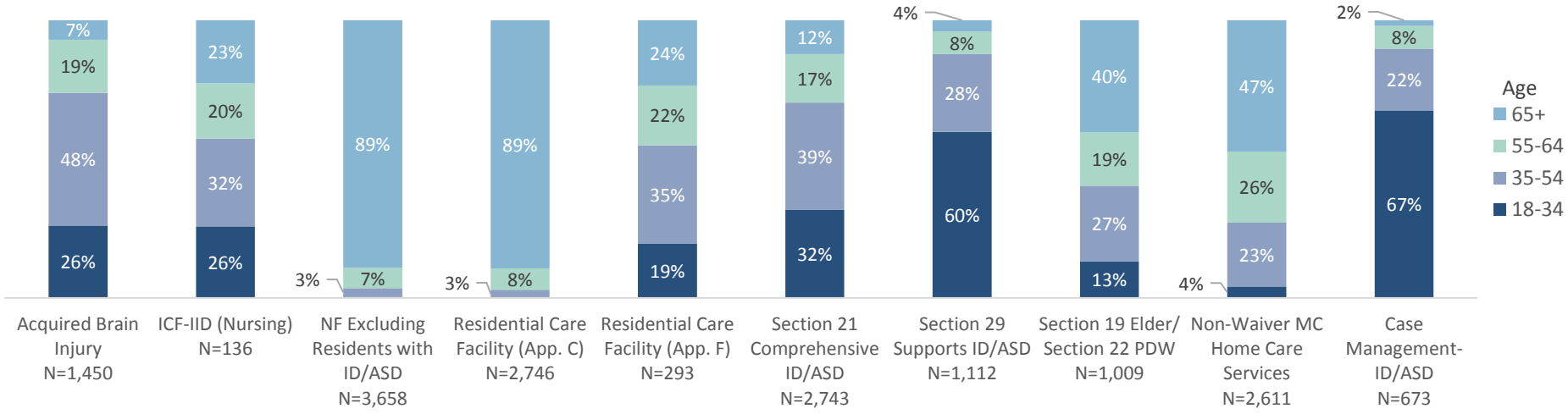
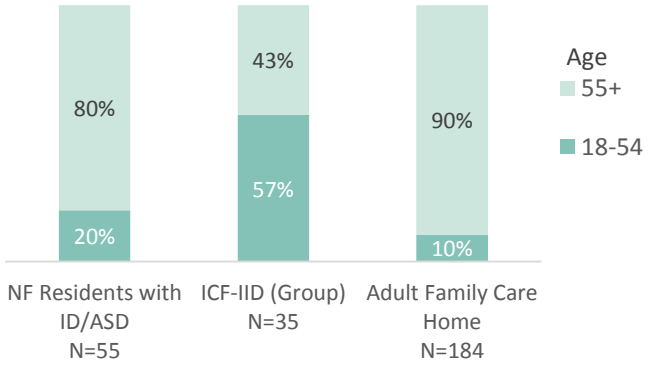



Figure 4.3 shows the average total annual per person MaineCare LTSS **and** non-LTSS expenditures by group, based on the hierarchy established for this analysis. The highest total per person annual expenditure was for adults in the ICF-IID (Nursing) category followed by ICF-IID (Group), and then the Section 21 Comprehensive ID/ASD waiver. Note that on the preceding charts, adults using either level of ICF-IID care accounted for just over 1% of members and 5% of MaineCare expenditures identified in this hierarchy. Please note that this chart is not reflective of actual program level cost.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS. Expenditures identified in MIHMS for SFY 2014. Members in the ABI category were identified through MaineCare ID with **any** use of brain injury service during the year, not six months of use as in the other categories; therefore, this group may include members with just a few months of brain injury service. Further explanation of how we established the hierarchy groups can be found in Appendix A of this chartbook.

### *Figure 4.4 Age Distribution of Adult MaineCare Members across LTSS Categories, SFY 2014**




These figures illustrate the variation in age distribution of members served in the different LTSS settings. The chart above shows that members in the NF (excluding residents with ID/ASD) and Residential Care Facilities (App. C) categories are, primarily, over 65. The members in the ABI, waivers for ID/ASD, and Case Management-ID/ASD categories are, primarily, a younger population. Columns may not add to 100% due to rounding.

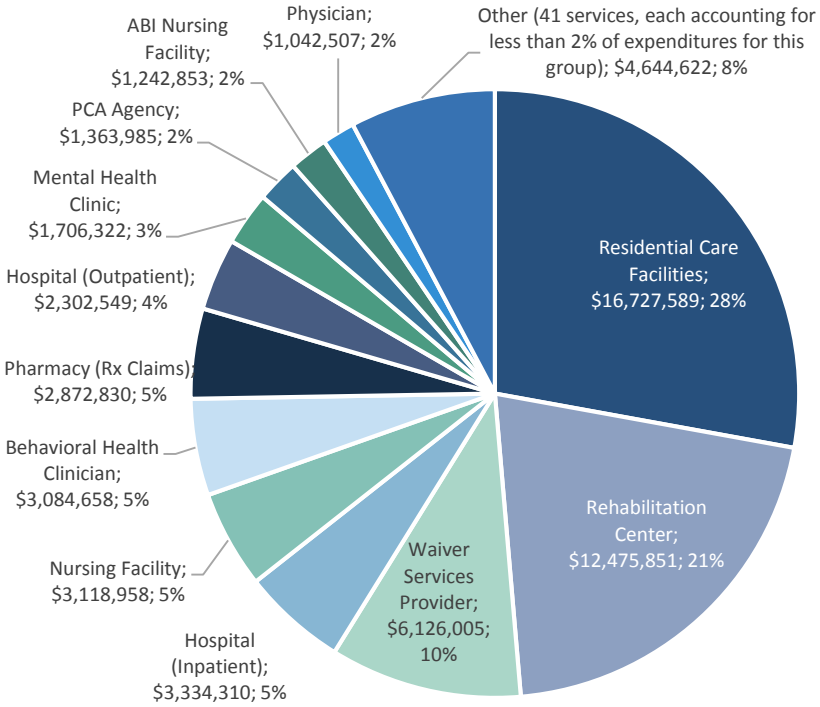
The figure on the left shows the smaller categories of LTSS users. Due to privacy regulations, we are unable to show the more detailed age breakdowns when doing so would identify fewer than 11 people.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS. Expenditures identified in MIHMS for SFY 2014. Members in the ABI category were identified through MaineCare ID with **any** use of brain injury service during the year, not six months of use as in the other categories; therefore, this group may include members with just a few months of brain injury service. Further explanation of how we established the hierarchy groups can be found in Appendix A of this chartbook.

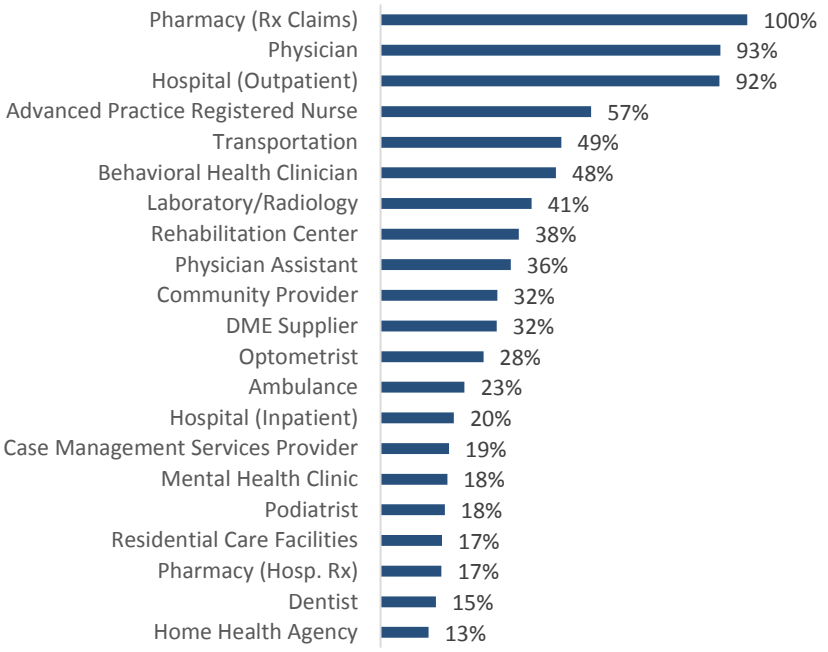
## Acquired Brain Injury

***Figure 4.5 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Acquired Brain Injury Category, SFY 2014****

**Total Expenditures: $60,043,040**




**Utilization Rates for 1,450 Members in this Category**



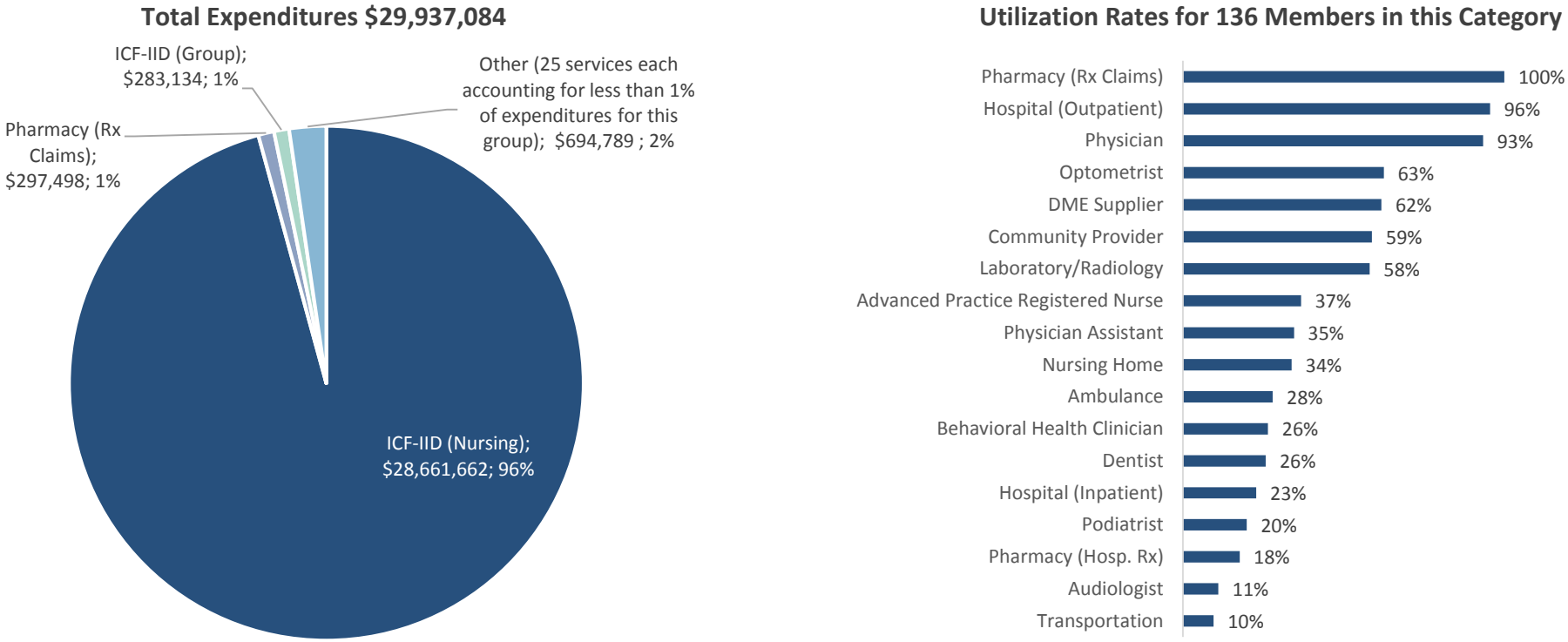

These figures show that residential care facilities make up 28% of expenditures, while only 17% of members in this category used these services. The majority of these facilities are for Appendix F facilities, although there are some Appendix C facility expenditures included in this figure as well.

The figure above shows utilization rates of services used by at least 10% of members of this category. While many members used a wide variety of MaineCare services, these services did not account for a significant proportion of overall costs. Most of the services fall into the "Other" category on the Expenditures chart, each accounting for less than 2% of total costs.

* Members identified through a combination of using MaineCare IDs and data from MIHMS. Expenditures identified in MIHMS for SFY 2014. Members in this category were identified through **any** use of brain injury service during the year. This group may include members with just a few months of brain injury service. Further explanation of how we established the hierarchy groups can be found in Appendix A of this chartbook.

## ICF-IID (Nursing)

***Figure 4.6 Total MaineCare Expenditures and Service Utilization Rates for Adults in the ICF-IID (Nursing) Category, SFY 2014****




ICF-IID (Nursing) care provides at least 8 hours of licensed nursing care, physical and occupational therapies, speech and hearing services, as well as individual developmental training that can include training in ADL skills; communication skills, physical development; behavior modification; work adjustment; and supported employment. The ICF-IID (Nursing) service accounts for the vast majority of expenditures for members in this category.

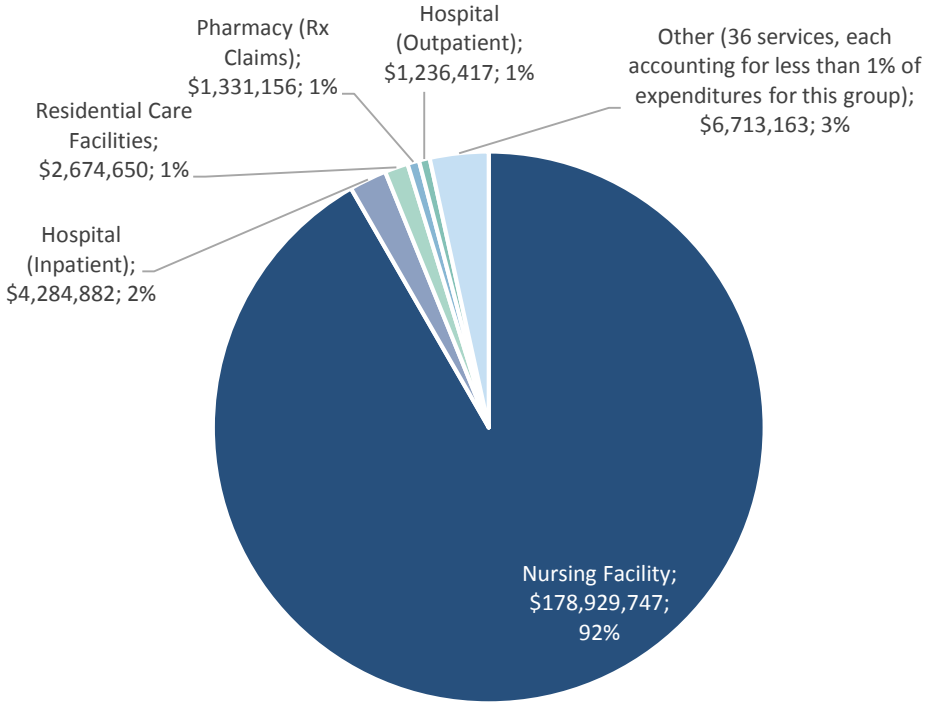
While ICF-IID (Nursing) care accounts for most of the MaineCare expenditures for this category, the chart above shows that these members utilize a wider variety of MaineCare services.

* Members and expenditures identified in MIHMS for SFY 2014.

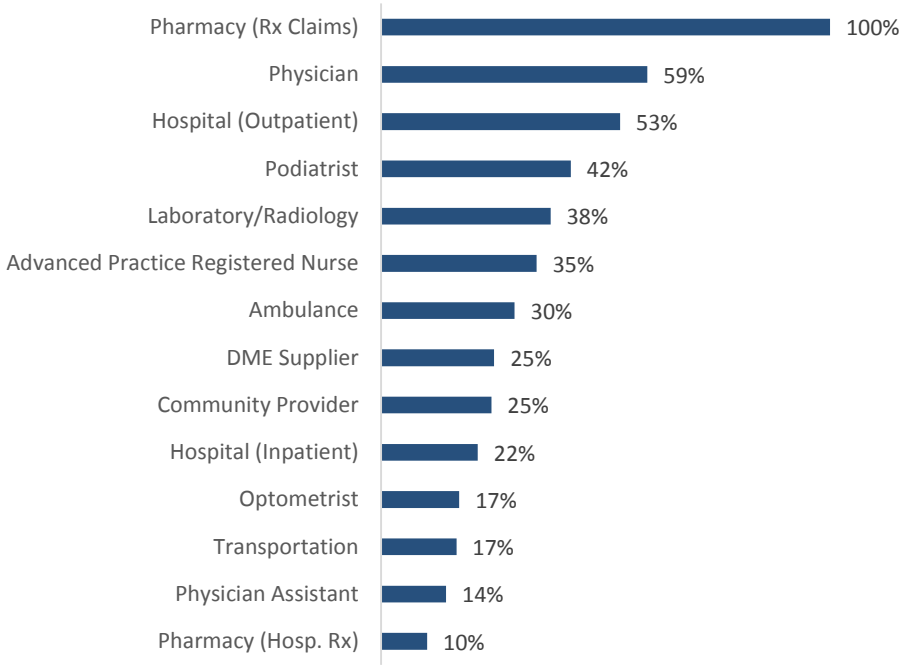
## Nursing Facility, Excluding Residents with ID/ASD

***Figure 4.7 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Nursing Facility (Excluding Residents with ID/ASD) Category, SFY 2014****

**Total Expenditures: $195,170,015**




**Utilization Rates for 3,638 Members in this Category**




The majority of MaineCare expenditures for adults in the Nursing Facility (excluding residents with ID/ASD) category are for the facility services themselves.

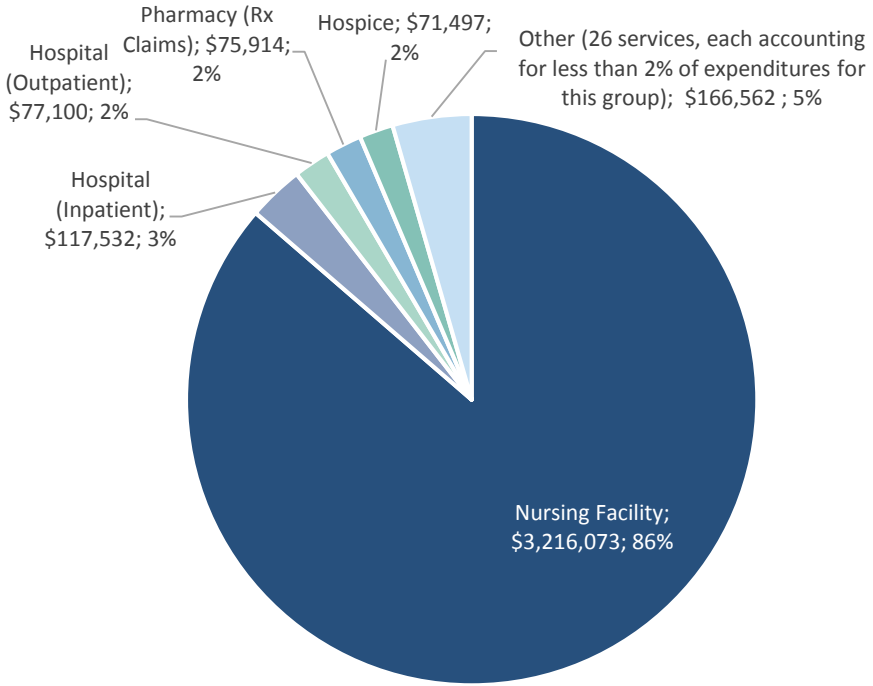
The chart above shows some of the variety of services used by adults in nursing facilities. Included in this chart are services used by at least 10% of members of this group.

* Members identified through a combination of MDS data and data from MIHMS. Expenditures identified in MIHMS for SFY 2014.

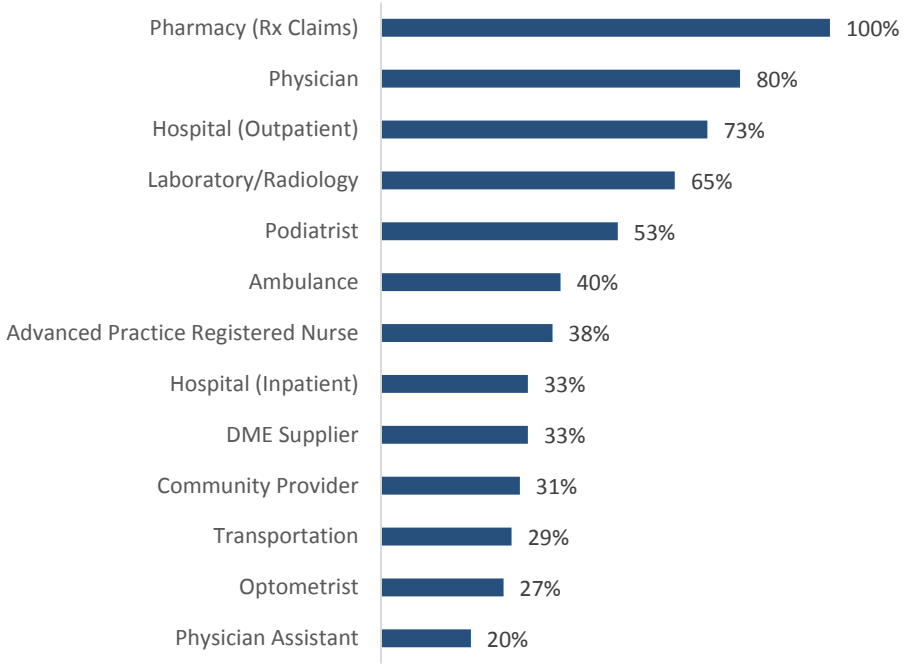
## Nursing Facility Residents with ID/ASD

***Figure 4.8 Total MaineCare Expenditures and Service Utilization Rates for the Adults with ID/ASD in Nursing Facilities Category, SFY 2014****

**Total Expenditures: $3,724,679**




**Utilization Rates for 55 Members in this Category**




There was a small group of adults who used nursing facility services for six or more months during SFY 2014 who were identified via the MDS as having ID/ASD. Similar to adults in nursing facilities who do not have ID/ASD, the facility services accounted for the majority of expenditures.

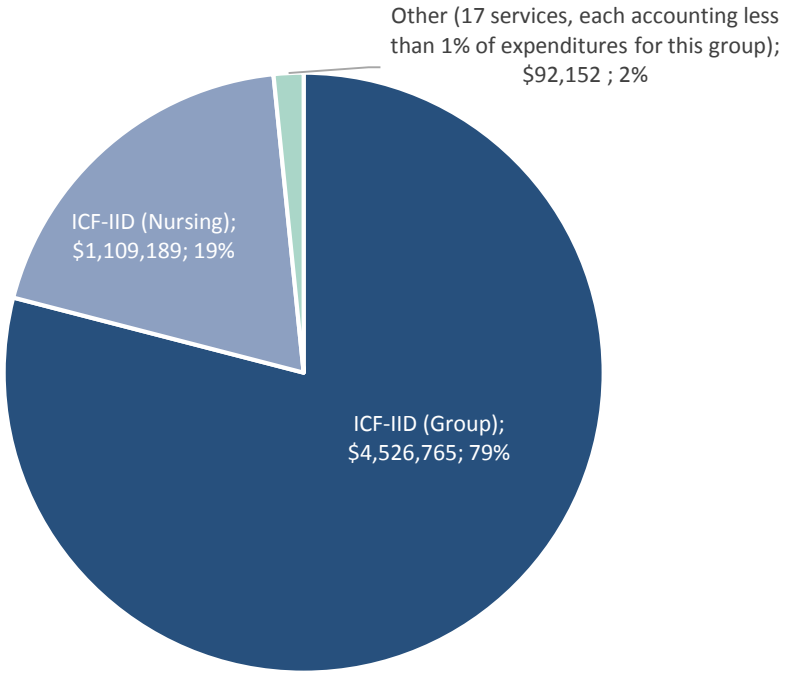
The service utilization chart shows services used by at least 20% of this population, the smallest proportion that we are able to show due to privacy regulations. Other services were used by members of this category, but by fewer than 11 people.

* Members identified through a combination of using MDS data and data from MIHMS. Expenditures identified in MIHMS for SFY 2014.

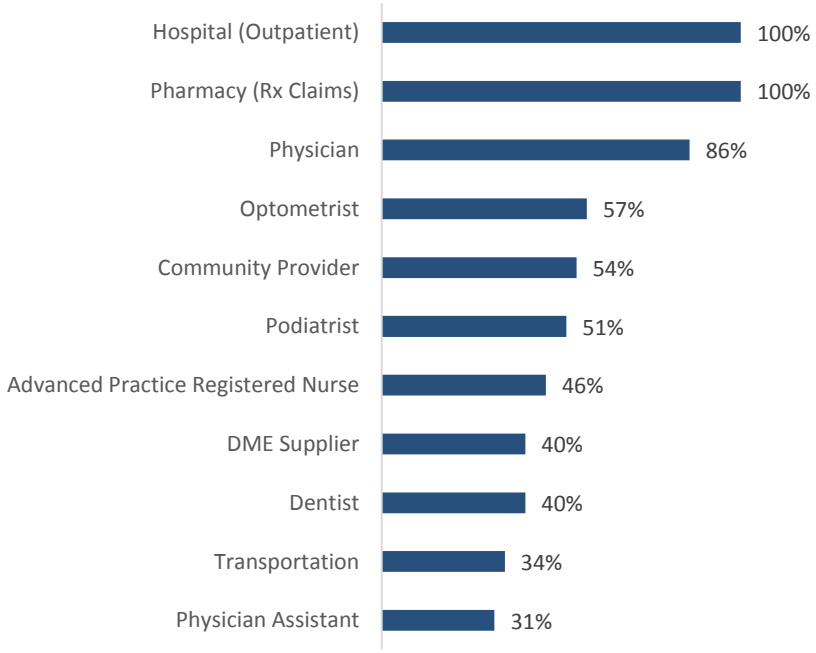
## ICF-IID (Group)

***Figure 4.9 Total MaineCare Expenditures and Service Utilization Rates for Adults in the ICF-IID (Group) Category, SFY 2014****

**Total Expenditures: $ 5,728,106**




**Utilization Rates for 35 Members in this Category**



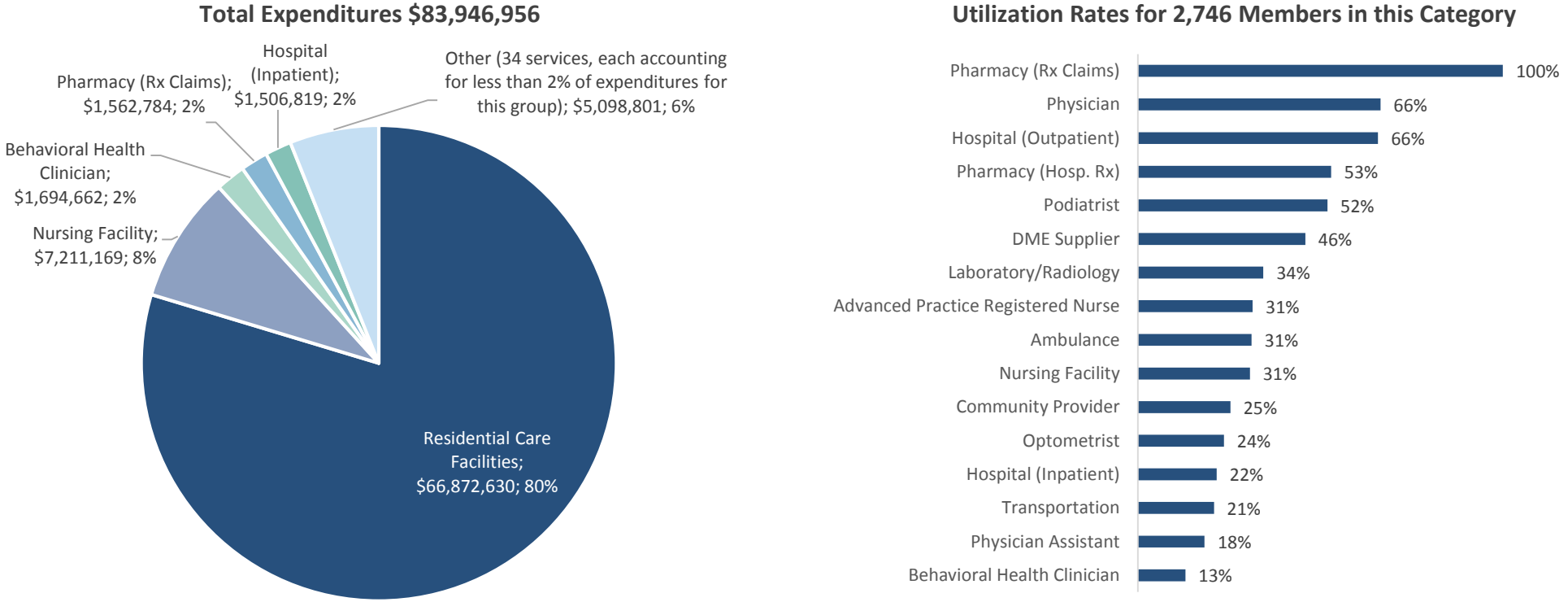

There was a small group of adults identified in the ICF-IID (Group) category. Similar to other categories of LTSS users in institutional settings, the majority of MaineCare expenditures for this group were attributed to the facility services themselves. ICF-IID (Group) provides the same types of services as ICF-IID (Nursing) except that members do not require 8 hours of licensed nursing care on a daily basis.

Fewer services are shown on the utilization chart above than in other categories because privacy regulations prevent us from showing the service utilization rates when they would identify fewer than 11 people.

* Members and expenditures identified in MIHMS for SFY 2014.

## Residential Care Facility (Appendix C)

***Figure 4.10 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Residential Care Facility (Appendix C) Category, SFY 2014[*]***




Residential care facilities (App. C) provide personal care, nursing, social work, and other support services, and they are reimbursed according to the level of need of their residents, also known as case-mix reimbursement. Expenditures for this service comprised the majority of MaineCare spending on the members in this category.[†] Members in this category have a service utilization pattern similar to residents in nursing facilities.

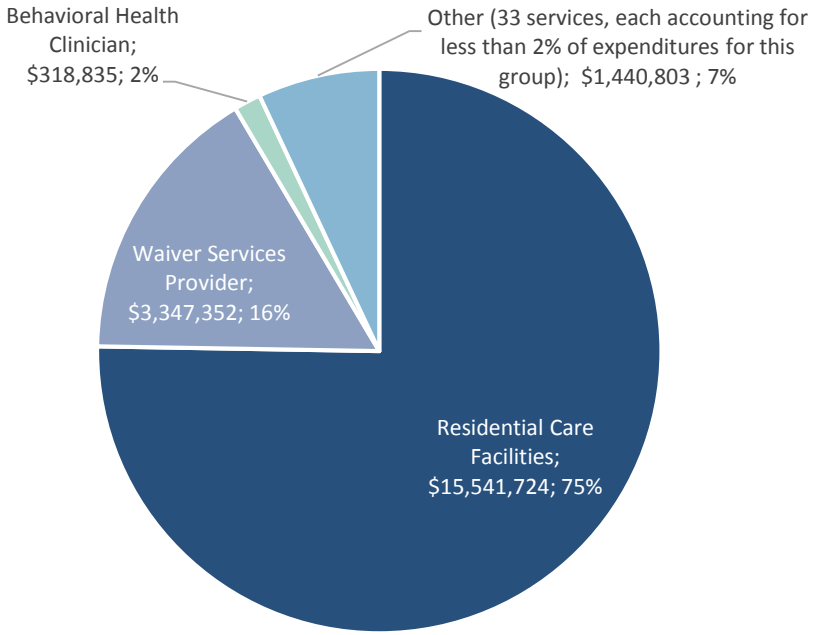
[*] Members and expenditures identified in MIHMS for SFY 2014.

[†] While the vast majority of expenditures on residential care facilities in this category were for Appendix C care, there was a small number of members identified in this category who used Appendix F care at some point during the year; their expenditures are also included under Residential Care Facilities on the pie chart.

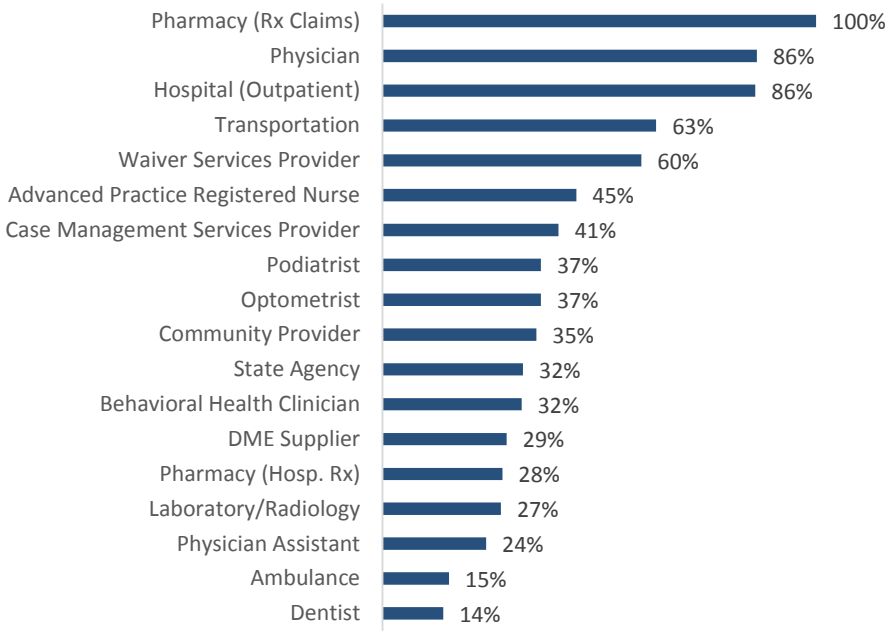
## Residential Care Facility (Appendix F)

***Figure 4.11 Total MaineCare Expenditures and Service Utilization Rates for Adults in Residential Care Facility (Appendix F) Category, SFY 2014[*]***

**Total Expenditures: $20,648,713**




**Utilization Rates for 293 Members in this Category**



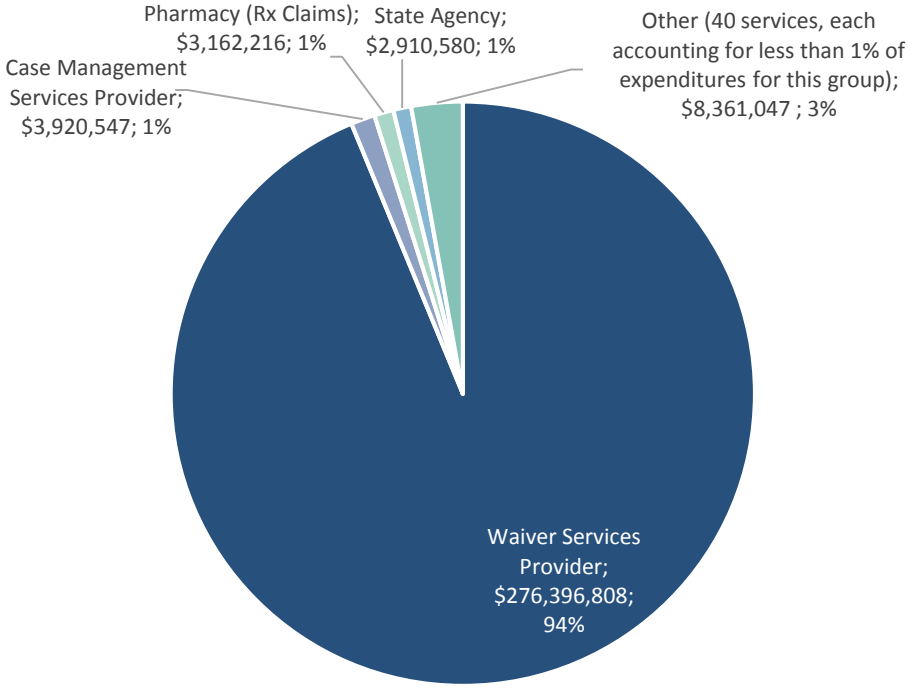

Residential care facilities (App. F) provide personal care and support services as well as occupational, physical, and speech therapies, social work, and other services to residents who have ID/ASD, mental health conditions, or who are served by Adult Protective Services. Members with acquired brain injury also use Appendix F facilities, but these members were included in the Acquired Brain Injury category. The majority of members using Appendix F facilities in this analysis were adults with ID/ASD.[†] Sixty percent of members in this category used the home and community based waivers for adults with ID/ASD at some point during SFY 2014.

[*] Members identified through a combination of using facility data obtained from OADS and data from MIHMS. Expenditures identified in MIHMS for SFY 2014.
[†] While the vast majority of expenditures on residential care facilities in this category were for Appendix F care, there was a small number of members identified in this category who used Appendix C care at some point during the year; their expenditures are also included under Residential Care Facilities on the pie chart.

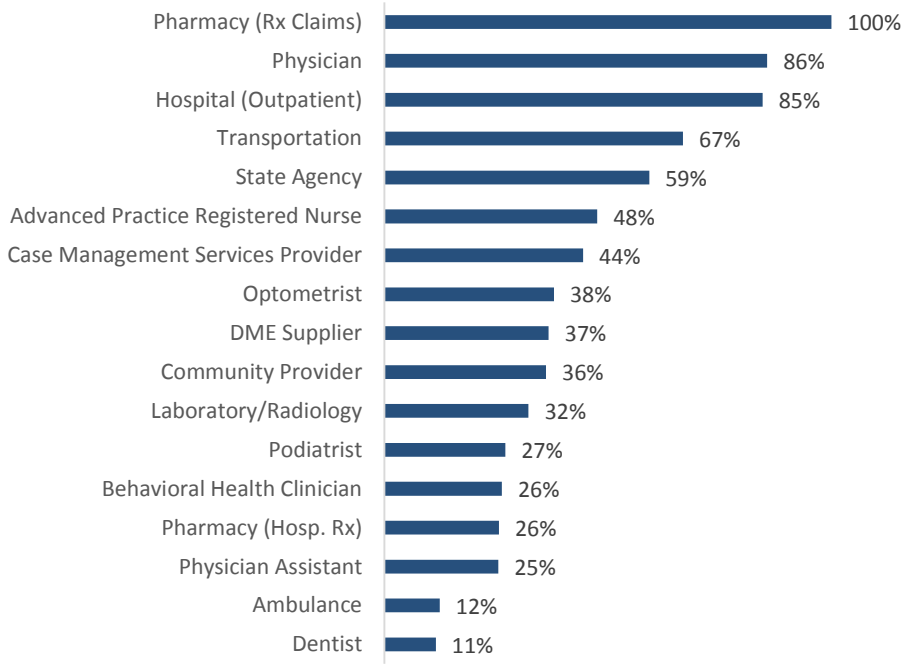
## Section 21 Comprehensive ID/ASD Waiver

***Figure 4.12 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Section 21 Comprehensive ID/ASD Waiver Category, SFY 2014****

**Total Expenditures: $294,751,199**




**Utilization Rates for 2,743 Members in this Category**




Waiver services comprised the bulk of expenditures for this category. While this category is comprised of members who were on the Section 21 Comprehensive ID/ASD Waiver for 6 or more months, there is some movement between this waiver and Section 29 Supports ID/ASD Waiver. Some members of this category may have used Section 29 services at some point the year.

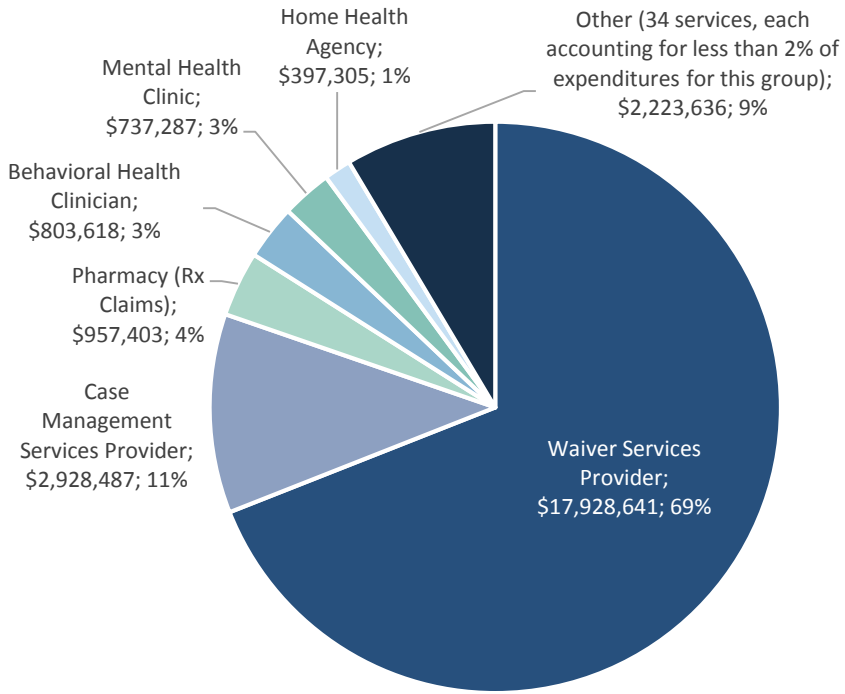
Transportation services were used by 67% of this category, compared to 17% of nursing facility residents who did not have ID/ASD and 21% of residential care facility (App. C) residents. Transportation is included as a component of the direct support activities under the waiver to help members live in the community; this is in addition to the MaineCare coverage for non-emergency transportation.

* Members and expenditures identified in MIHMS for SFY 2014.

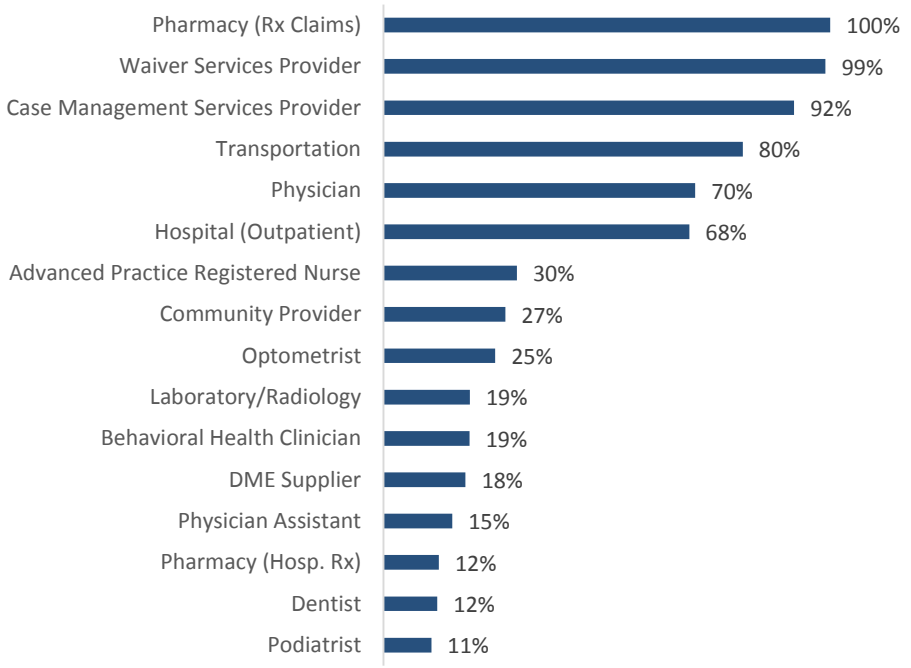
## Section 29 Supports ID/ASD Waiver

***Figure 4.13 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Section 29 Supports ID/ASD Waiver Category, SFY 2014****

**Total Expenditures: $25,976,378**




**Utilization Rates for the 1,112 members in this Category**




The Section 29 Supports ID/ASD Waiver provides home, community and work support for adults with ID/ASD who live independently or with family members. Compared to the Section 21 Comprehensive ID/ASD waiver, expenditures for this population are more broadly attributed to services other than waiver services.

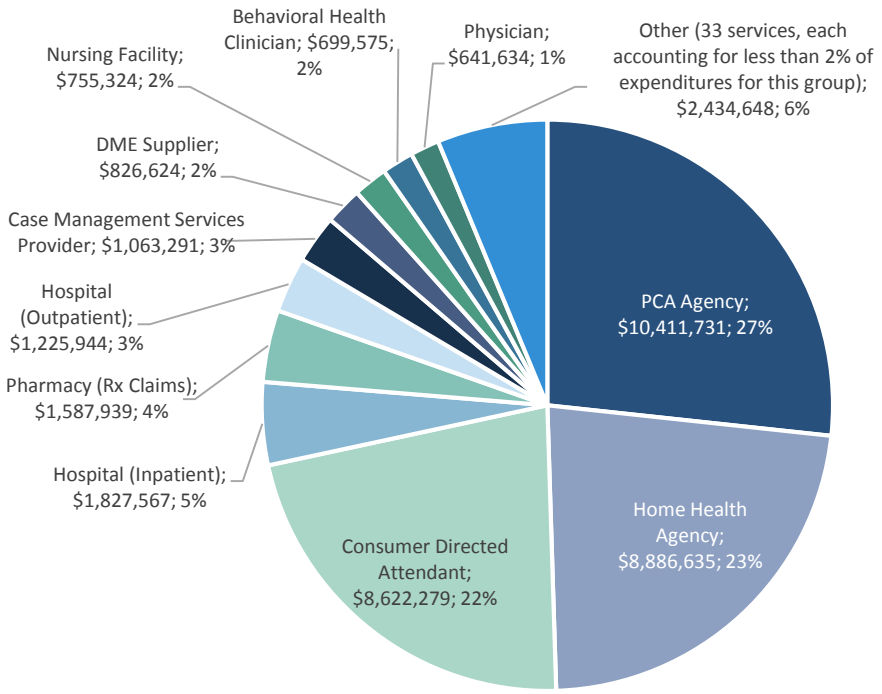
Eighty percent of members in this category used transportation services; transportation is offered under this waiver to support access to members' Personal Plan.

* Members and expenditures identified in MIHMS for SFY 2014.

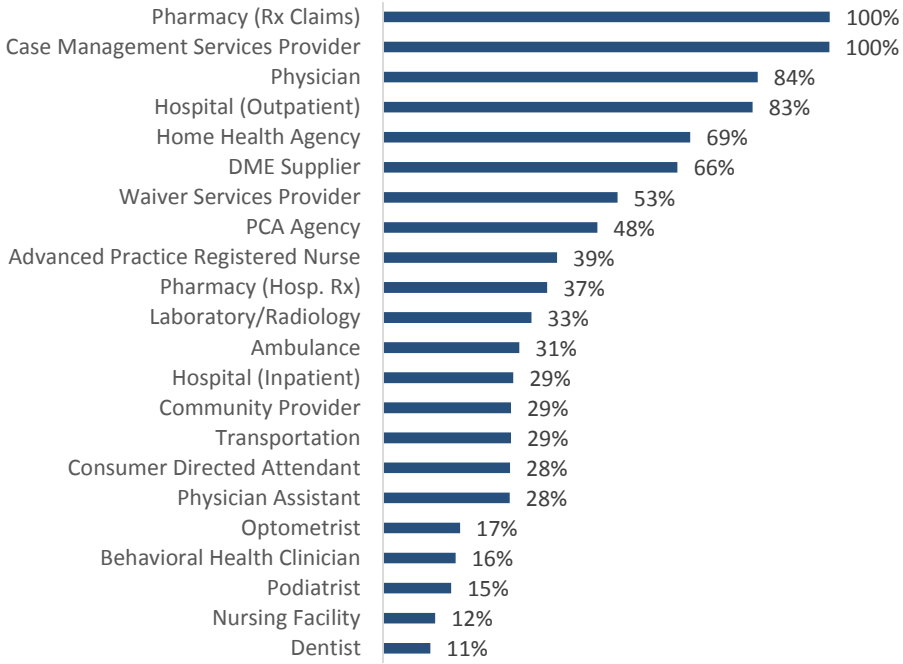
## Section 19 Elderly and Adult and Section 22 Adults with Physical Disabilities Waivers

***Figure 4.14 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Section 19 Elderly and Adult and Section 22 Adults with Physical Disabilities Waiver Category, SFY 2014****

**Total Expenditures: $38,983,191**




**Utilization Rates for 1,009 Members in this Category**



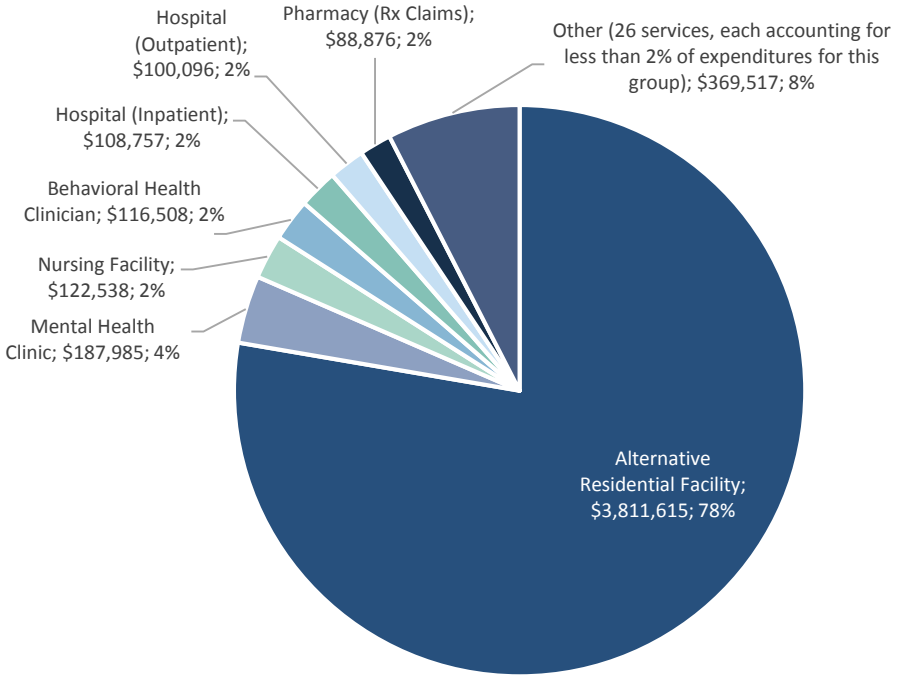

Personal care and support services provided under the waivers for elders and adults with physical disabilities may be provided by a variety of agencies such as home health agencies or personal care agencies. This differs from those services under the ID/ASD waivers which are provided almost entirely by "waiver services providers". So, while the expenditure chart shows PCA Agency, Home Health Agency, and Consumer Directed Attendant as separate services and together accounting for nearly 75% of MaineCare costs, these are mostly waiver services. Waiver Services Providers under Sections 19 and 22 bill primarily for atypical services such as Emergency Response and Environmental Modifications.

* Members and expenditures identified in MIHMS for SFY 2014.

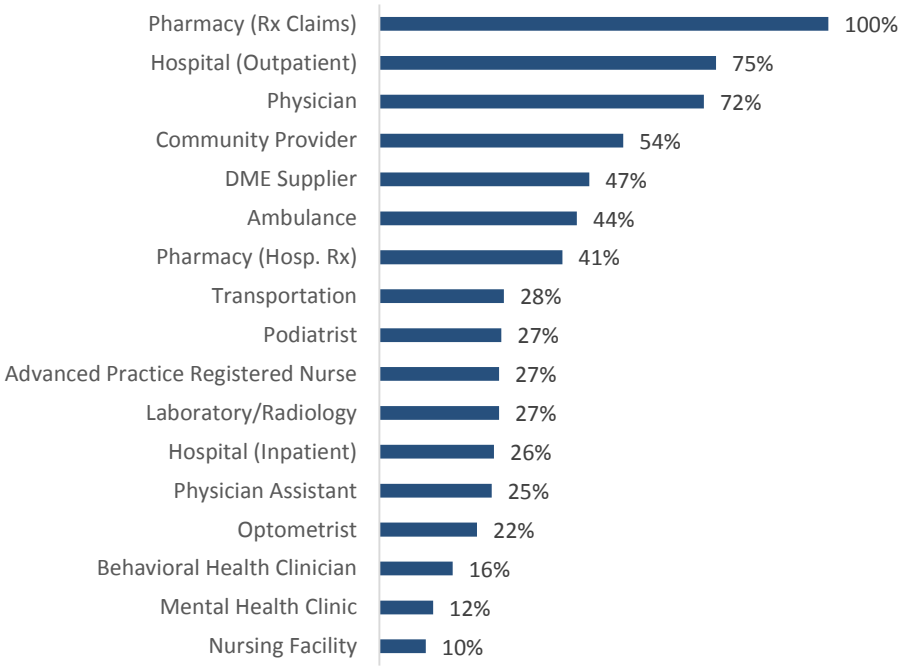
## Adult Family Care Home

***Figure 4.15 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Adult Family Care Home Category, SFY 2014****

**Total Expenditures: $4,905,892**




**Service Utilization Rates for 184 Members in this Category**




Adult family care homes (AFCHs) provide assistance with ADLs and IADLs for 8 or fewer residents who are assessed to need assistance with at least 2 ADLs. The majority of MaineCare expenditures for members in this category are for the AFCH services themselves.

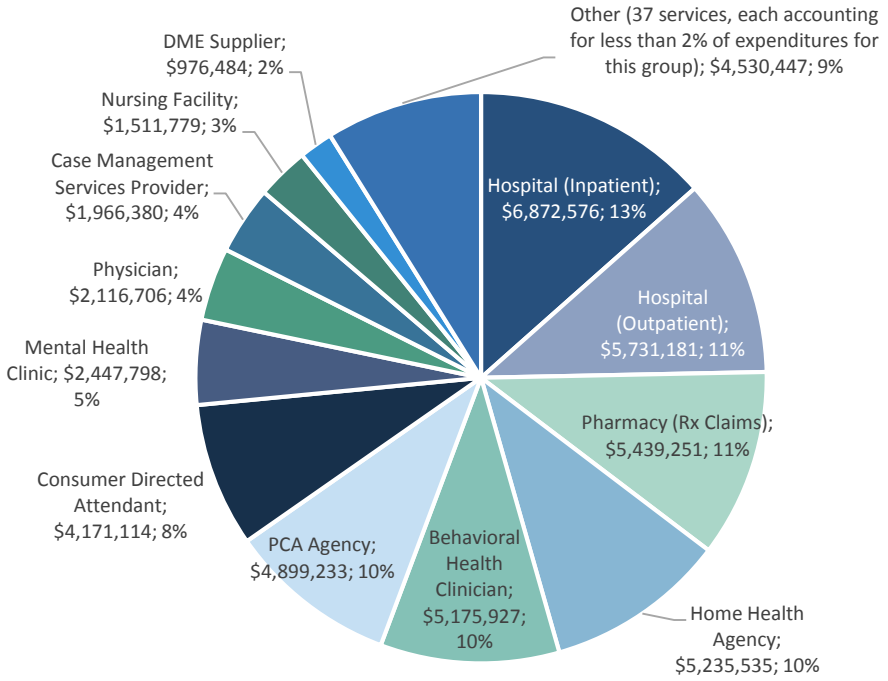
Though this category is small, it had one of the higher utilization rates of Community Provider services. These services are those provided by Federally Qualified Health Centers, Rural Health Clinics, and the Indian Health Service and include clinic services, diabetes management, and vaccines among others care.

* Members and expenditures identified in MIHMS for SFY 2014.

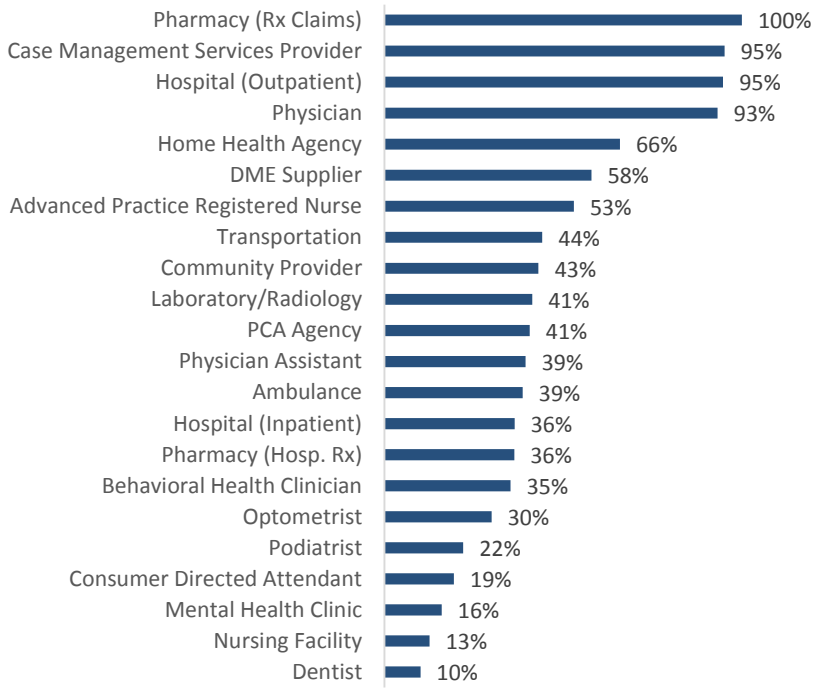
## Non-waiver MaineCare Home Care Services

***Figure 4.16 Total MaineCare Expenditures and Service Utilization Rates for Adults in the Non-waiver MaineCare Home Care Services Category, SFY 2014****

**Total Expenditures: $51,074,410**




**Service Utilization Rates for 2,611 Members in this Category**



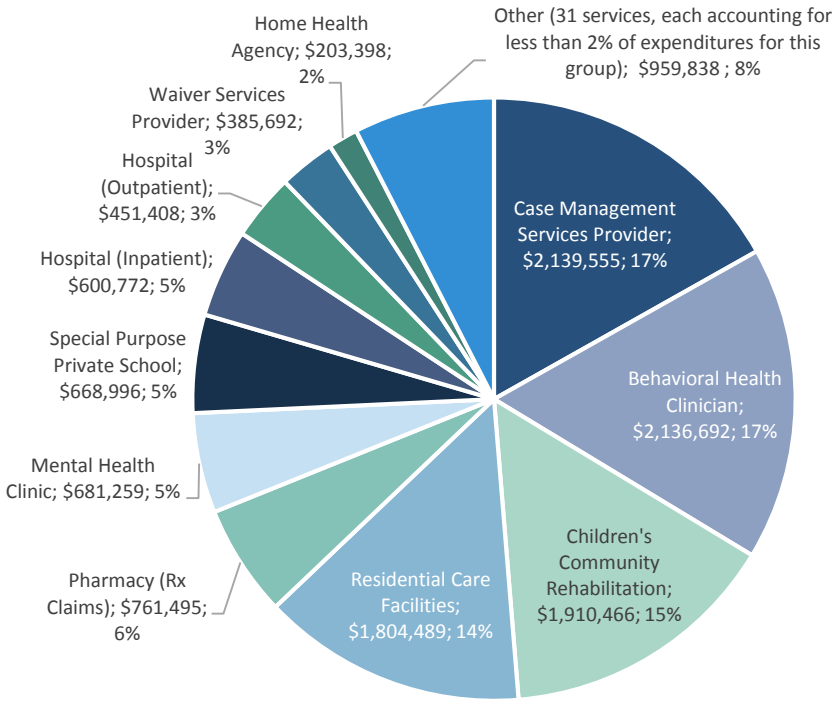

Non-waiver MaineCare Home Care services are personal care, skills training, care coordination, and nursing services under either Section 12 Consumer Directed Care Attendant Services or Section 96 Private Duty Nursing in the MaineCare Benefits Manual. Members receiving services under either section are assessed for the level of assistance with IADLs and ADLs they require; members receiving Section 96 services are assessed for nursing services as well. This category of LTSS users has a wide range of needs from assistance with ADLs to more intensive nursing services. This category had the highest proportion of expenditures attributed to inpatient hospital services.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS. Expenditures identified in MIHMS for SFY 2014.

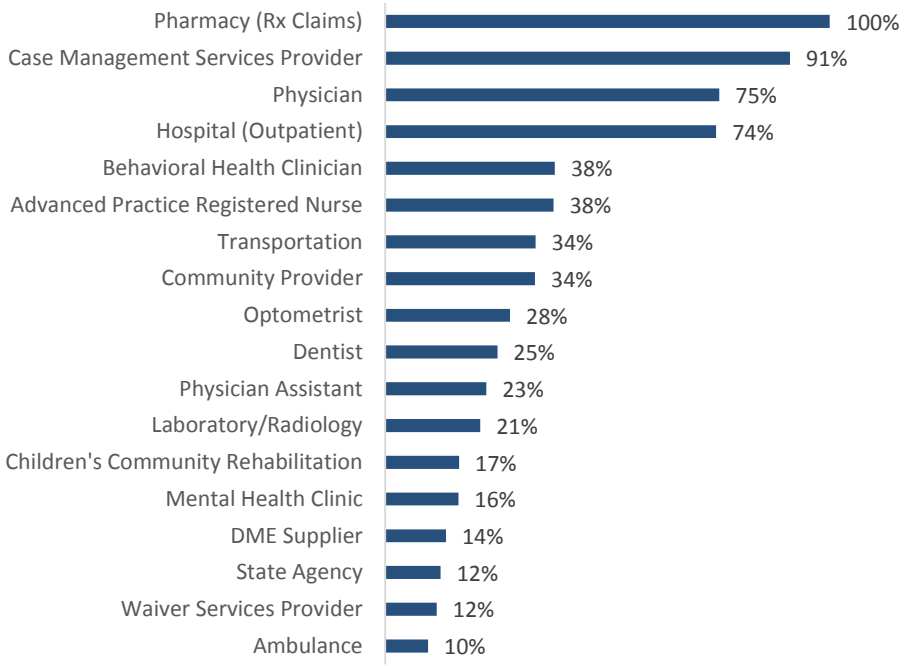
## Case Management—ID/ASD

***Figure 4.17 Total MaineCare Expenditures and Service Utilization Rates for Adult Members in the Case Management—ID/ASD Category, SFY 2014****

**Total Expenditures: $12,704,058**




**Service Utilization Rates for 673 Members in this Category**




Members in this category used case management services for ID/ASD as their primary LTSS service. Some members in this category did use other LTSS during the year, but not for 6 or more months; doing so would put them into one of the higher categories in this analysis.

Note that some of the services used by these members are targeted to children. MaineCare members age 18-21 can continue to use children's developmental services, such as children's community, before they transition to adult services.

* Members and expenditures identified in MIHMS for SFY 2014.

## HEDIS© Quality Measures

The following three charts reflect quality measures collected through the Healthcare Effectiveness Data and Information Set (HEDIS®). Information on the number of emergency room visits, hospital readmissions within 30 days of discharge, and access to ambulatory or preventive care services can serve as an indicator of the quality of health care received by different populations. Some of the LTSS categories established by the hierarchy in this chartbook have too few members to report on for some of the measures. In cases where there were fewer than 11 members reflected in a measure, we omitted that information from the charts.

Also included at the end of this section is a chart showing the variation in hospital admission rates by the different LTSS categories. While this is not a HEDIS© measure, it is interesting to see how the different groups vary on this use of inpatient care.

## Emergency Room Use

***Figure 4.18 Percentage of Adult MaineCare Members in Select LTSS Settings with Emergency Room Visits, by Number of Visits, SFY 2014****

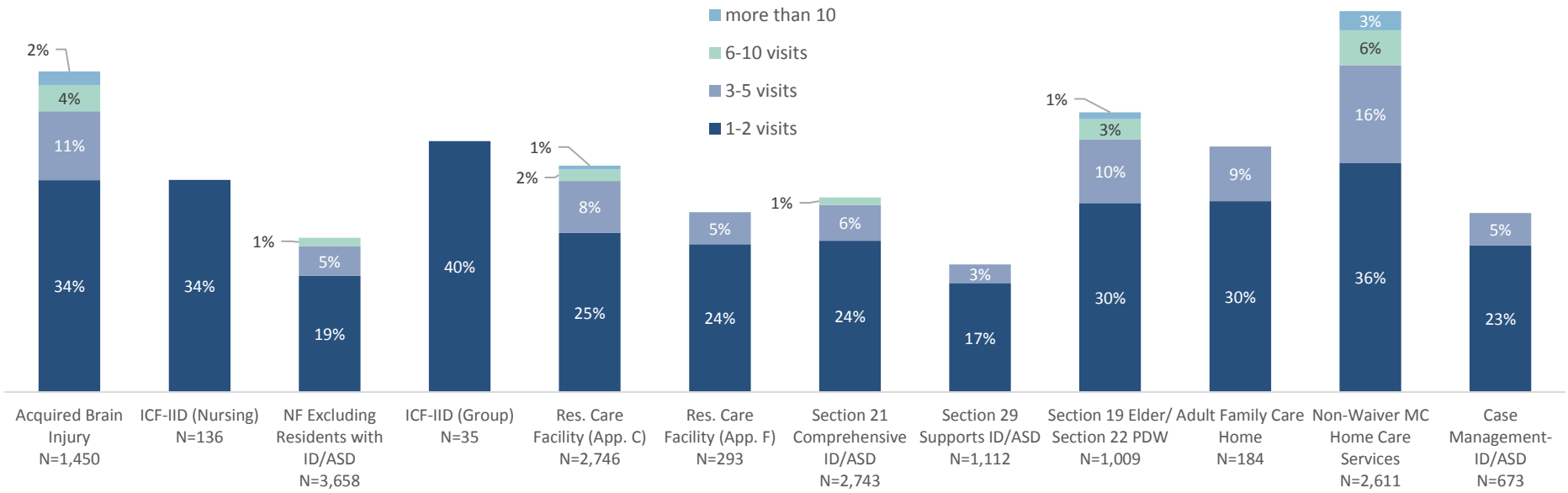


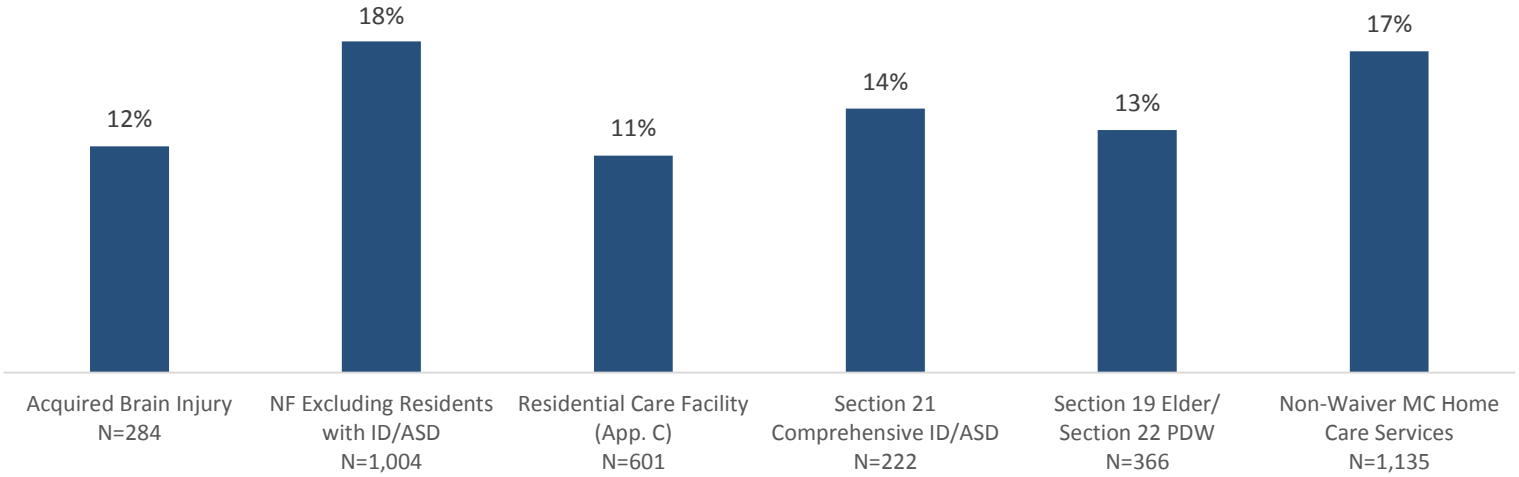

Figure 4.18 shows emergency room use across the different LTSS categories by the number of visits. Across all of the LTSS settings in this analysis, the Section 29 Supports ID/ASD waiver had the lowest percentage of members who had emergency room visits during SFY 2014.

Although 31% of members in the Nursing Facility Residents with ID/ASD had at least one emergency room visit during SFY 2014, there were too few individuals in this category to present the information on the number of visits on this chart.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS, SFY 2014. For more information on HEDIS© measures, please see http://www.ncqa.org/HEDISQualityMeasurement.aspx.

## Hospital Readmissions

***Figure 4.19 Percentage of Adult MaineCare Members in Select LTSS Settings with at Least One Hospital Admission and who were Re-hospitalized within 30 Days at Least Once, SFY 2014****



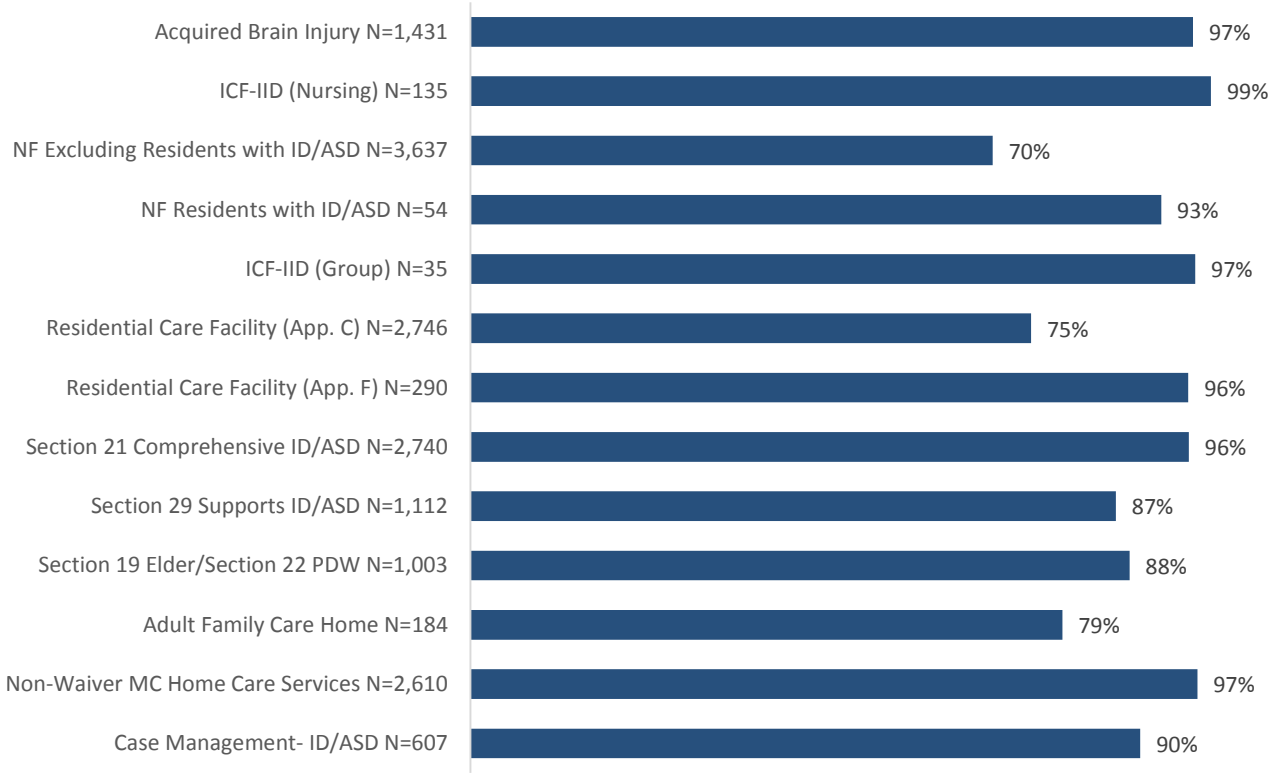

N = the number of members of each group who had had a hospital discharge, as defined by HEDIS, in SFY 2014.

Members in the Nursing Facility (excluding residents with ID/ASD) category had the highest rate of readmissions within 30 days after discharge from the hospital, followed by the Non-waiver MaineCare Home Care Services category. Members in the other LTSS categories not shown on this chart, with the exception of those in ICF-IID (Group), did have re-admission during the year, but due to the small numbers, we are unable to show that information on this chart. No members in the ICF-IID (Group) who had hospitalizations during the year had to be re-hospitalized within 30 days. Please note the number in each category on this figure is the number who had had at least one hospital discharge, as defined by HEDIS©.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS, SFY 2014. For more information on HEDIS© measures, please see http://www.ncqa.org/HEDISQualityMeasurement.aspx.

## Access to Ambulatory or Preventive Care

***Figure 4.20 Adult MaineCare Members Age 20+ with Access to Ambulatory or Preventive Care, SFY 2014****

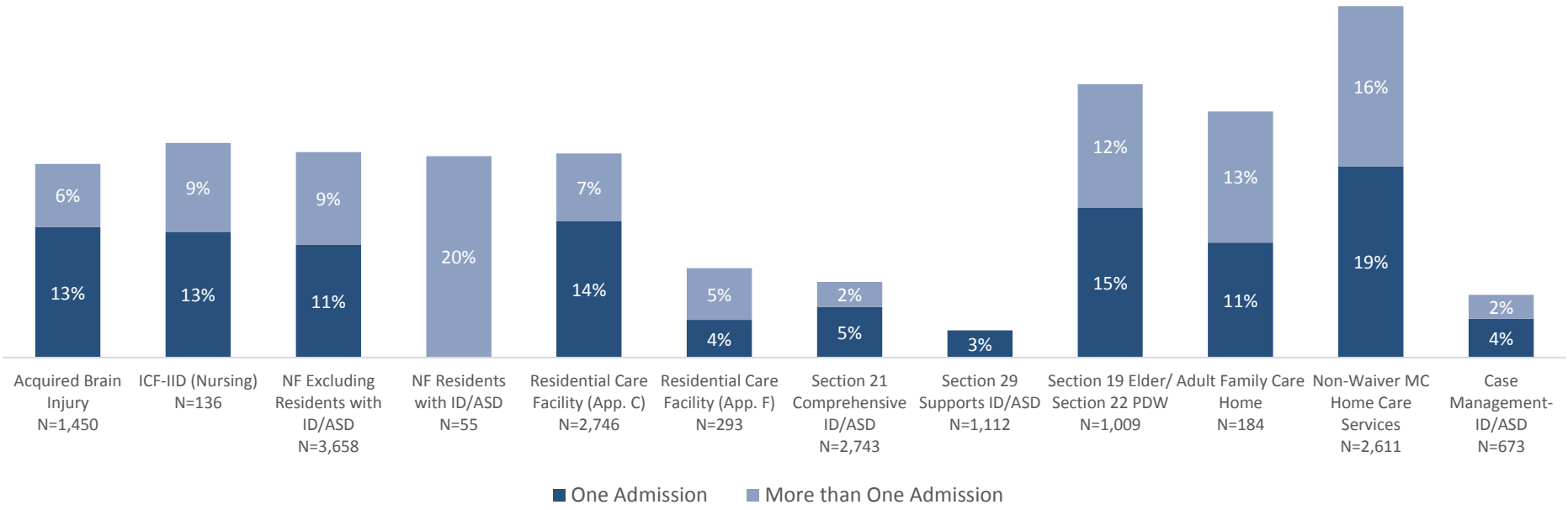



This HEDIS© measure covers adults at 20 and older; note the number in each group has been adjusted accordingly. Members in Nursing Facility (excluding residents who did not have ID/ASD) and those in the Residential Care Facility (App. C) categories had the lowest rates of access to ambulatory or preventive care during SFY 2014, at 70% and 75%, respectively.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS, SFY 2014. For more information on HEDIS© measures, please see http://www.ncqa.org/HEDISQualityMeasurement.aspx.

## Hospital Admissions

***Figure 4.21 Percent of Adults MaineCare Members in Select LTSS Settings with One or More Hospital Admission, SFY 2014****




While this chart is not a HEDIS© quality measure, we have included it to show the variation in inpatient hospital admissions by LTSS category. Inpatient hospital admission was determined by type of bill and type of claim reflected in MIHMS and may include transfers from one facility to another. Members in the Non-Waiver Home Care category had the highest hospitalization rate in SFY 2014, followed by adults on the Section 19 Elder/Section 22 Physically Disabled Waiver. Members in the ID/ASD waiver and case management categories had some of the lowest rates of having at least one hospital admission. Members in the ICF-IID (Group) category did have admissions during the year, but due to privacy regulations, we are unable to show that information.

* Members identified through a combination of using MaineCare IDs, MDS data, and data from MIHMS, SFY 2014. Data may reflect transfers between inpatient facilities as well as new admissions.

# Appendix A: Identifying MaineCare Long Term Services and Supports in MIHMS

For several years the Muskie School has generated a Long Term Services and Supports Chartbook for the Maine Department of Health and Human Services (DHHS), Office of Aging and Disability Services (OADS)[*]. These chartbooks use information from various DHHS administrative data systems including MaineCare claims and eligibility, nursing home (MDS), residential care (MDS-RCA) and the Medical Eligibility Determination (MED) assessment systems.

This SFY 2014 edition of the chartbook is the first one to include all the populations served by OADS: the elderly; adults with physical disabilities; adults with an intellectual disability or autism spectrum disorder; adults with other related conditions; and adults with acquired brain injury. The chartbook reflects data for state fiscal year 2014 (July 1, 2013 – June 30, 2014), and so, it is also the first chartbook to use data from Maine's claims processing system, the Maine Integrated Health Management Solution (MIHMS).

MIHMS introduced many changes to the provider, member and claim systems including re-enrolling providers and their specialty identification, introducing HIPAA compliant coding that replaced local codes, and identification of coverage codes for members that were tied to authorization of specific services that require both financial and medical eligibility –all of which impact long term care services.

This appendix describes our approach to identifying long term care services and members using those services in SFY2014. We used two methods to 1) identify all LTSS services – including members' use of the service at all during the year and claims paid; and 2) identify "typical users" of the long term care services and place them in a hierarchy based on the intensity of the service or setting and duration of use.

[*] See for example https://usm.maine.edu/muskie/cutler/older-adults-and-adults-disabilities-population-and-service-use-trends-maine-2012-edit

# Identifying LTSS – MIHMS Approach

In reviewing options to identify LTSS, several elements of the MIHMS claims and eligibility data extract the Muskie School receives were evaluated including:

- Allocation Provider Type and Specialty -- data elements that are used for financial reporting by the Department;
- Coverage Codes – data elements that are assigned to a member to identify services they are financially or medically eligible to receive; and
- Procedure or Revenue codes – data elements that identify specific services provided to a member and billed on the claim. Each long term care service has specific codes that are allowed and identified in Chapter III of the MaineCare Benefits Manual.*

## Allocation Provider Type and Specialty

As a first step to identifying LTSS, Muskie School staff reviewed Allocation Provider Types and Specialty codes. The combination of these two items are used for financial reporting by the Department. Table A.1 identifies the combinations of allocation provider type and specialty Muskie has identified as related to long term care services.

***Table A.1: MaineCare Services by Allocation Provider Type and Specialty, Long Term Care Services, SFY2012-2014***

| Allocation Provider | | | |
|---|---|---|---|
| Provider Type Code | Provider Type Description | Specialty Code | Specialty Description |
| 04 | 04-Alternative Residential Facility | 000 | No Specialty Required |
| 07 | 07-Assisted Living Service Provider | 000 | No Specialty Required |
| 13 | 13-Boarding Home | 000 | No Specialty Required |
| 13 | 13-Boarding Home | 022 | Cost Reimbursed Boarding Homes (Case Mix) |
| 13 | 13-Boarding Home | 023 | Cost Reimbursed Boarding Homes (Non-Case Mix) |
| 14 | 14-Case Management Services Provider | 021 | Consumer Directed Attendant Services |
| 14 | 14-Case Management Services Provider | 042 | Elderly and Adults with Disabilities Waiver |
| 14 | 14-Case Management Services Provider | 142 | Private Duty Nursing |
| 14 | 14-Case Management Services Provider | 168 | Homeward Bound (MFP) |
| 31 | 31-Fiscal Employer Agent | 047 | Family Provider Service Option (FPSO) |
| 31 | 31-Fiscal Employer Agent | 115 | Physically Disabled Waiver |
| 31 | 31-Fiscal Employer Agent | 141 | EADW-FPSO |
| 32 | 32-Group Home - IID | 063 | ICF/IID |

* MaineCare Benefits Manual: http://www.maine.gov/sos/cec/rules/10/ch101.htm

| Allocation Provider | | | |
|---|---|---|---|
| 33 | 33-Home Health Agency | 042 | Elderly and Adults with Disabilities Waiver |
| 33 | 33-Home Health Agency | 060 | Home Health Agency |
| 33 | 33-Home Health Agency | 142 | Private Duty Nursing |
| 34 | 34-Hospice | 000 | No Specialty Required |
| 41 | 41-Nursing Home | 000 | No Specialty Required |
| 41 | 41-Nursing Home | 009 | Brain Injury Facility |
| 41 | 41-Nursing Home | 022 | Cost Reimbursed Boarding Homes (Case Mix) |
| 41 | 41-Nursing Home | 063 | ICF/IID |
| 41 | 41-Nursing Home | 085 | Nursing Home |
| 62 | 62-Rehabilitation Center | 113 | Physical Medicine & Rehabilitation |
| 73 | 73-Waiver Services Provider | 000 | No Specialty Required |
| 73 | 73-Waiver Services Provider | 042 | Elderly and Adults with Disabilities Waiver |
| 73 | 73-Waiver Services Provider | 078 | IID Supports Waiver |
| 73 | 73-Waiver Services Provider | 079 | IID Waiver |
| 73 | 73-Waiver Services Provider | 115 | Physically Disabled Waiver |
| 73 | 73-Waiver Services Provider | 134 | Speech Therapy |
| 73 | 73-Waiver Services Provider | 167 | Board Certified Behavior Analyst (BCBA) |
| 73 | 73-Waiver Services Provider | 168 | Homeward Bound (MFP) |
| 73 | 73-Waiver Services Provider | 169 | Adults with Other Related Conditions Waiver |
| 73 | 73-Waiver Services Provider | 174 | Brain Injury Waiver |
| 75 | 75-Adult Day Health | 000 | No Specialty Required |
| 77 | 77-Multi-Disciplinary Provider | 085 | Nursing Home |
| 78 | 78-Facility-Agency-Organization NR Provider | 078 | IID Supports Waiver |
| 79 | 79-PCA Agency | 000 | No Specialty Required |

When we reviewed the claims data with these code combinations against other financial reports provided by the Department, we found several discrepancies. Upon closer examination, we found that many providers are enrolled in MIHMS as one type of provider, but they render many different types of services. For example, a provider serving members who are either on the Section 21 Comprehensive ID/ASD waiver or the Section 29 Supports ID/ASD waiver may be enrolled as both a Section 21 and Section 29 provider, yet all the claims were attributed to one specialty code regardless of whether the member was on that particular waiver. To better assign the claims to one program or service, we found we needed to use the additional information from both coverage codes, procedure codes, and provider lists described below.

## Coverage Codes

These data elements are captured in the eligibility data the Muskie School receives from MIHMS. Our understanding is that individuals receiving long term care services will have both a classification and financial coverage code. For LTSS, the financial

coverage code is most often ME0001 Adult and Children Services that authorizes members to full MaineCare services as well as a classification coverage code that is specific to the LTSS program (e.g., Section 19 HCB Elderly and Adults with Disability Waiver).

Initially, our understanding was that classification coverage codes would be identified in the paid claims data and associated with the actual claim. While this is generally the case, there were enough exceptions that came through with only a financial coverage code and not the classification code. In these cases where the financial eligibility is associated with the claim, the classification code from the eligibility file was used.

### Procedure or Revenue Codes

Chapter III of the MaineCare Benefits Manual identifies the specific codes providers are to use when billing for LTSS services by section of policy. Most often the procedure and modifier combinations identify a specific service that can be provided under that section of policy. There are instances where these services however are not unique to one section of policy and may be reimbursed under a different section of policy. Defining a service only by procedure and revenue codes would not necessarily equate to a particular program.

### Provider Lists

There were a few instances when using the combination of the various codes still returned results that were not in keeping with what we expected to find. After consulting with OADS staff, we determined that the most accurate method of identifying Residential Care Facilities (Appendix F) as well as the Group and Nursing level ICF-IIDs was to use provider lists obtained from OADS.

After using the above procedures based on provider types, coverage codes, procedure or revenue codes, and the provider lists, we found there were still instances where a claim for a type of procedure or service did not match up accurately with either the provider type or the member coverage code. In these instances, we relied on a manual assignment of the claim into the appropriate expenditure line based on our knowledge of the procedures provided by the various programs.

## Claims Analysis Hierarchy Criteria SFY 2014

Conducting the claims analysis of typical members utilizing a specific LTSS service or program during the year required us to establish a hierarchy of members so that we could examine their service utilization throughout SFY 2014. With the exception of members in the Acquired Brain Injury and the Nursing Facility Residents with ID/ASD categories, we based placement in a particular group on whether a member had an open coverage code for a particular LTSS service or program for six or more months. The categories were hierarchical from most intensive to least; a member in one category would be excluded from the other categories. Adults in the Acquired Brain Injury category were identified through using a list of member ID numbers provided by OADS in combination with

whether they used any brain injury service during the year; they were then excluded from the other categories. In using this approach we ensured that those members whose primary need for LTSS was based on brain injury were included in the ABI category and excluded from the other categories such as the ID/ASD waivers or Residential Care (Appendix F). Adults in the Nursing Facility who also had ID/ASD were identified in SFY 2014 through data from MDS assessments. The hierarchy with the coverage codes assigned to each category is shown in Table A.2.

***Table A.2: LTC Hierarchy Criteria****

| Order | Group | Coverage Codes (Based on Coverage Codes and eligibility dates in the Eligibility File) | Criteria |
|---|---|---|---|
| 1 | Brain Injury (using Section 102 or 67 services) | **ME00063**: Section 67 Nursing Facility Traumatic Brain Injury Services<br>**ME00067**: Section 102 Brain Injury Services<br>Brain Injury Private Non-Medical Institutions (PNMIs) list – This criteria uses claims data for identification | Any use<br><br>Member ID lists obtained from OADS were also used to identify members in this group. |
| 2 | ICF-IID (Nursing) | **ME00068**: Section 50 ICF-IID Nursing Home | 6 or more months |
| | NF | | |
| 3 | NF excluding residents with IID | **ME00020**: Section 67 - Nursing Facility<br>**ME00049**: Community MaineCare Nursing Facility - 30 days with 11+ months (see note) | 6 or more months – *Exception include members in ME00049 with 11+ months of eligibility in this coverage code;* Other NF related coverage codes – Extraordinary Circumstances (ME00054), 30 day (ME00049) and bed holds (ME00056) placed based on the other qualifying hierarchy criteria. |
| 4 | NF residents with ID/ASD from MDS† | N/A | List of MaineCare numbers from MDS with 6 or more months |
| 5 | ICF-IID (Group) | **ME00019**: Section 50 ICF-IID (Group) | 6 or more months;<br>**ME00050**: Section 19 Family Provider Service Option will also have a Section 19 coverage code and will be picked up there. |
| | Residential Care Facility | | |
| 6 | Appendix C | **ME00069**: Section 97 - PNMI (Appendix C) | 6 or more months; **ME00072** Awaiting placement for RCF will be placed based on the other qualifying hierarchy criteria. |
| 7 | Appendix F | **ME00035**: Section 97 PNMI (Appendix F) | 6 or more months |

* Population: Adult MaineCare members with 11 or more months of full MaineCare eligibility
Adult: 18 years of age or older as of 7/1/2013.

† Included in the listing are residents who had stays in one or more nursing homes during SFY 2014 that ran for 6 or more months. Some residents moved from one facility to another. These were treated as a continuous stay if they began the stay at the second facility within 30 days. If a resident was discharged with return anticipated and returned to the facility or another facility within 30 days that was counted as a continuous stay.

| Order | Group | Coverage Codes (Based on Coverage Codes and eligibility dates in the Eligibility File) | Criteria |
|---|---|---|---|
| | | **ME00070**: Section 97 - PNMI (Appendix F Developmentally Disabled) | Provider lists obtained from OADS were also used to identify members in this group. |
| 8 | Section 21 Comprehensive ID/ASD | **ME00037**: Section 21 HCB Developmental Services Comprehensive Waiver | 6 or more months; **ME00046**: Section 96 Private Duty Nursing Level 8 will be placed based on the other qualifying hierarchy criteria. |
| 9 | Section 29 Supports ID/ASD | **ME00038**: Section 29 HCB Developmental Services Support Waiver | 6 or more months; **ME00046**: Section 96 Private Duty Nursing Level 8 will be placed based on the other qualifying hierarchy criteria. |
| 10 | Section 19 Elder/ Section 22 PDW | **ME00033**: Section 19 HCB Elderly and Adults with Disabilities Waiver<br>**ME00034**: Section 22 HCB Physically Disabled Waiver | 6 or more months; **ME00046**: Section 96 Private Duty Nursing Level 8 will be placed based on the other qualifying hierarchy criteria. |
| 11 | Adult Family Care Home | **ME00047**: Section 2 Adult Family Care Home | 6 or more months |
| 12 | Non-waiver MaineCare Home Care Services: includes personal care, PDN, hospice, day health, home health, consumer directed care attendant | **ME00029**: Section 26 Adult Day Health Level 1, 16 Hours per Week<br>**ME00030**: Section 26 Adult Day Health Level 2, 24 Hours per Week<br>**ME00031**: Section 26 Adult Day Health Level 3, 40 Hours per Week<br>**ME00032**: Section 12 Consumer Directed Attendant Services Level 1<br>**ME00039**: Section 96 Private Duty Nursing Level 1<br>**ME00040**: Section 96 Private Duty Nursing Level 2<br>**ME00041**: Section 96 Private Duty Nursing Level 3<br>**ME00051**: Section 43 - Hospice - Routine<br>**ME00052**: Section 12 Consumer Directed Attendant Services Level 2<br>**ME00053**: Section 12 Consumer Directed Attendant Services Level 3<br>**ME00057**: Section 96 Private Duty Nursing Level 9 (ALFs)<br>**ME00060**: Section 43 Hospice - General Inpatient<br>**ME00062**: Section 43 Hospice - Inpatient Respite | **ME00065**: Section 96 Family Provider Service Option coverage code will also have a PDN Section 96 coverage code and will be picked up there.<br>**ME00046**: Section 96 Private Duty Nursing Level 8 is nursing in combination with another program above, so members will end up in that program category above. |
| 13 | Case Management-ID/ASD | Procedure code **G9012 HI** | 6 or more months |

# Appendix B: Additional Population Projection Tables

***Table B.1 Forecast Change in Maine's Older Population, by Age Groups, over Five Years 2015 to 2020 and Ten Years 2015 to 2025[*]***

| | Age Groups | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 65-74 | | | | 75-84 | | | | 85+ | | | |
| | 2015-2020 | | 2015-2025 | | 2015-2020 | | 2015-2025 | | 2015-2020 | | 2015-2025 | |
| | Change in Number | % Change | Change in Number | % Change | Change in Number | % Change | Change in Number | % Change | Change in Number | % Change | Change in Number | % Change |
| **Maine** | 35,493 | 24% | 58,827 | 39% | 17,343 | 24% | 50,278 | 69% | 1,392 | 4% | 4,435 | 14% |
| **Androscoggin** | 1,769 | 20% | 2,679 | 31% | 639 | 14% | 2,166 | 46% | 41 | 2% | 163 | 9% |
| **Aroostook** | 948 | 25% | 1,747 | 47% | 546 | 30% | 1,419 | 78% | 23 | 3% | 72 | 11% |
| **Cumberland** | 3,324 | 25% | 5,609 | 43% | 1,460 | 23% | 4,376 | 68% | 103 | 4% | 349 | 12% |
| **Franklin** | 978 | 18% | 1,338 | 25% | 919 | 36% | 2,351 | 91% | 112 | 10% | 299 | 26% |
| **Hancock** | 3,426 | 23% | 5,655 | 38% | 1,073 | 14% | 3,847 | 49% | 136 | 4% | 422 | 12% |
| **Kennebec** | 1,008 | 24% | 2,001 | 47% | 736 | 35% | 1,616 | 77% | 62 | 7% | 179 | 21% |
| **Knox** | 1,139 | 23% | 1,567 | 31% | 719 | 34% | 1,961 | 93% | 71 | 9% | 191 | 24% |
| **Lincoln** | 6,128 | 28% | 1,0644 | 48% | 2,643 | 24% | 7,751 | 72% | 400 | 8% | 1,102 | 23% |
| **Oxford** | 1,689 | 25% | 2,945 | 43% | 561 | 16% | 1,895 | 54% | -15 | -1% | 32 | 2% |
| **Penobscot** | 3,371 | 23% | 5,794 | 39% | 1,025 | 13% | 3,520 | 45% | 68 | 2% | 279 | 9% |
| **Piscataquis** | 470 | 18% | 754 | 28% | 378 | 32% | 946 | 81% | -1 | 0% | 22 | 4% |
| **Sagadahoc** | 1,188 | 26% | 2,140 | 48% | 730 | 34% | 1,805 | 84% | 63 | 7% | 180 | 21% |
| **Somerset** | 1,153 | 19% | 2,276 | 37% | 737 | 25% | 1,922 | 64% | -15 | -1% | 24 | 2% |
| **Waldo** | 1,206 | 24% | 1,705 | 34% | 645 | 30% | 1,917 | 89% | 74 | 9% | 201 | 25% |
| **Washington** | 763 | 17% | 1,148 | 26% | 331 | 15% | 1,102 | 49% | -41 | -5% | -45 | -6% |
| **York** | 6,473 | 29% | 11,460 | 52% | 2,535 | 24% | 7,703 | 71% | 375 | 8% | 1,046 | 22% |

[*] 2015 Woods and Poole Economics, Inc., "2015 New England State Profile: State and County Projections to 2050". Woods & Poole does not guarantee the accuracy of this data. The use of this data and the conclusions drawn from it are solely the responsibility of the Muskie School at USM.

*Table B.2 Percentage of Population with Disability in Maine by Age Group and by County, ACS 2013 5 Year Estimates*[*]

| | 18 to 34 | 35 to 64 | 65 to 74 | 75 and over | All Adults 18+ |
|---|---|---|---|---|---|
| **Maine** | **9%** | **15%** | **26%** | **51%** | 18% |
| **Androscoggin** | 9% | 16% | 29% | 54% | 18% |
| **Aroostook** | 13% | 21% | 35% | 56% | 25% |
| **Cumberland** | 7% | 11% | 19% | 48% | 14% |
| **Franklin** | 8% | 18% | 22% | 55% | 19% |
| **Hancock** | 8% | 14% | 24% | 48% | 17% |
| **Kennebec** | 12% | 16% | 28% | 50% | 19% |
| **Knox** | 10% | 15% | 23% | 47% | 19% |
| **Lincoln** | 8% | 13% | 19% | 48% | 17% |
| **Oxford** | 11% | 18% | 27% | 57% | 21% |
| **Penobscot** | 10% | 19% | 30% | 51% | 20% |
| **Piscataquis** | 14% | 22% | 29% | 62% | 26% |
| **Sagadahoc** | 11% | 14% | 23% | 50% | 17% |
| **Somerset** | 11% | 19% | 32% | 56% | 22% |
| **Waldo** | 10% | 15% | 28% | 57% | 19% |
| **Washington** | 11% | 21% | 31% | 57% | 24% |
| **York** | 8% | 13% | 23% | 48% | 16% |

[*] U.S. Census Bureau, 2009-2013 American Community Survey, B18101, "Sex by Age by Disability", aggregated estimates.

# Appendix C: Glossary

**Definitions of LTSS settings and programs with section number references to the MaineCare Benefits Manual available at: http://www.maine.gov/sos/cec/rules/10/ch101.htm**

**Adult Day Health** services are provided to adults who are assessed through the Medical Eligibility (MED) tool who require at least daily cuing for ADLs or for limited assistance and a one-person physical assist in two ADLs. Day health services are provided outside the member's home and include monitoring of health care, supervision and assistance with ADLs, nursing, rehabilitation, health promotion activities, exercise groups, counseling, and noon meals and snacks. **Section 26**

**Adult Family Care Homes** are residential style homes for 8 or fewer residents, licensed by the State, that provide services primarily to the elderly. Services provided include personal care such as assistance with ADLs and IADLs, protection from environmental hazards, diversional and motivational activities, dietary services, and care management. **Section 2**

**Case-Management-ID/ASD** services are provided by a social services or health professional or other qualified staff to identify the medical, social, educational, and other needs such as housing and transportation of eligible members with intellectual disabilities or autism spectrum disorder. Case management activities consist of intake/assessment, plan of care development, coordination/advocacy, monitoring, and evaluation. These services are provided to all MaineCare members with ID/ASD, including those on the ID/ASD waivers. **Section 13**

**Consumer-Directed Care Attendant Services** are personal care services provided by attendants hired, trained, supervised, and if necessary, fired by the member requiring the services who live in the community and not in an institutional setting. Members are assessed for medical eligibility for this service and must require at least limited assistance plus a one-person physical assist with at least two ADLs. The members must also have the cognitive capacity, as measured on the MED form, to be able to self-direct the attendant. Members are given skills training in managing and directing personal care attendants. Family members are not eligible to serve as attendants. **Section 12**

**ICF-IID Nursing and Group** facilities serve members who have intellectual disabilities, autism spectrum disorder, or other related conditions. Residents of Nursing level facilities must require at least 8 hours of licensed nursing supervision on a daily basis; residents of Group level facilities must **not** need 8 or more hours of daily nursing care. Services in both levels include nursing, rehabilitation treatment, physical and occupational therapies, speech and hearing services, among others and are provided according to an individual's care plan. In addition, each resident must have a developmental training program designed to maximize a person's functioning capabilities. **Section 50**

**Definitions of LTSS settings and programs with section number references to the MaineCare Benefits Manual available at: http://www.maine.gov/sos/cec/rules/10/ch101.htm**

**Non-waiver MaineCare Home Care Services** are those services provided under Section 12 Consumer Directed Care Attendant and Section 96 Private Duty Nursing. Please see those definitions for more details.

**Nursing Facility** services are those provided by licensed facilities and are primarily professional nursing care or rehabilitative services for injured, disabled, or sick persons; needed on a daily basis and as a practical matter can only be provided in a nursing facility; ordered and provided under the direction of a physician; and less intensive than hospital inpatient services. **Section 67**

**Private Duty Nursing (PDN)** services are those nursing services provided by a registered nurse or a licensed practical nurse, under the direction of the member's physician, in the member's place of residence or outside the residence such as at school or medical appointments; **Personal Care** services are assistance with ADLs or IADLs provided by a home health aide, certified nursing assistant, personal support specialist, or certified residential medication aide. There are nine levels of PDN care, and members are assessed through the MED tool for this service; levels 1-3 provide personal care and nursing services to members with increasingly severe need; level 4 is for children under 21 who are medically eligible for nursing facility services; level 5 is for intensive nursing care for members who are ventilator dependent; levels 6 and 7 are focused on medication and venipuncture services; level 8 is limited to nursing services for members who receive personal care services under other programs such as the Section 21 Comprehensive IID waiver; level 9 is focused on personal care services for members with daily medication needs. For this chartbook, levels 4 and 5 were excluded from the hierarchy analysis of claims experience for adults who use LTSS; level 4 is for children under 21 and level 5 is more akin to hospital level of care. **Section 96**

**Residential Care Facilities (Appendix C)** provide medical and remedial treatment services to residents who are assessed through the MED tool assessment. Facilities provide personal care, nursing, and social work services, as well as arranging for other necessary clinical and therapeutic services. Appendix C facilities are reimbursed according to the severity of their case load of residents. **Section 97**

**Residential Care Facilities (Appendix F)** provide medical and remedial treatment services. These facilities specialize in the treatment of adults with ID/ASD, brain injury, mental illness or other disabilities. Facilities provide personal care, nursing, and social work services, as well as arranging for other necessary clinical and therapeutic services. The Appendix F facilities detailed in this chartbook serve adults with ID/ASD. **Section 97**

**Definitions of LTSS settings and programs with section number references to the MaineCare Benefits Manual available at: http://www.maine.gov/sos/cec/rules/10/ch101.htm**

**Section 20 Other Related Conditions Waiver** provides home and community based services to adults with cerebral palsy or epilepsy or any other condition closely related to intellectual disabilities whose condition manifested before age 21, is likely to continue indefinitely, and results in substantial functional needs. Services are provided according to an individual's care plan and can include assistive technology devices and services, care coordination, communication aides, community support services, employment specialist services, home modifications, home support, transportation to gain access to Section 20 services, personal care, and work support services, among others. **Section 20**

**Section 21 Comprehensive—ID/ASD Waiver** services are home and community based services provided to adults with intellectual disabilities or autism spectrum disorder who are medically eligible for ICF-IID care. Services include home support, community support, employment specialist services, work support, home modifications, communication aids, counseling, crisis intervention services, transportation, OT, PT, and speech therapies, among other services. **Section 21**

**Section 29 Supports—ID/ASD Waiver** services are home and community based services provided to adults with intellectual disabilities or autism spectrum disorder who are medically eligible for ICF-IID care but who live in their own homes or with their families. Services include community support, employment specialist services, work support, home modifications, transportation, and respite services.

**Sections 19/22 Elderly and Adults with Disabilities Waiver and Benefits for Adults with Physical Disabilities Waiver** services are those home and community based services provided to members who are assessed through the MED tool and who meet the medical eligibility requirements for nursing facility care. Services include adult day health, care coordination, environmental modifications, homemaker services, home health services, financial management services to assist members directing their care attendants, personal support services, personal emergency response systems, respite services, transportation, skills training, supports brokerage and medical social services. Services are provided according to the member's plan of care. **Sections 19 and 22**

| MaineCare Services Identified in MIHMS used by Members who Use LTSS |
|---|
| **Behavioral Health Clinician** services are provided under Section 65 and include outpatient behavioral health, crisis intervention, neuropsychological testing, substance abuse treatment, and other services. |
| **Case Management Services Providers** are approved to provide case management services by the Department of Health and Human Services or its authorized agent. They may be firms, partnerships, associations, corporations, or other organizations. |
| **Children's Community Rehabilitation** services are provided under Section 28 Rehabilitative and Community Support Services for Children with Cognitive Impairments and Functional Limitations. These services are available to members up to age 21. In this chartbook, a small group of adults age 18-21 use these services. |
| **Community Providers** are either Section 31 Federally Qualified Health Centers; Section 9 Indian Health Services; or Section 103 Rural Health Clinic Services. These services are mostly focused on primary and ambulatory care, although the Indian Health Service also includes meal delivery, home health services, and asthma and diabetes management services among others. |
| **DME Suppliers** are suppliers of durable medical equipment. |
| **Consumer Directed Attendant services** are available for members who meet eligibility requirements and allow the members to have control over their care. Members receive training on how to direct their attendants, and administrative services are available to assist members comply with state and federal tax and labor regulations. Administrative services include preparing payroll and withholding taxes and making payments to suppliers of goods and services. |
| **Hospital** services identified in this chartbook includes not only inpatient care but also outpatient and hospital-based professional services. |
| **Mental Health Clinic** services in this chartbook include community support services, behavioral health services, and assertive community treatment. |
| **PCA Agency** refers to an agency providing personal care services. |
| **Pharmacy (Hosp. Rx)** refers to MaineCare's share of pharmacy claims when a person is in the hospital; for members also eligible for Medicare, this includes MaineCare's cost-sharing. |
| **Pharmacy (Rx Claims)** refers to pharmacy claims for MaineCare covered services, including for DME, when a member is not in the hospital. |
| **Psychiatric Hospital** services refer to both inpatient and outpatient psychiatric services. |
| **State Agency** in this chartbook refers to targeted case management services provided by state employees. |

# References

[1] Woods & Poole Economics, Inc., Washington, D.C. "2015 New England State Profile: State and County Projections to 2050".

[2] Kemper, P. et al. Long-Term Care over an Uncertain Future: What Can Current Retirees Expect? *INQUIRY*, 2005 42:335. Available at http://inq.sagepub.com/content/42/4/335.full.pdf+html. Accessed October 30, 2014.

[3] Georgetown University. "The Importance of Federal Financing to the Long-Term Care Safety Net," (February 2012). Available at: http://www.thescanfoundation.org/sites/thescanfoundation.org/files/Georgetown_Importance_Federal_Financing_LTC_2.pdf

[4] Centers for Disease Control and Prevention. *What Are the Potential Effects of TBI?* [Web Page]. 2012, September 25. Available at http://www.cdc.gov/traumaticbraininjury/outcomes.HTML. Accessed October 30, 2014.

[5] http://assets.aarp.org/rgcenter/ppi/ltc/fs229-ltc.pdf Accessed October 31, 2014.

[6] Disability - American Community Survey (ACS) - People and Households - U.S. Census Bureau. (n.d.). http://www.census.gov/people/disability/methodology/acs.html Retrieved April 14, 2015.