September 25, 2026

Ensuring Health and Welfare in Self-Directed Home- and Community-Based Services

Review of findings and policy option

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MACPAC

Medicaid and CHIP Payment and Access Commission

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Overview

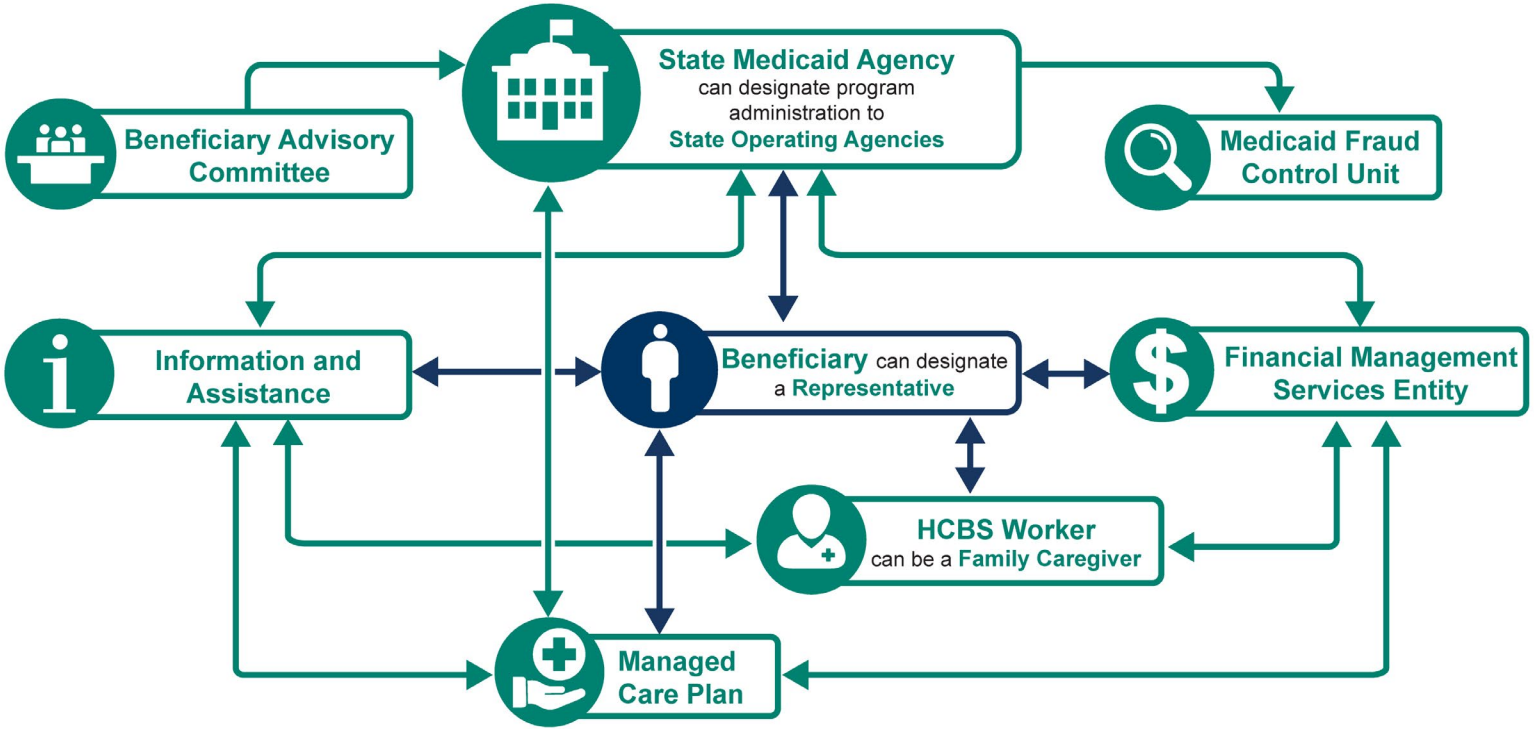
- Background
- State approaches to ensuring health and welfare
- Findings
- Policy option
- Next steps

Background

Medicaid Coverage of Self-Direction

- Self-direction is a Medicaid home- and community-based services (HCBS) delivery model that allows individuals to choose their HCBS providers and have control over the amount, duration, and scope of services and supports in their person-centered service plan (PCSP)
- Federal requirements for self-direction models
  - Person-centered planning process and PCSP
  - Quality assurance and continuous improvement system
  - Information and Assistance (I&A) supports
  - Financial management services (FMS)
  - Individualized budget

Key Stakeholders in Self-Direction



Supports System

I&A

- Provide counseling and training about the program
- Assist participants in identifying personnel
- Help ensure supports are properly managed
- Resource navigation

FMS

- Assist with managing budgets
- Handle payroll
- Withhold and pay taxes
- Monitor and track expenses, payments and budgets

Federal Health and Welfare Safeguards

- States must provide assurances that they safeguard HCBS users by establishing provider standards, operating an incident management system, and other regulatory requirements
- States must meet conflict of interest standards to protect beneficiaries from abuse, neglect, and exploitation
- In self-directed programs, states also
  - Monitor utilization and other data
  - Ensure continuity of care during transitions between services
  - Provide specialized supports for self-direction, including I&A and FMS; these requirements are most explicit under Section 1915(j) authority

State Approaches to Ensuring Health and Welfare

Methodology

- We conducted a federal policy scan of all Medicaid HCBS authorities under which self-direction may be authorized to identify assurances of beneficiary health and welfare, focusing on incident management systems, conflict of interest standards, and safeguards unique to self-direction
- MACPAC conducted comprehensive case studies among three states with variation in their Medicaid authorities, delivery systems, and geography
  - In-depth document reviews of state policy documents, contracts, guidance and other written materials
  - Interviews with stakeholders
  - Cross-case analysis to identify key findings
- Our findings in this presentation refer to these three states

Incident Reporting

- States' definitions of incidents largely overlap, with differences generally due to expanded definitions or language that broadens incident reporting to be more inclusive
- One state in our study requires action on triggering events, which are treated as potential precursors to critical incidents
- All states define certain parties as mandatory reporters and all states have pathways for immediate reporting of serious events and harms, such as abuse, neglect, or exploitation
- The means by which reports are submitted vary by program, and the availability of information on these reports and subsequent follow-up responsibilities varies by entity

Incident Reporting, cont'd.

- Health plans and vendors, such as FMS or I&A vendors, create and rely on their own data systems
  - These entities often have contractual requirements to track and trend incidents
- Health plans and vendors are also using administrative data, such as claims or electronic visit verification (EVV) data, to monitor care and intervene accordingly
  - For example, states flag underutilization of self-directed services as a data point that requires follow-up
- Plans and vendors may not have access to each others' systems or relevant state databases, although in some cases states or other stakeholders aggregate data to track incidents systematically
- Even when data are aggregated, follow-up and tracking can be siloed

Incident Reporting, cont'd.

- In self-directed HCBS, beneficiaries, employers of record (EORs), and workers require effective training on incident reporting, and underreporting can stem from confusion about reporting or other circumstances
- Stakeholders characterize incident reporting as a necessary, but alone insufficient, part of ensuring beneficiary health and welfare in self-direction

Intervention

- States have implemented standards for follow-up when issues arise
  - Responses to formal incident reporting or events
  - Flags arising from routine care monitoring
  - Routine care management, outreach, and engagement
- Specific to self-direction, states implement thresholds or indicators to recommend or require changes to services
  - Certain circumstances may warrant a change away from self-direction
  - Other circumstances may require a change of EOR or worker(s)

Complex Operations

- States operate self-direction in both managed care and fee-for-service environments, and under different authorities
- Programs typically have one or more vendors each operating in multiple spaces, such as comprehensive health plans, FMS, and I&A providers
- Health and welfare activities are distributed across the state and these other entities, and all of their staff
- These entities all play a role in ensuring health and welfare, such as authorizing services, monitoring service delivery and planning, and reporting incidents or events

Complex Oversight

- These multi-entity arrangements introduce intentional redundancy to assure essential functions operate continuously; however, this introduces overlapping responsibilities and ambiguous accountability
- Roles are defined in state policy, but these overlaps can be conflated and confused in practice
- Stakeholders identified clear contractual terms specifying responsibilities and performance standards, such as in vendor contracts, as a tool for conveying and enforcing accountability

Findings

Quality, Oversight, and Accountability in I&A

Role clarity and accountability

- Overall, the I&A role is unclear in self-direction
- Overlapping responsibilities creates ambiguity about which entity should report, follow-up, or remain accountable for issue resolution
  - Supports brokers or case managers take on additional responsibility to compensate
- Interviewees asked for clear policies around how self-direction programs structure and reimburse I&A supports

Quality, Oversight, and Accountability in I&A

Delivery of supports

- Stakeholders characterized I&A quality as highly variable
  - Poor quality leads to inappropriate service delays or denials, inaccurate paperwork, delayed payment for HCBS providers, and enrollee frustration
- States have little oversight or accountability for service provision when I&A is provided as a distinct service
- The complexity of communicating across multiple entities further exacerbates these issues
- Advocates described the design of I&A supports, especially supports brokerage, as disconnected from how it functions in practice
  - Beneficiaries must navigate unclear communication pathways and I&A providers are not providing resource navigation

Quality, Oversight, and Accountability in I&A

Reimbursement

Case management activity:
CASE MANAGERS

Beneficiaries may prefer the streamlined approach and fewer contacts

Limited capacity and self-direction knowledge to provide effective I&A

Distinct service coverage:
INDIVIDUAL I&A PROVIDERS

Beneficiaries have many I&A providers to choose from

Risk of overutilization and budget depletion while others are unaware of the support

Variable quality without contractual performance expectations

Administrative activity:
CONTRACTED ENTITIES

Administrative contracts allow states to establish and enforce quality and performance expectations

Data Systems Infrastructure and Interoperability

Data fragmentation

- Stakeholders consistently described information and data exchange across entities as fragmented and confusing
- State officials reconcile multiple data sets across health plan portals, FMS systems, supports brokers, and state reporting tools
- Interviewees shared that a lack of standardization in data systems increases the likelihood of miscommunication, missed deadlines, service disruptions, and delayed payment to workers

Data Systems Infrastructure and Interoperability

Program integrity

- Distributed data systems create blind spots that allow bad actors to operate in a self-directed program and require state officials to manually review data across systems
- Stakeholders are committed to program integrity, continuously seeking data outliers and ways to link data to maintain compliance

Policy Option

Findings and Policy Option

Findings

- Overlapping I&A responsibilities creates ambiguity about which entity should report, follow-up, and remain accountable
- I&A breakdowns have widespread consequences resulting in service disruption and health and safety concerns
- Reimbursement methodologies for I&A providers influence I&A quality
- Data fragmentation increases miscommunication, missed deadlines, service disruptions, and delayed provider payment

Policy option

Congress and CMS should clarify and streamline all self-direction supports under a single entity and reimburse those supports through an administrative contract

Policy Option: Streamline and Clarify Supports for Individuals Who Self-Direct

Rationale

- This approach increases the likelihood of identifying health and welfare concerns by reducing duplicative supports functions and identifying clear accountability
- Beneficiaries would have fewer entities with which to coordinate
- States would oversee fewer entities and set clear, enforceable expectations through an administrative contract
- Streamlining the supports system reduces data fragmentation
- This option offers reduced administrative complexity and expense, more data integration, and aligns I&A requirements across authorities

Policy Option: Streamline and Clarify Supports for Individuals Who Self-Direct

Policy mechanism

- A support system is statutorily defined in Title XIX, Section 1915(j) of the Social Security Act (42 U.S.C. § 1396n(j)(2)(d))
  - Regulatory language and subregulatory guidance across authorities lack specificity into the roles and responsibilities of I&A providers
  - Only 10 states use Section 1915(j) authority for self-direction
  - In 2023, 46 states offered self-direction under Section 1915(c) authority, which has no parallel statutory or regulatory requirements for I&A
- Given the variability and ambiguity of what constitutes I&A across authorities and self-direction programs, states do not have sufficient, specific guidance for establishing effective I&A in self-direction

Next Steps

Next Steps

- Commissioner feedback on the policy option
  - Does the presented evidence support the policy option?
  - Are there outstanding questions about the policy option that staff can answer?
  - Are there other factors for staff to consider while developing recommendation language and the rationale?
- If there is support for moving forward with this policy option, we will include draft recommendation language for consideration at a future meeting

Findings and Policy Option

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SEPTEMBER MEETING

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