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Brief Report

Community integration of people with intellectual and developmental disabilities: A national longitudinal analysis

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ABSTRACT

Background: Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are the largest providers of long-term supports and services (LTSS) for people with intellectual and developmental disabilities (IDD) in the United States. National and longitudinal analyses of HCBS 1915(c) waivers for people with IDD are critical because of changes in the fiscal landscape, the variability produced by states ability to flexibly customize their programs, and the significant changes required by the HCBS final settings rule.

Objective/Hypothesis: The aim of this study was to determine spending allocations and state priorities for LTSS for people with IDD through Medicaid HCBS waivers over a five-year period (fiscal year 2011 to fiscal year 2015).

Methods: Medicaid HCBS 1915(c) waivers for people with IDD from fiscal year (FY) 2011 to FY 2015 were analyzed to determine total projected spending, unduplicated participants, and average spending per participant across fiscal years and states. Over 10,000 services from the five years were also analyzed to determine service priorities.

Results: This longitudinal analysis of HCBS IDD waiver allocation revealed large fluctuation across five years in terms of total participants, total spending, and average spending per participant. Trends also revealed a shifting away from residential habilitation settings towards supports for living in one's own home.

Conclusions: When revising waivers to meet the Final Settings Rule, states should utilize our findings to determine areas of need and how to best apply limited funding.

Medicaid is responsible for the majority of government funding (federal, state, and local) for people with intellectual and developmental disabilities (IDD) in the United States.[1] Medicaid Home and Community Based Services (HCBS) 1915(c) waivers in particular are the largest provider of long-term services and supports (LTSS) for people with IDD.[1] HCBS waivers were originally developed in 1981 as an alternative to intermediate care facilities for individuals with intellectual disabilities (ICF/IIDs) by allowing states to 'waive' some of the main provisions of the Social Security Act: state-wideness, comparability, and income and resource rules.[2] As such, states are able to develop customized programs tailored to underserved populations that would typically require institutional based care, such as people with IDD. States are given the flexibility to determine their waivers' target groups, services, participant direction, provider qualifications, health and welfare strategies, and cost-effective delivery systems.[3]

Because of the preferences of people with IDD, the cost-effectiveness of HCBS waivers, and the improved outcomes associated with community living, HCBS waiver funding surpassed ICF/IID funding in 2000.[1,4–7] In FY 2010 states projected spending $23.5 billion on HCBS waivers for approximately 515,000 people with IDD.[8] However, Rizzolo, Friedman, Lulinski-Norris, & Braddock (2013)'s analysis of FY 2010 waivers also revealed large variability across states and services, with vast differences in total projected spending, unduplicated participants, and spending per participant. Rizzolo et al. (2013) concluded "with the increased utilization of the HCBS Waivers to support individuals with IDD, there is a great need to better understand the variability of services provided through this funding" (p. 19); indicating the need for longitudinal analyses of HCBS waivers.

In addition to the complex variability found by Rizzolo et al. (2013), there have also been a number of critical changes to the fiscal landscape since FY 2010 because of recovery from the

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2007–2009 Great Recession.[9] For example, inflation changed significantly from 2009 (−6.4%) to 2014 (2.6%).[1] Since FY 2010 the Centers for Medicare and Medicaid Services (CMS) have also passed a number of rule and regulation changes directly applicable to HCBS waivers. The most significant of which is the new HCBS 1915(c) final settings rule (CMS 2249-F/2296-F) which was raised in 2009 and officially implemented in 2014.[10,11] Significantly, the final rule shifts "away from defining home and community-based settings by 'what they are not,' and toward defining them by the nature and quality of participants' experiences" (p. 2).[11] As a result, the final settings rule "establish[ed] a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics" (p. 2).[11] As such, attention is drawn to community integration in new ways, with a move away from segregated services and settings. For example, the rule specifies that people with disabilities must interact with community members without disabilities that are not paid staff. The final settings rule also requires person-centered planning with LTSS directed by individuals' goals and preferences. These new requirements could significantly impact how states provide their services. As such, the rule also requires state HCBS programs develop thorough transition plans to ensure all settings are truly community based [10,11].

National and longitudinal analyses of HCBS 1915(c) waivers for people with IDD are critical because of the significant changes required by the final settings rule, changes in the fiscal landscape, the variability produced by states ability to flexibly customize their programs. Therefore, the aim of this study was to determine spending allocations and state priorities for LTSS for people with IDD through Medicaid HCBS waivers over a five-year period. To do so, Medicaid HCBS 1915(c) waivers for people with IDD from fiscal year (FY) 2011 to FY 2015 were analyzed to determine total projected spending, unduplicated participants, and average spending per participant across fiscal years and states. Over 10,000 services from the five years were also analyzed to determine service priorities.

Methods

Medicaid HCBS 1915(c) waivers were obtained from the Centers for Medicare and Medicaid Services (CMS) Medicaid.gov website every year over a period of approximately five years. In 2012 we collected data for FY 2011, 2013 for FY 2012, 2014 for FY 2013, 2015 for FY 2014, and 2016 for FY 2015. The first step in data collection was the exclusion of all waivers that were not 1915(c). Next, waivers whose target populations were not people with IDD (developmental disabilities (DD), intellectual disabilities (ID), and autism spectrum disorder (ASD)) were excluded. No age limitations were imposed. Waivers that were pending, terminated, or inactive were then excluded. Next, waivers that did not include the target FY were excluded from the analysis; most commonly this was the state FY but sometimes the calendar year or the federal FY were used. The term FY is used for consistency. This process resulted in the collection of 93 waivers for FY 2011, 93 for FY 2012, 99 for FY 2013, 110 for FY 2014, and 111 for FY 2015.

Waiver data were then utilized to determine wavier utilization across states and fiscal years, including projected spending, unduplicated participants, and average projected spending per participant. All expenditure data was adjusted for inflation using the 'The State and Local Government Sub-Index of The Gross Domestic Product (GDP) Government Consumption Expenditure' and Gross Domestic Product data [12,13].

Information about service planning and delivery was also utilized to organize waivers into a taxonomy mirroring Rizzolo et al. (2013)'s FY 2010 HCBS IDD waiver taxonomy, which was developed based on an analysis of over 1300 HCBS IDD waiver services. Doing so was necessary to determine what types of services categories were being provided as well as service priorities in terms of funding allocation.

Results

From FY 2011 to FY 2015, HCBS waivers served an average of 563,116 unduplicated participants per year, with the average state projecting to serve 12,784 participants a year (see Table 1). Across the five years there was an average overall growth of 1.9% in unduplicated participants. Appendix A details change across states.

Over the five years, $161.6 billion was projected for HCBS IDD waivers. Across FY 2011 to FY 2015 inflation adjusted total spending decreased by an average of 1.1%. The average state projected to spend $606.7 million a year (Appendix A). The average adjusted spending per capita from FY 2011 to FY 2015 was $111.88 per year. Across the five years, spending per capita increased on average of 0.2%.

Fiscal effort is a metric to determine "state's commitment to IDD services after controlling for state wealth. Fiscal effort is theoretically based on the competitive struggle for government funding described by Key (1949) and Wildavsky (1974) as the essence of politics" (p. 14).[1] Fiscal effort is calculated by dividing the state's total projected waiver spending (FY 2015) by the state's total personal income (FY 2015). Total personal income is the income received by, or on behalf of, all persons from all sources: from participation as laborers in production, from owning a home or business, from the ownership of financial assets, and from government and business in the form of transfers. It includes income from domestic sources as well as the rest of world. It does not include realized or unrealized capital gains or losses.[14]

The average adjusted fiscal effort from FY 2011 to FY 2015 was $2.45 a year (Table 1). Across the five fiscal years there was an average of 1.0% decrease in fiscal effort (inflation adjusted).

There was an overall decrease of 0.6% on average across FY 2011 to FY 2015 in average spending per participant, with the average spending of $49,002 per participant per year (Table 1; Appendix A).

Service taxonomy

Over 10,000 services were reviewed and sorted into themes according to an updated version of *Citation for review*'s FY 2010 HCBS IDD taxonomy: residential habilitation; individual goods and services; prevocational; transportation; self-advocacy training; day habilitation; community transition supports; respite; health and professional services (crisis, dental, clinical and therapeutic services, nursing and home health); supports to live in one's own home (companion, homemaker, chore, personal assistance, supported living); care coordination; adult day health; specialized medical and assistive technologies; recreation and leisure; financial support services; family training and counseling (family training and counseling, family supports); and supported employment.

Across all five years the most funding was projected for residential habilitation services. A total of $64.2 billion was projected for residential habilitation services over the five years; on average $12.8 billion was projected for residential habilitation a year. The second and third largest services across all five years were day habilitation and 'supports to live in one's own home' (companion, homemaker, supported living, personal assistant, and chore). The rest of the services were projected to receive less than $5 billion each, or less than 3% of spending each, over the five years (Table 2).

In addition to comparing total projected spending by service, we compared change in the proportion of spending the service categories made up across the five years (Fig. 1). Supports for living in