CONSUMER DIRECT CARE NETWORK

Role of **Home and Community Based Services**

WHITE PAPER

Presented by Consumer Direct Care Network

HCBS Utilization **and Trends**

Background **on HCBS**

The establishment of Home and Community Based Services (HCBS) in the early 1980s stems from a parent who wanted her child (Katie Beckett) to be able to receive care for her permanent disability in her home rather than in a nursing home. HCBS is intended for people like Katie, who have chronic or long term healthcare needs due to a disability, life event (such as a brain injury), or because they are older and require functional assistance. HCBS exists because basic Medicaid was designed to pay for care delivered in institutions (nursing homes, hospitals, facilities for intellectual and developmental disabilities, and institutes for mental disease). HCBS offers a means of allowing people to live and receive care in community and in-home settings.

HCBS developed out of a gap **left by basic Medicaid, Medicare, and commercial insurance markets, which do not pay for long term services provided outside of institutions.**

As mandated by federal regulations regarding state participation in the Medicaid program, states share the cost of expenditures on HCBS with the federal government. The Medicaid program was designed with this prerequisite, and states are required to monitor utilization and control cost. States are legally unable to obtain the federal portion of Medicaid dollars without having these and other controls for access to care in place. When state budgets experience shortfalls, cuts in healthcare spending can result since health and human services programs frequently take up a large portion of a state's budget. This means there are often state controls in place to account for quality and cost of HCBS in addition to federal requirements.

Two major sources provide comprehensive data points on HCBS utilization and trends in the United States, and are the basis for this paper:

1. **Medicaid Expenditures for Long-Term Services and Supports (LTSS)** in FY 2015 from CMS's Medicaid.gov retrieved from https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015final.pdf
2. **Medicaid Home and Community –Based Services Programs:** 2013 Data Update, from the Kaiser Family Foundation. Retrieved from http://www.kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/

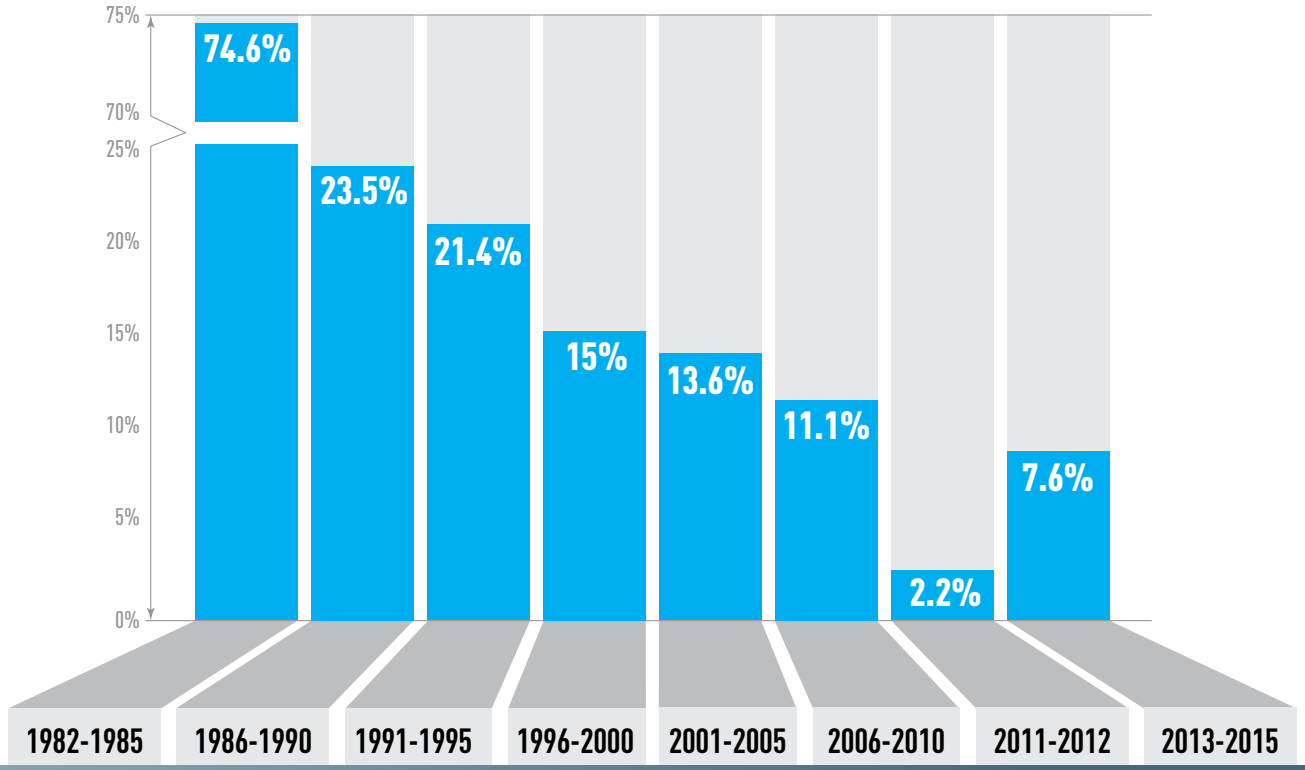
Expenditure growth **of HCBS**

Since the program's inception, expenditures in HCBS has shown continued growth over time, indicating beneficiaries continued preference for HCBS models of service delivery. As shown in Figure 1, strong growth occurred in the years immediately following the availability of HCBS. The initial surge in enrollees was seen as reflective of pent-up demand for these services as participants transitioned from traditional institutional settings to Home and Community Based settings. Growth leveled off after that initial surge, but expenditures continue to rise, year-on-year, a reflection of increased popularity, growing populations, and growing numbers of an aging adults.

Percentages in chart reflect year-on-year growth in HCBS expenditures, showing slowed but continued growth over time.

Figure 1:

Average Annual Growth in Medicaid HCBS Expenditures. FY 1982-2015

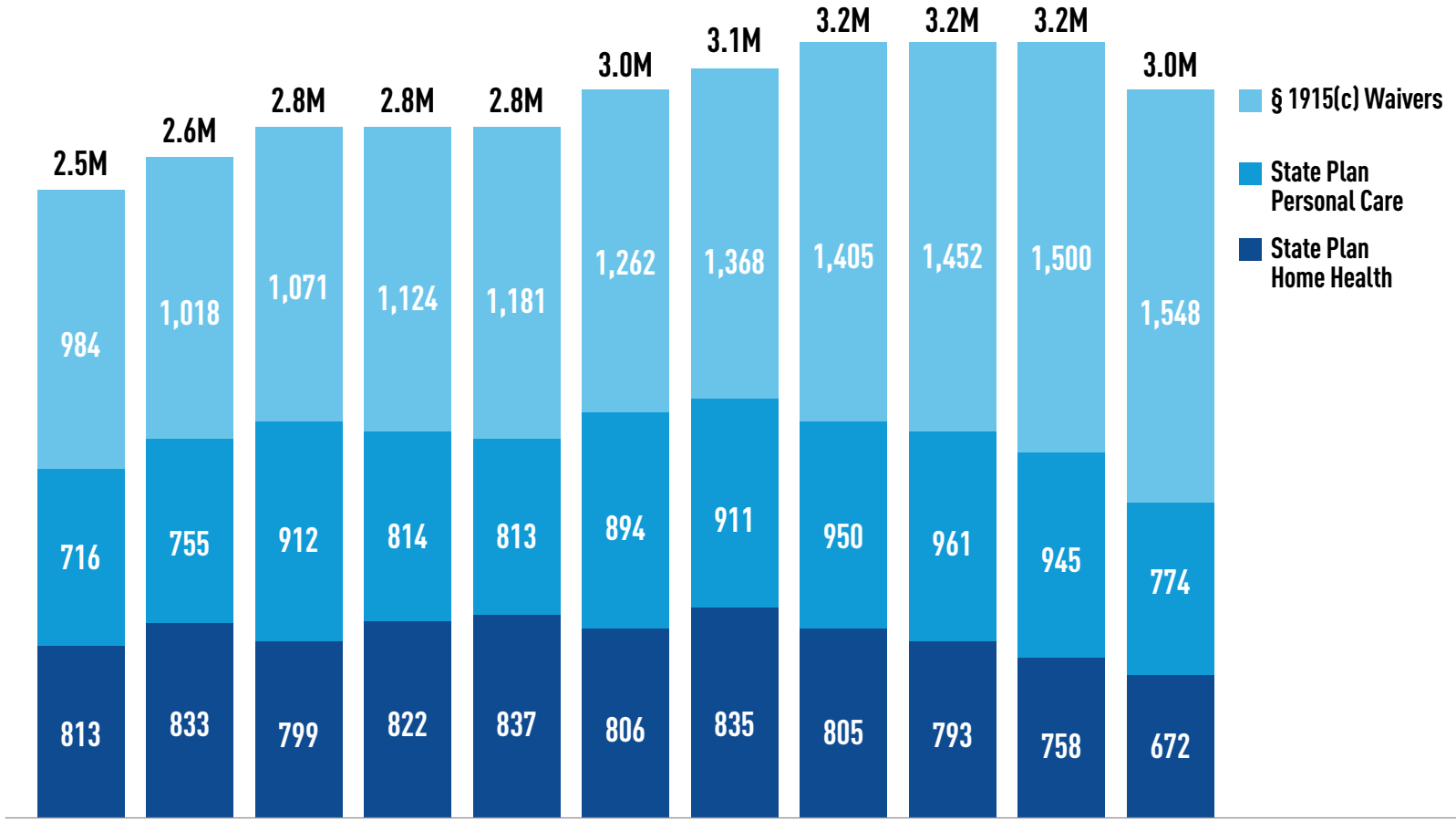


SOURCE: *2013 Data Update*. Kaiser Family Foundation. Retrieved from http://www.kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/

Population growth **of HCBS**

Figure 2:

Growth in Medicaid HCBS Participants, by Program, 2003-2013



NOTE: Figures updated annually and may not correspond with other reports. Data exclude enrollment in Community First Choice, Section 1915 (i) HCBS, and section 1115 waivers that include HCBS.
SOURCES: KCMU and UCSF analysis of CMS Form 372 data and program surveys.

Populations **Covered Under HCBS**

Populations covered under HCBS vary by state and by population served; services available to each vary based on specific population's requirements for in-home care. Delivery of HCBS services can occur for multiple years or for the remainder of a person's lifespan. People who qualify for HCBS often have chronic or lifelong conditions that create stable healthcare needs over the span of their lifetimes (this is different from acute medical care wherein a person's health condition is unstable for a shorter timeframe). HCBS serves people who need long term care, which **Medicare does not provide**, and **private commercial insurance does not cover.**

People who qualify for HCBS often have chronic or lifelong conditions that create stable healthcare needs over the span of their lifetimes...

Generally speaking, **HCBS serves** (this list is not exhaustive):

- **People with developmental disabilities**
- **Children and adults with severe disabling mental illness**
- **Children and adults with substance use disorder**
- **People with spinal cord injury**
- **Children and adults with mental health needs**
- **People with physical disabilities**
- **People with autism**
- **People with brain injury**
- **People who are elderly**

Impacts of Cuts **to Funding for HCBS**

Cutting Medicaid funding for LTSS and HCBS will leave people who are served by Medicaid HCBS with nowhere to turn but to institutions and nursing homes since their needs cannot otherwise be addressed in the private market. While out-of-pocket HCBS is an option for those who can afford it, most Medicaid recipients are low income and would not be able to pay for in-home care for the span of their lives. Medicaid HCBS services are specialized to fit the population they serve, and at this time there is no affordable substitute.

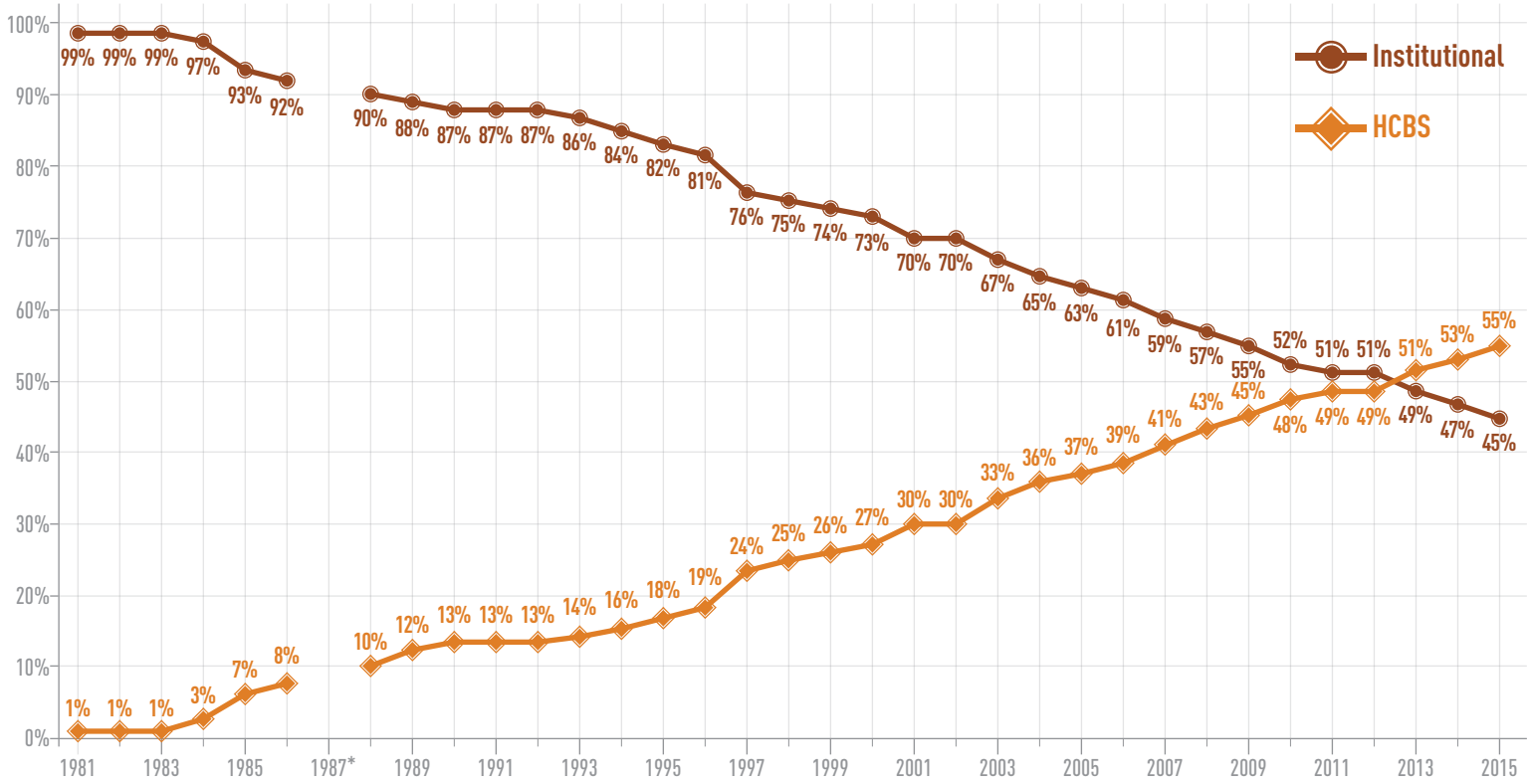
Growth in **HCBS Utilization-Trends in Data**

The utilization of HCBS services for long term care health needs continues to grow. The highest growth occurred in the years following the establishment of HCBS in 1982, due to the pent-up need for HCBS by those who were in institutions or nursing homes and did not have HCBS options available.

Even with increases in the numbers of aging populations in need of long term services and supports[1], enrollment in institutional care continues to decline which enables us to infer people are choosing HCBS over institutional settings for their long term care needs.

Figure 3:

Medicaid HCBS and Institutional LTSS Expenditures as a Percentage of Total Medicaid LTSS Expenditures FY 1981-2015



1 Ortman, J., Velkoff, V., and Hogan, H (2014). *An Aging Nation: The Older Population in the United States. Population Estimates and Projections.* U.S. Department of Commerce. United States Census Bureau, Economics and Statistics Administration. Available online a https://www.census.gov/prod/2014pubs/p25-1140.pdf

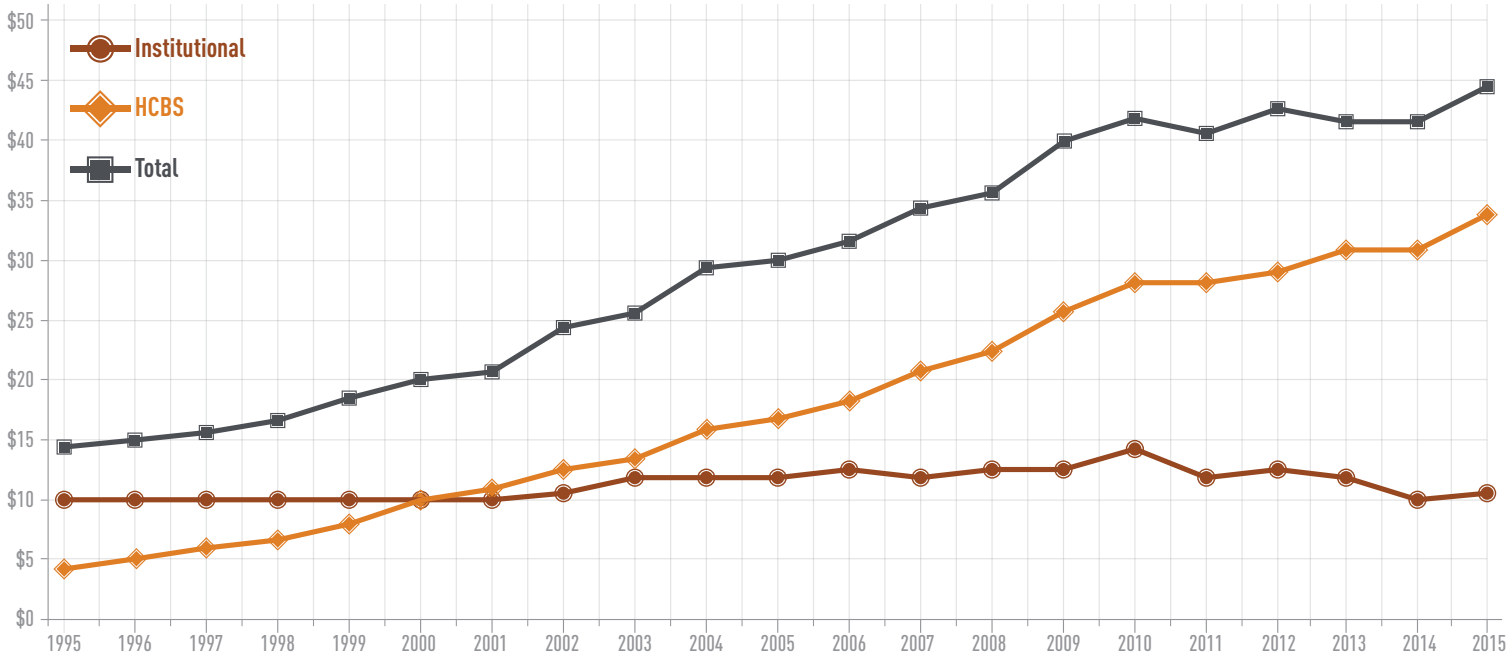
Costs **Over Time**

Spending on HCBS overtook spending on institutional care as a percentage of spending on LTSS around 2012 and the proportion of total Medicaid LTSS spent on HCBS continues to rise, while spending on institutional care as a proportion of total Medicaid LTSS spending continues to decline, which tells us that HCBS continues to gain traction as one of the primary delivery mechanisms for long term care services.

The diagram below titled Medicaid Expenditures Targeted to People with Developmental Disabilities shows HCBS spending continues to increase over time, while spending on institutional services remains relatively flat[2]. From this information, we can infer that HCBS spending is increasing due to increased enrollment in HCBS services as the numbers of people served by Medicaid continues to rise due to an aging population in the United States .

Figure 4:

Medicaid HCBS LTSS Expenditures Targeted to People with Developmental Disabilities, by Service Category, FY 1981-2015 (in billions)



Institutional includes ICF/IID. HCBS includes supports targeting people with intellectual disability, autism spectrum disorder, and/or other developmental disabilities authorized in section 1915 (c) waivers, section 1915 (i) state plan benefits, and in a fee-for-service 1115 demonstration or a managed care program (e.g., a section 1915 (b) waiver) that were not authorized under another state plan or waiver authority (called "HCBS-unspecified" in the data tables).

2 Eiken, S., Sredl, K. Burwell, B., & Woodward, R. (2017). Citation for graph - Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2015. Retrieved from https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015final.pdf

HCBS **options**

Since the inception of HCBS as a service delivery option for Medicaid long term care in the early 1980s, the federal government continues to support new statutory authorities which allow states to develop Medicaid-funded programs supporting HCBS and in-home care settings.

Social Security Act -1915(c) Medicaid Waivers- This section of the SSA enables states to limit enrollment in a HCBS waiver program to specific populations. States can use this federal authority to offer specific sets and limits on services to these populations.

ACA (2010): **Expansion of HCBS**

The Patient Protection and Affordable Care Act (PPACA or simply ACA) offers states additional mechanisms to expand the use of HCBS: Community First Choice (1915k), State Plan Personal Assistance and State Plan Self-Direction (1915i and 1915j authorities).

Cost Savings **from Utilization of HCBS over Institutional Care:**

For a number of reasons, there is a lack of federally-mandated and formalized data collection on realized cost savings due to HCBS. Over the past several years, state Medicaid agencies have partnered with academic and non-profit research facilities to fill the gap in information through development of research and reporting on the various ways in which HCBS allows for cost savings to states[3]. Data provided in these reports is specific to each state's Medicaid agency or program and many examples are referenced throughout this paper.
While the aged and disabled population comprises 48% of Medicaid Waiver enrollment (through 1915c of the SSA), they accounted for only 21% of Medicaid spending from 2003-2013[5]. People with intellectual and developmental disabilities use a larger proportion (71%) of LTSS dollars due to this population exhibiting higher services utilization of LTSS over time[4].

> "While the aged and disabled population comprises 48% of Medicaid Waiver enrollment, they accounted for only 21% of Medicaid spending from 2003-2013."[5]

3 - AARP Public Policy Institute (2013). *State Studies Find Home and Community Based Services to Be Cost-Effective*, Appendix A. Retrieved from http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2013/state-studies-find-hcbs-cost-effective-bibliography-AARP-ppi-ltc.pdf

4 - Ng, T., Harrington, C., Musumeci, M., & Uri, P. (2016) *Medicaid Home and Community –Based Services Programs: 2013 Data Update*. Kaiser Family Foundation. Retrieved from http://www.kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/

5 - ibid

Cost Controls **in Place for HCBS**

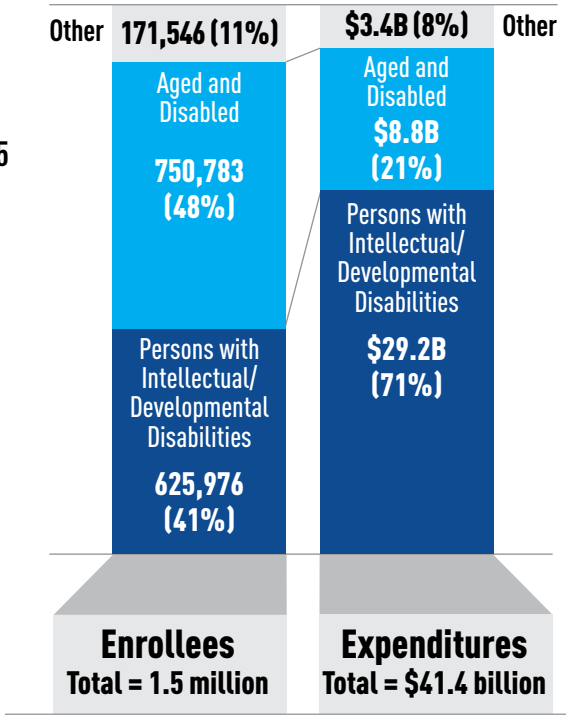
Figure 5:

Medicaid § 1915(c) HCBS Waiver Enrollees and Expenditures, by Enrollment Group, 2013

The HCBS Medicaid program is designed to be paid for by both state and federal dollars. States bear anywhere from 27% to 50% of the cost of all Medicaid expenditures, to include HCBS. Because states share part of the cost of services, they also have an interest in controlling and monitoring spending.

Kaiser Family Foundation conducted a report in 2016 on the ways in which states control cost:

- **"In 2015, all states reported using cost controls in § 1915 (c) waivers, such as restrictive financial and functional eligibility standards, enrollment limits, or waiting lists.**
- About 25 percent of § 1915 (c) waiver programs used financial eligibility standards that were more restrictive than those used to determine eligibility for Medicaid coverage for institutional care.
- 59%* of states offering personal care state plan services (59% or 20 states) had some form of cost controls in place, with the majority utilizing service unit limitations.
- Over half of states (59% or 30 states) had some form of expenditure or service restriction in place in their home health state plan programs."[6]



NOTES: Percentages may not sum to 100 percent due to rounding. Data excludes enrollment and spending for Community First Choice, Section 1915 (i) HCBS, and Section 1115 waivers that include HCBS. The "Other" enrollment group includes waiver enrollees who are people with physical disabilities, children, people with HIV/AIDS, people with mental health needs, and people with traumatic brain and spinal cord injuries.
SOURCES: KCMU and UCSF analysis of CMS Form 372 data.

HCBS plays a vital role in providing services for people with disabilities and the elderly, and service delivery under these programs is monitored closely by state Medicaid agencies. Because states already have a vested interest in controlling HCBS expenditures, a reduction in revenue to the state for purposes of HCBS service delivery often results in a reduction in rates or services; both of these options cause harm to HCBS systems, including populations which Medicaid and HCBS are intended to serve.

* Because states share part of the cost of services, they also have an interest in controlling and monitoring spending.

6 - Ng, T., Harrington, C., Musumeci, M., & Uri, P. (2016) *Medicaid Home and Community–Based Services Programs: 2013 Data Update*. Kaiser Family Foundation. Retrieved from http://www.kff.org/medicaid/report/medicaid-home-and-communitybased-services-programs-2013-data-update/