Community Integration Fact Sheet

Community integration refers to people with disabilities being fully participating, equally valued members of our communities. Historically there has been a tendency to erroneously believe that disabled people need, and want, to live and get our services with other disabled people – often in institutions or other segregated settings. This is known as the "institutional bias".

In Medicaid, the institutional bias refers to a specific, problematic service bias where Medicaid covers nursing facilities and other institutions as a mandatory service while home and community-based services are optional. However, over the last several decades disabled people have fought against this bias, arguing that the right supports and services provided in the community are all that is needed to ensure that disabled people succeed alongside our peers.

As a result of our education, advocacy, and often demands, the picture for community integration and inclusion in the United States has begun to change.

This document provides an overview of some of the laws, policies, decisions, and advocacy efforts that have helped advance the fight for community integration.

Contents

Olmstead Decision

The *Olmstead* decision refers to a ruling by the United States Supreme Court on June 22, 1999 in *Olmstead v. L.C.* The Court upheld the Americans with Disabilities Act's (ADA) integration mandate by ruling that unjustified segregation of people with disabilities constitutes discrimination under the ADA, and that people with disabilities must be provided with community-based services when they are appropriate, wanted by the individual, and can be reasonably accommodated. The case was brought by Lois Curtis and Elaine Wilson, two individuals with intellectual and psychiatric disabilities who, after voluntary psychiatric institutionalizations, remained stuck in the state-run facility for years. With the help of the Legal Aid Society, they sued the state of Georgia and won. The state appealed, and the case went all the way to the Supreme Court, where Lois and Elaine won again. Olmstead is the last name of Tommy Olmstead, the Commissioner of the Georgia Department of Human Resources at the time.

Community First Choice (also known as 1915(k))

The Community First Choice (CFC) option is a Medicaid State plan option that incentivizes States to provide long term services and supports (LTSS) in the community instead of in institutional settings. The CFC option provides a 6% point increase in Federal Matching Assistance Percentage (FMAP) payment for states who provide new, or expanded, home and community-based services (HCBS) to people with disabilities determined to have an "institutional level of care". (A state's FMAP determines the amount the federal government will contribute to specific state programs.)

CFC was established as part of the Affordable Care Act (ACA) in 2010, which established a new section 1915(k) State plan option to provide home and community-based services and supports. As of 2018, nine states have chosen to use this option: Alaska**,** California, Connecticut, Maryland, Montana, New York, Oregon, Texas and Washington.

Resources:

- CMS CFC Information Page
- CFC Final Regulation (PDF)
- CMS 2015 Community First Choice Final Report to Congress (PDF)

Money Follows the Person

The Money Follows the Person (MFP) Rebalancing Demonstration Grant was a demonstration program that was designed to help states transition people with disabilities from institutions into the community and rebalance their Medicaid long-term

care systems. States that are awarded grants receive an enhanced Medicaid matching rate to provide relevant services and supports.

MFP was established as part of President George Bush's New Freedom Initiative, and was included in the Deficit Reduction Act of 2005. It launched in 2007 and was re-authorized and expanded in 2010 in the Affordable Care Act. 47 States participated in MFP and over 88,000 people with disabilities were liberated from nursing facilities and other institutions.

MFP expired in 2016. States that still had money left in their grants at the end of 2016 were allowed to spend that money through 2020. In January 2019, Congress extended MFP through September 2019 and provided three months of funding. At the time of this document's writing, there are several MFP bills being considered, and the ultimate goal is for a permanent MFP solution.

Resources:

- CMS MFP Information Page
- MFP Grant Amounts by State (PDF)
- MFP Rebalancing Report to Congress (PDF)
- Final Report: MFP Demonstration: Overview of State Grantee Progress, January to December 2016 (PDF)
- MFP 2015 Annual Evaluation Report (PDF)

1915(c) Medicaid Waivers (also known as Home and Community Based Services Waivers)

Section 1915(c) Medicaid Waivers, also known as Home and Community Based Services (HCBS) Waivers, allow states to develop and provide Medicaid services and supports to people in their homes or communities, rather than in institutional settings. States providing services through 1915(c) waivers can offer a variety of services, and they can provide a combination of medical and non-medical services and supports. States can decide to limit waiver applicability to certain locations or populations.

Medicaid HCBS Waivers were authorized in 1981 (as freedom-of-choice waivers), and now nearly all states operate 1915(c) waivers. Waivers vary from state to state, and many states offer more than one 1915(c) waiver.

Resources:

- CMS 1915(c) Information Page
- Section 1915 of the Social Security Act
- Medicaid Expenditures for Section 1915(c) Waivers in FY 2015 (PDF)

1915(i) Home and Community Based Services State Plan Option

The Section 1915(i) Home and Community Based Services (HCBS) State Plan Option, allows states to provide certain HCBS to people who do not require an 'institutional level of care' and therefore would not be eligible for 1915(c) waivers, as long as they are under certain income limits. States providing services through the 1915(i) option are allowed to waive Medicaid's comparability requirement, which means they can decide the amount, duration, and scope of services different people are eligible for, but they are not allowed to cap eligibility.

Medicaid HCBS State Plan Option was added to the Social Security Act in 2005. In 2016, eighteen states uses the 1915(i) option.

Resources:

- CMS 1915(i) Information Page
- Section 1915 of the Social Security Act
- CMS 1915(i) Fact Sheet (PDF)

1915(j) Self-Directed Personal Assistant Services

Section 1915(j) Self-Directed Personal Assistant Services (PAS) allows people to self-direct their services for State Plan personal care and / or the 1915(c) (home and community based-services) waivers. Participants must receive choice counseling and must be allowed to manage, direct, and make key decisions about their services.

Medicaid HCBS State Plan Option was added to the Social Security Act in 2005. In 2016, five states (CA, FL, OR, TX, and WI) used the Section 1915(j) state plan option.

Resources:

- Medicaid 1915(j) information
- Section 1915 of the Social Security Act
- CMS Letter to State Medicaid Directors (PDF)

Katie Beckett Waiver / TEFRA Option

The Katie Beckett Waiver and the TEFRA State Plan Option allow the family of disabled children to deem the child's income as separate from the family's income so the child can qualify for Medicaid (if they are otherwise qualified) without the traditionally required 30-day hospital stay. This allows states to provide Medicaid services and supports to children (under age 19) in their homes or communities, regardless of parents' income.

The Katie Beckett Waiver was created in 1981. It was named for Katie Beckett, a disabled three year old for whom the HHS Secretary waived her parents' income, thereby allowing her to quality for SSI and leave the hospital to receive Medicaid-funded services and supports at home. The Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) expanded on the waiver by establishing a TEFRA State Plan option, also known as the Katie Beckett provision. Most states have converted their Katie Beckett Waivers to TEFRA programs. The next year, the waiver was formalized.

Resources:

- Understanding Medicaid HCBS: A Primer, 2010 Edition. Katie Beckett Option

The "Cash and Counseling" Demonstration / Evaluation

The "Cash and Counseling" Demonstration / Evaluation was intended to introduce or expand participant direction of personal assistance services among Medicaid-eligible individuals with disabilities. This was still a novel concept as the history of Medicaid programs had traditionally been to give funds to provider agencies to then pay caregivers; under this program, disabled individuals are able to find, hire, and train their own caregivers, including family members.

The original Cash and Counseling demonstration program ran from 1996 through 2009. Three states participated during its initial demonstration phase, and 12 states implemented the Cash and Counseling model during the replication phase, with around 13,500 individuals participating. Since the pilot, both the scope of the project and the number of participating states have expanded, with some form of this program existing in every state. Now these programs go by a variety of different names, many which refer to Self-Directed Care or Consumer Directed Care. They also have now expanded to include several non-Medicaid programs.

Resources:

- Robert Wood Johnson Foundation Program Results Report
- Mathematica Evaluation of Three Cash and Counseling Programs
- List of Cash and Counseling Programs by state

Balancing Incentive Program

The Balancing Incentive Program (BIP) authorized grants to states to increase access to home and community based services. BIP increased the Federal Medical Assistance Percentage (FMAP) to states that made changes to increase access to non-institutional long-term services and supports (LTSS) and increase diversion from nursing facilities

and other institutions. (A state's FMAP determines the amount the federal government will contribute to specific state programs.) Only states who spent less than 50% of their Medicaid expenditures on non-institutionally-based LTSS for fiscal year 2009 were eligible to participate in BIP.

BIP was created in 2010 by the Affordable Care Act. It authorized grants from 2011 to 2015. Eighteen states participated in BIP, and thirteen states continued to participate after the deadline by spending their grant funds.

Resources:

- CMS Balancing Incentive Information Page
- Balancing Incentive Program Website
- Final Outcome Evaluation of the BIP

Other Resources

- CMS Long Term Services and Supports Page
- CMS LTSS Reports and Evaluations Page

Glossary

Americans with Disabilities Act (ADA): Passed in 1990, this law provides protection from discrimination for people with disabilities in the areas of employment, programs and services of State and local governments, public accommodations, telecommunications, and other miscellaneous areas of life.

Community Integration: this refers to people with disabilities being fully participating, equally values members of their communities who have control over their own lives, including the services and supports necessary for their full participation.

Demonstration Project (in Medicaid): projects funded by Medicaid to test and measure the effect of potential program changes.

Enhanced Match (or enhanced FMAP): When the Federal Government pays States a larger share of the cost of a program for meeting certain requirements.

Federal Medical Assistance Percentage (FMAP): This is the percentage of State Medicaid payment reimbursed by the Federal government. The FMAP determines the amount of money the Federal government will contribute to State Medicaid programs to pay for covered services. FMAP is calculated annually.

Institution: any settings where some people with disabilities are congregated and/or segregated and have limited control over their lives. Institutions can be of any size. People in institutions often did not make the choice to live there and usually cannot leave when they want to.

Institutional Bias: The way the long term services and supports (LTSS) system, by design, often forces disabled people into institutional settings to receive the services and supports they need.

Integration Mandate: part of the Americans with Disabilities Act (ADA) that requires State and local governments to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

Medicaid: a government healthcare program. Medicaid is a joint Federal/State entitlement program. Every State has its own Medicaid program that receives funding from the Federal government. Medicaid helps many people who need healthcare, and also pays for long term services and supports (LTSS).

Medicaid State Plan: State Medicaid Agencies all have their own State plans, which are agreements between the State and the Federal government to provide health insurance to State citizens. Medicaid State Plans require that certain specific services always be offered by States.

Medicaid Waiver: An exception to the usual requirements of Medicaid granted to the State by CMS. Under a Medicaid waiver, a State can waive certain Medicaid program requirements, allowing them to provide services and supports for people who might not otherwise be eligible for Medicaid or in ways they might not be otherwise covered; for example: HCBS waivers allow people who would otherwise be required by Medicaid to receive services and supports in institutional settings to receive them in the community.

Personal Assistance: direct services provided by one person to another to support people with disabilities. Personal care attendants (PCAs), direct support professional (DSPs), family caregivers, and others provide this. This can include things like assistance with activities of daily living (for example: bathing, dressing, or toileting) and instrumental activities of daily living (for example: laundry, grocery shopping, paying bills, or medication management).

Self-Directed Services (in Medicaid): services where participants (or their representatives) have decision-making authority and take direct responsibility to manage them with the assistance of a system of available supports.

Self-Direction: a philosophy that supports disabled people in making decisions about their own lives.

Transition (services): in this context, this often refers to moving people out of institutional settings and into the community with the appropriate services and supports.

All CILs are required to provide a set of transition services which includes: moving people out of institutions and into the community; providing assistance to people who are at risk of entering institutions so they may remain in the community (also known as diversion); and helping disabled youth who have completed their secondary education or otherwise left school move on to postsecondary life.