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Self-Direction for Home- and Community-Based Services

Findings from interviews with key stakeholders

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MACPAC

Medicaid and CHIP Payment and Access Commission

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Overview

- Background
  - Purpose
  - Study methods
- Interview findings
  - State design considerations
  - Considerations for state administration
- Next steps

Background

Purpose

- In December, we presented an overview of key requirements and actors in Medicaid self-direction programs
- Staff conducted interviews to gain insights
  - Statutory and regulatory framework that guides self-direction
  - How states design and administer self-directed programs for home- and community-based services (HCBS)
  - Potential challenges to effective program administration

Study Methods

- Staff interviewed federal officials along with other national self-direction experts and researchers
- Additionally, staff interviewed stakeholders in six states
  - State Medicaid officials, state officials from other state agencies involved in self-direction, financial management services (FMS) agencies, support brokers, managed care organizations (MCOs), beneficiary advocates, and an Area Agency on Aging (AAA)
- Conducted 33 interviews between September 2024 and January 2025

Interview Findings:
State Design Considerations

HCBS Authorities States Use for Self-Direction

- Section 1915(c) waiver authority is the most commonly used
  - States shared that Section 1915(c) provides flexibility in selecting specific populations, setting enrollment limits, waiving "statewideness," and choosing which services can be self-directed
- States may also use Section 1915(i), Section 1915(j), and Section 1915(k) state plan options
- Many states operate self-direction programs across multiple authorities

Populations Served

- Interviewees raised several considerations regarding the appropriate level of supports necessary for beneficiaries to self-direct
  - Individuals with dementia, low technological literacy, or those experiencing homelessness may need additional supports to effectively self-direct their HCBS
  - Beneficiaries with strong natural supports may need fewer additional supports to effectively self-direct their HCBS
- One researcher said that strong advocacy may have contributed to younger people with disabilities being among the first populations to self-direct

Self-Directed Services

- Interviewees shared that states generally take one of two approaches when deciding what services to offer through self-direction
  - Choose to add self-direction options to an existing authority already operating in the traditional service delivery model
  - Develop a new suite of self-directed services, often in response to advocacy
- Researchers and state officials said that states are more likely to allow personal care services, such as bathing and dressing, to be self-directed
- Officials at two state Medicaid agencies shared that they consider the level of training or licensing required to provide specific services when defining which services can be self-directed

Budget and Employer Authorities

- States have significant flexibility and can allow budget authority, employer authority, or both by service within a self-direction program
- Interviewees broadly characterized budget authority as more comprehensive and administratively complex, and employer authority as more straightforward for beneficiaries
- States shared various processes for determining beneficiary budgets under budget authority
- States emphasized the importance of ensuring that beneficiaries understand their responsibilities and risks as employers when they have employer authority

Family Caregivers

- All case study states allow family caregivers to be paid employees for at least one of their self-direction programs
- Stakeholders noted family caregivers can help address the national HCBS workforce shortage and provide culturally competent care
- Some researchers and state officials raised concerns about the role of family caregivers
  - One MCO raised concerns about beneficiaries' reluctance to report critical incidents involving family caregivers
  - Some interviewees shared that decision making in self-direction may include family members, which can be an issue when a family member is also the caregiver

Interview Findings: Considerations for State Administration

Variation and Collaboration Across Agencies

- States may administer self-direction programs across multiple state agencies, including the Medicaid agency
- Program administration can vary across operating agencies
- Administering self-direction across multiple state agencies requires collaboration to implement policy or operational changes

Information and Assistance Entities

- States vary in how they define and structure information and assistance entities
  - Case management
  - Support brokerage services
  - AAA, and Aging and Disability Resource Center (ADRC) supports
- The roles of different information and assistance entities often overlap and may be difficult to clearly distinguish both within, and across, states

Information and Assistance: Case Managers

- States generally designate case management across three different models
  - In-house, state case management
  - Vendor case management
  - Hybrid of in-house and vendor case management
- Interviewees agreed that case managers must be well-trained in a state's self-direction model

Information and Assistance: Support Brokers

- States may structure support brokers across three different models
  - Establish independent support brokers
  - Nest the support broker role within the FMS agency
  - Incorporate the support broker role into case management

Information and Assistance: AAAs and ADRCs

- AAAs and ADRCs provide resources and education to beneficiaries in self-direction
- States may designate AAAs and ADRCs to perform information and assistance supports, as they are well-established in communities
- Interviewees identified two different approaches to AAAs and ADRCs supporting self-direction
  - Providing pre-enrollment supports
  - Fulfilling information and assistance roles post-enrollment, such as case management

FMS Agencies and State Contracting Strategies

- Interviewees shared that the state Medicaid agency and operating agencies should set clear expectations when contracting with FMS agencies
- State Medicaid agencies and operating agencies can contract with multiple FMS agencies, a single FMS agency, or provide FMS in-house, and can take different approaches within a state

Quality Reporting, Monitoring, and Oversight

- States leverage their information and assistance support entities, MCOs, and FMS agencies to support their quality reporting, monitoring, and oversight efforts
  - Support brokers may file reports to the state that support program integrity efforts and monitor beneficiary utilization reports
  - MCOs monitor EVV data to ensure service delivery and identify potential instances of fraud, waste, and abuse
  - FMS agencies monitor service use and payments and ensure they remain within established thresholds, notifying the state of potential instances that need to be escalated

Quality Reporting, Monitoring, and Oversight, cont.

- State and federal officials as well as researchers are limited in their data analysis and reporting capacities for self-direction as systems are not designed to stratify self-directed HCBS beneficiary data from the overall HCBS population
  - State officials shared that they need a robust data infrastructure to accurately validate hours for reimbursement
  - Some state officials struggle to stratify self-directing beneficiaries in data analysis and reporting
  - Nationally, researchers cannot compare costs and outcomes between self-directed and agency-directed HCBS

Next Steps

Next Steps

- Staff would appreciate Commissioner feedback on the findings that should be emphasized in the descriptive chapter for June and how these findings should inform MACPAC's future work in this area
  - Are Commissioners interested in learning more about the roles and responsibilities of information and assistance entities, including FMS agencies and MCOs?
  - Are there additional data and information Medicaid should collect to learn more about program administration and quality of care?
- Staff will return in April to present the draft chapter to the Commission

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FEBRUARY MEETING

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