



OFFICE OF THE SECRETARY
PATIENT-CENTERED OUTCOMES
RESEARCH TRUST FUND

PROJECT REPORT

FINAL REPORT

Feasibility of Obtaining Identifiers for Self-Directing Home and Community-Based Services Users in Medicaid Claims

Prepared for
The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
at the U.S. Department of Health and Human Services

by
NORC at the University of Chicago

November 2024

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This report was funded by the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) under Contract Number HHSP233201500048II of the HHS Office of the Assistant Secretary for

Planning and Evaluation (ASPE). The work was carried out by NORC at the University of Chicago and ASPE. The authors are solely responsible for this document's contents, findings, and conclusions, which do not necessarily represent the views of HHS, ASPE, or NORC. Readers should not interpret any statement in this product as an official position of ASPE or of HHS.

Suggested Citation: Srinivasan M, Doty P, Jiménez F, Gauthreaux N, Shah A, Dullabh P, and Karimi M. Feasibility of obtaining identifiers for self-directing home and community-based services users in Medicaid claims. Washington, D.C.: Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. November 2024.

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Executive Summary

Background. Self-directed home and community-based services (HCBS) allow participants to control their care, including hiring and managing caregivers who can be family or friends. However, outdated research and limited data in the Centers for Medicare & Medicaid Services (CMS) Transformed Medicaid Statistical Information System (T-MSIS) hinder comparisons of outcomes between self-directed and traditional HCBS users. In response to this, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) proposes developing a pilot database that brings together information about Medicaid recipients who self-direct their HCBS and their direct care workers. The proposed database would enable patient-centered outcomes research (PCOR) and comparative effectiveness research (CER) for Medicaid HCBS self-direction programs.

Objective of the Study. This study explores the feasibility of developing this database by assessing the types of data collected by Financial Management Services (FMS) entities who provide payroll services, data quality variations, and considerations for potentially linking this database to T-MSIS. This feasibility study will guide database participant selection, resource planning, and database design.

Methods. We conducted 17 virtual key informant interviews between February and May 2024 with CMS officials, FMS informants, and state Medicaid agency officials involved in self-direction HCBS programs. We performed a thematic analysis of the interviews, coding for pre-specified and emerging themes.

Results. We found that FMS entities collected a wide range of data on self-direction programs, participants, and direct care workers providing services. Due to their role as payroll agents, data needed for billing and reimbursements (e.g., name, address, waiver, service code) are universally collected across FMS entities, while other data collection (e.g., demographics, previous self-direction participation) is dependent on program or state requirements. To strengthen data quality across FMS entities, developers will need to harmonize data to standardize variables and account for longitudinal data gaps that may occur during FMS transitions and could consider supplementing FMS data with non-FMS data sources. To plan for potential linkages to T-MSIS, informants recommended collecting as many high-quality self-direction participant identifiers as possible to facilitate accurate linkage. They also recommended starting the pilot database with a few select states to explore data sharing considerations, such as data sharing contracts between states, FMS entities, and managed care organizations; funding or resources needed; and data governance processes established with state and federal stakeholders for making a database linked with T-MSIS available for research. In addition, this pilot phase should determine where the database will be housed and how external users can access it securely.

Conclusion. Interviews established that necessary data for this database are being comprehensively collected by FMS entities, although there may be some variation in volume and quality, and FMS entities and states echoed the importance and value of creating this database to enable CER for self-direction programs. As next steps, the project should determine the appropriate scope for the pilot phase as well as the approach for standardizing data elements and hold discussions with potential stakeholders on the data sharing and governance process. If linked with T-MSIS and other PCOR databases, this proposed database would enable studies on the impact of workers' characteristics on participant outcomes, HCBS utilization and participant health outcomes, and participant HCBS program satisfaction.

Introduction

Since 2010, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) has managed the Office of the Secretary’s Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) on behalf of the U.S. Department of Health and Human Services (HHS). The OS-PCORTF aims to strengthen the capacity for the collection, linkage, and analysis of high-quality data for conducting rigorous patient-centered outcomes research (PCOR). Under the OS-PCORTF, ASPE commissioned NORC at the University of Chicago (NORC) to conduct a study to gauge the feasibility of creating a database that brings together information about Medicaid recipients who self-direct their home and community-based services (HCBS) and the direct care workers providing Medicaid-covered personal care services. The proposed database would be implemented in stages, with an initial pilot focused on data from a select number of states and then expanded to the national level.

In April 2023, a Presidential [Executive Order](#), *Increasing Access to High-Quality Care and Supporting Caregivers*, identified addressing gaps in HCBS workforce knowledge as a federal priority and called for expanded data collection efforts.¹ HHS and the U.S. Department of Labor joined efforts to form the *HCBS Federal Opportunities Regarding Workforce and Research Data (HCBS FORWARD) Workgroup* to address the goals set forth in the Executive Order. In a [2024 issue brief](#), the workgroup called for improvements to HCBS workforce data by increasing the availability of existing administrative data sources for research on the HCBS workforce.² ASPE’s proposed database would also directly respond to this call for enhanced administrative data to enable PCOR for Medicaid HCBS self-direction programs.

Self-Direction in HCBS

HCBS offer Medicaid participants support for personal care and activities of daily living in their homes or communities.⁵ HCBS can be provided through an agency or through recipient self-direction. States cover HCBS under several different financing authorities. The oldest of these is the state plan personal care services optional benefit which can be traced back to the mid-1970s,⁶ followed by the 1915(c) HCBS waiver program in 1981.⁷ The 2005 Deficit Reduction Act expanded opportunities for states to finance HCBS including self-directed services under the Section 1915(i) and Section 1915(j) state plan optional coverage.⁸ Most recently, the Affordable Care Act of 2010 further expanded state financing options for HCBS via the 1915(k) Community First Choice optional state plan benefit.⁸ Many states use multiple Medicaid HCBS authorities to finance HCBS, including self-directed services. States often choose to serve several populations in different waiver programs, including older adults, people with physical disabilities or intellectual and/or developmental disabilities (ID/DD), people with HIV/AIDS, and individuals who are medically fragile or technology dependent, among others.

Self-direction is a long-term care services and support (LTSS) model that empowers participants to decide for themselves how, when, and from whom they receive services and supports.⁹ Self-directing HCBS participants have the authority to hire, oversee, and terminate their paid caregivers, which often include family, friends, or neighbors.^{3,8} Self-direction programs offer either or both employer authority (where an HCBS participant chooses and manages their direct care workers or “aides”) and budget

Current Participation in Self-Direction

In 2023, over 1.5 million individuals self-directed their publicly funded HCBS, the majority of whom were Medicaid HCBS users but also including Veterans Administration HCBS users,³ marking a 23% increase since the COVID-19 pandemic began.⁴

authority (where a participant chooses how their budget is allocated to allowable goods and services). As required by Medicaid, Financial Management Services (FMS) entities support direct care worker payroll processing and compliance and program fiscal accountability. FMS are provided in self-direction programs through the following models: Fiscal/Employer Agent (F/EA), Agency with Choice (AwC), or Fiscal Conduit. **Appendix A** depicts the key differences among these models.^{8,10}

Uptake of self-directed services options under Medicaid HCBS financing authorities has grown significantly over the past 25 years. The most recent inventory of self-direction programs and participants, which surveyed state Medicaid program administrators in all 50 states and the District of Columbia, identified almost 1.5 million self-directing HCBS program participants in 2023 – an increase of 23 percent from the previous inventory conducted in 2019.³ Additionally, a Kaiser Family Foundation study reported that 4.2 million Medicaid beneficiaries used any HCBS in 2020, suggesting that, conservatively, at least one in four Medicaid HCBS users self-direct their HCBS.¹¹ The prevalence and growth of self-directed services provides a strong rationale for learning more about the characteristics of Medicaid HCBS participants who choose to self-direct their services compared to those who rely on professionally organized service providers, as well as comparisons of different self-direction models. Furthermore, the rise in self-direction has the potential to mitigate the longstanding direct care workforce shortage by providing an avenue for family members, friends, or acquaintances to become paid employees.

Prior evaluations of self-direction programs (including the In-Home Supportive Services program in California and the Cash & Counseling Demonstration)^{12,13} have found statistically significant better outcomes in self-directed HCBS compared to professionally managed services.¹⁴ However, this research is outdated, since these evaluations were conducted over two decades ago. A barrier to comparing outcomes and service utilization between self-directing and traditional Medicaid HCBS participants is the absence of robust data across states within the Centers for Medicare & Medicaid Services (CMS) Transformed Medicaid Statistical Information System (T-MSIS) to accurately identify self-directing participants.

Purpose and Objectives of the Report

To address the identified data gap, this study explored the feasibility of developing a pilot database of individual-level identifiers for self-directing HCBS participants, and of the characteristics of their direct care workers who provide personal care, homemaker/chore, and/or habilitation services. This database will be designed to eventually become national and longitudinal in scope, with the potential capability to link to T-MSIS and other data sources. The goal is to enable comprehensive comparative effectiveness research (CER) and PCOR across a broad spectrum of claims-based and additional outcomes. The proposed database will primarily leverage data from FMS entities that provide billing, payroll management, tax processing, and other supportive services to self-directing HCBS participants and their direct care workers.

The feasibility study focused on three **key research questions**:

1. What types of data do FMS entities collect about self-directing participants and direct care workers providing personal care services? How does data quality vary across FMS entities?

2. What are the key considerations and challenges for implementing a multi-state database of identifiers for self-directing HCBS participants and direct care worker characteristics?
3. What are the key considerations and challenges for linking this auxiliary database to T-MSIS?

The findings of this report are intended for a wide range of stakeholders, including federal and state policymakers, program administrators, managed long-term services and supports (MLTSS) plan administrators, FMS entities, and other stakeholders involved in Medicaid HCBS self-direction programs. Additionally, the findings of this report are pertinent to PCOR researchers interested in conducting CER for self-directing HCBS participants.

The subsequent sections of the report are structured as follows. The **Methods** section describes the qualitative data collected and analyzed for the feasibility study. The **Findings** section details insights on the research questions. The **Discussion** section describes implications for research and policy and the limitations of the study. The report concludes with a summary of the feasibility assessment.

Methods

We conducted a series of individual and small group key informant interviews (KIIs) with a range of people, including CMS officials, representatives of select FMS entities, and officials from select state Medicaid agencies operating self-direction HCBS programs.

ASPE and NORC engaged with several subject matter experts to identify informants for this feasibility study, including self-direction experts from the Administration for Community Living, Applied Self Direction (ASD), Public Consulting Group, Public Partnerships Ltd., ADvancing States, Human Services Research Institute, and National Association of State Directors of Developmental Disabilities Services. In consultation with these experts, we prioritized larger FMS entities serving multiple states. State selection criteria are in **Appendix B**.

Key Informant Sample

- 4 CMS informants
- 6 FMS entities
- 7 state Medicaid agencies

We conducted 17 virtual semi-structured interviews that lasted 60 minutes each. **Appendix C** includes interview protocols by stakeholder group. Additionally, informants from FMS entities and state agencies were asked to complete a form after their interview to report more detail about available data elements for self-directing participants and direct care workers. **Appendix D** includes a copy of the data form. We performed a thematic analysis of the interview data, which involved developing preliminary codes *a priori* based on the interview protocols and anticipated themes, and inductively and deductively coding each interview for these pre-specified themes while also highlighting additional emerging themes. Themes were then compared to build an understanding of the relationship among themes and to respond to each research question.

Findings

Key findings from the KIIs are organized into four subsections below. The first subsection summarizes the available data on self-directing HCBS participants and direct care workers from FMS entities, and the second subsection describes findings related to the quality of these data. The third subsection summarizes data available from non-FMS data sources. The final subsection summarizes considerations for developing and implementing the proposed database.

Available FMS Data on Self-Directing HCBS Participants and Direct Care Workers

FMS entities reported collecting a wide range of data on self-direction HCBS programs, participants, and direct care workers. Due to their role as payroll agents, data needed for billing and reimbursements (e.g., name, address, waiver, service code) are universally collected, while other data collection (e.g., demographics, previous self-direction participation) is dependent on program or state requirements.

[Data] could range by state and program...Beyond that, it could vary based on if the state has an additional identifier than we have tied to our system. The less relevant to billing, the less likely we have that number.

– FMS informant

Additionally, many FMS entities reported having access to data from Electronic Visit Verification (EVV) systems, which direct care workers use to electronically verify service and delivery information.¹⁵ Under the 21st Century Cures Act,¹⁶ states are required to use EVV for any Medicaid-funded personal care services.¹⁵ EVV programs collect consistent data on the type of services

performed, who received the service, who provided the service, the date of the service, when the service began and ended, and the location of service.¹⁷ Additionally, EVV vendors provide data aggregation capabilities to collect and analyze data from multiple systems. This data on direct care workers can be linked to self-directing participants at the individual level.

Exhibit 1 lists the types of data collected by FMS entities as described during interviews or reported in the post-interview data element form.

- **Self-direction program characteristics** commonly included the FMS model, employer or budget authority provisions, waiver type, and waiver population served.
- For **self-directing participants**, FMS entities collected at least one identifier to complete payroll processing, such as social security number (SSN), date of birth (DOB), Employer Identification Number (EIN), Medicaid Statistical Information System (MSIS) Identification Number, or Medicaid ID. Several FMS entities collected multiple identifiers. FMS entities regularly collected self-direction data such as the start date of services, authorized hours/budgets, participant's use of legal representatives (to assist in managing their services and budget), and number of workers employed. Demographic data (e.g., race/ethnicity, or primary language of the participant), unless required by the self-direction program, are not always routinely collected. Data such as rural/urban residence and the representative's relationship to the employer (e.g., friend, legally responsible relative) even if not directly collected could be determined through further analyses, such as by coding addresses by rural/urban designation and comparing the name of the person who signed the timesheet with the employer of record.
- FMS entities also collected identifiers for **direct care workers**. National Provider Identifiers (NPIs) were commonly reported, but some states also used state-designated unique identifiers or taxpayer IDs to verify self-directed workers in EVV systems. SSNs and DOB were less commonly reported. Worker data were consistent as they were collected and used for background checks, payroll information (e.g., rate of pay, hours worked, pay increases), and tax information (e.g., exemptions, taxpayer ID), yet data on workers' demographic and advanced training information were less consistent. For example, few FMS entities collected race/ethnicity, citizenship status, or the educational level of workers. Although citizenship status was not maintained in most systems, FMS entities are required to verify and collect data on direct care workers' legal work status.

- Finally, FMS entities also described collecting data on **non-participant employers of the direct care workers**. For participants who choose to elect an authorized representative to review and sign direct care workers' timesheets (e.g., when the participant is a child or has a cognitive impairment) the authorized representative becomes the employer. Some FMS entities stated that for those using an F/EA model, the employer demographic data are sometimes more frequently collected than the participant data because the employer is managing the day-to-day care, and there are tax implications if the employer lives with the participant.

Exhibit 1. Self-Direction Data Collected by FMS Entities

FMS Entity	Data Frequently Collected	Data Less Frequently Collected
Program Data	<ul style="list-style-type: none"> ■ FMS model (e.g., AwC, F/EA) ■ Employer authority or budget authority ■ Waiver type (e.g., 1915(c), 1915(j)) ■ Waiver population (e.g., ID/DD, adults aged 65 and over) 	<ul style="list-style-type: none"> ■ N/A
Participant Data	<ul style="list-style-type: none"> ■ Identifiers: MSIS ID, DOB, SSN ■ Contact information: email address, mailing address, phone number ■ Self-direction start date ■ Authorizations: use of representatives, option requirements, maximum monthly benefits (hours, budgets, usage) ■ Worker information: number of workers, determining hourly rates, gaps in employed workers, turnover rates ■ CMS reporting: diagnosis, claims, and billing codes ■ HCBS service codes, with associated limitations (e.g., how service codes can be paid, how services were altered) 	<ul style="list-style-type: none"> ■ Identifiers: EIN, Medicaid ID ■ Optional demographics: preferred pronouns, race, ethnicity, rural/urban residence ■ Previous self-direction participation ■ Representative's relationship to the participant ■ Outcomes and satisfaction of care data
Direct Care Worker Data	<ul style="list-style-type: none"> ■ Identifiers: NPI, unique state identifier, taxpayer ID ■ Background check information: criminal status, age, gender, height, weight, hair, eye color ■ Participant-facing information: live-in status, relationship to the participant (or employer, if living-in), number of participants served ■ Employment information (or EVV): vendor or worker code, length of time employed, number of hours worked, types of services provided, issues with services provided, date of service, location of service ■ Timesheet/payroll information: hours worked (number or average), overtime usage, retrospective schedules, hourly wage rates, pay increases, overtime pay, date of hire, banking/electronic payment information, benefits (paid time off, sick leave) ■ Training or certifications: completion of requirements, types of trainings (first aid, CPR) ■ Tax information: tax exemptions, W-2s, non-profit organization 	<ul style="list-style-type: none"> ■ Identifiers: SSN, DOB ■ Optional demographics: race, ethnicity, citizenship status, education level ■ Completion of advanced aide training

FMS Entity	Data Frequently Collected	Data Less Frequently Collected
Non-Participant Employer Data*	<ul style="list-style-type: none"> ■ Live-in status ■ Wages paid (historical or current) ■ EVV information (if applicable) ■ Tax information: Foreign Account Tax Compliance Act (FATCA) identification number, tax ID, state income tax ID 	<ul style="list-style-type: none"> ■ N/A

*Note: This category was not included in the data element form but was mentioned in KIIs.

FMS Data Quality

Considering the pilot database's reliance on FMS data as the primary source, key informants highlighted several important factors. These include the consistency and accuracy of FMS data, as well as the variability in data quality across different FMS entities, all of which can impact the design and development of the pilot database. **Our interviews revealed that data necessary for FMS functions tend to be more consistently collected across FMS entities than other types of data.** For instance, data related to payroll, tax, and billing services are systematically collected across FMS entities, exhibiting a high degree of accuracy due to strict compliance with Internal Revenue Service (IRS) and tax reporting requirements. FMS informants reported that there is less certainty in the accuracy and comprehensiveness of data that are not needed for payroll purposes, such as workers' demographic information, hiring data, and the worker's relationship to participant except when it affects tax filings.

I think one thing you might want to consider as you're gathering data sources is to ensure that you're really clearly defining certain data points.

– FMS informant

Key Takeaways on FMS Data Quality

- *There is high standardization and validation for data use for payroll, tax reporting, and billing.*
- *Not all variables of interest for the pilot database are consistently defined or collected across FMS entities due to differences in state/program reporting requirements or an FMS' operational definition. Data translation will be needed to ensure standardized reporting of variables within the pilot database.*
- *Historical data is often not preserved during an FMS transition, limiting the availability of longitudinal data within a single FMS.*

Although FMS entities consistently collect billing and payroll information, the specific data elements might vary within (across states serviced by the same FMS entity) and across FMS entities due to unique self-direction program requirements. For example, some FMS informants reported relying on Medicaid ID numbers to

identify individual self-direction participants, while others reported using SSNs. Service authorizations are also reported differently depending on self-direction program or waiver definitions for hours/units budgeted or hours/units authorized. Similarly, elements like "client" and "worker" are not clearly defined or standardized across programs and can refer to different roles across FMS data. Given this variability, implementing data cleaning and validation processes to standardize the coding of data elements from FMS entities is essential to ensure consistent measurement units across all FMS sources within the pilot database.

To ensure data accuracy, FMS entities reported having procedures and policies in place for required data elements. For example, to ensure payroll data accuracy, FMS entities described following the standard employee vetting process outlined by the Department of Labor, including performing background checks and verifying the information of a new hire or applicant. Some entities have data integrity committees that examine data points with varying levels of reliability due to state-specific nuances, such as Medicaid authorizations. Additionally, entities described sophisticated processes to update contact information for both participants and workers, such as a call system that automatically routes phone numbers to the correct individual and flags phone numbers that the system does not recognize.

Many FMS entities noted that they already share data routinely with states via standard reports that pull data from their databases for variables of interest to states. Most state agency informants stated confidence in the quality of the data collected by FMS entities for program reporting and

monitoring. Depending on the state’s contract with the FMS entity, generated reports may include data on enrollment/disenrollment, customer service issues, service utilization, demographics, workers hired, and worker relation to participant. While data shared with states via reports are mainly in aggregate, FMS entities reported sharing individual-level data with states to resolve case-specific

We have built quality assurance within our processes, and it’s been working for several years. [...] We check the quality of the data, and if there are issues, we send it back to the FMS to correct. So, the data is constantly in the quality assurance process.

– State Medicaid agency informant

issues. In addition to sharing reports, some FMS entities maintain data portals or direct data feeds so managed care organizations (MCOs) and states can access raw data, including one FMS entity that operates a case management portal for states and MCOs they work with. Half of the state Medicaid agencies interviewed reported conducting quality assurance processes for FMS data. If states identify errors in the FMS data, the state asks the FMS entity to correct the data. Other states reported that rather than auditing FMS systems, they cross check data sent by the FMS entity with internal data and address discrepancies as they arise.

While FMS entities reported storing data since their involvement with an HCBS program, states and programs commonly experience FMS turnover when states award new contracts. **While many FMS entities preserve their historical data, FMS informants described the lack of a formal or standard mechanism for transferring detailed data between FMS entities during an FMS transition.** Usually, data transfers are confined to the essential data for pending worker payments. These potential longitudinal data gaps need to be accounted for in the design, development, and maintenance of the future database.

Available Data from non-FMS Sources

A few states noted that due to variability across FMS entities, it may not be feasible to rely on FMS data as the sole source of data for the proposed database. State agency informants recommended other data sources containing identifiers on self-directing participants that could supplement FMS entity data. Each data source has limitations that should be considered when supplementing primary FMS entity data.

Some states directly collect data on HCBS participants and direct care workers for Medicaid reporting and decision making. This state Medicaid data, located in the state’s **Medicaid Management Information Systems (MMIS)**, sometimes contain identifiers for self-directing participants that make them distinguishable from traditional HCBS participants. Data available in MMIS systems may be similar to FMS data for self-directing participants (e.g., representatives, legal guardians, plans of care, claims, waivers) and, if collected, direct care workers (e.g., identification numbers, background check information, services provided, authorizations). However, the comprehensiveness of state Medicaid data varies by state, and many states do not collect data on worker characteristics. For example, one state reported it did not collect information on the participant-worker relationship, and other states reported not collecting worker demographic information and recommended their FMS contractor as the source for that data. Data collection and reporting approaches also varied by interviewed states. Two examples of rigorous approaches include one state that conducts a workforce satisfaction survey with comprehensive data on direct care worker demographics, and another state that directly transmits data to T-MSIS with a flag for self-directing participants (through a combination of waiver ID, waiver type, and self-direction type codes for their self-direction waiver). It should be noted that, in general, the availability of longitudinal data on self-direction will likely vary by state. While 42 Code of Federal Regulations §431.17 mandates that Medicaid agencies retain records necessary for service verification and claims justification for a minimum of three years after the beneficiary’s active period ends,¹⁸ individual state data retention policies often differ, with some extending up to 7–10 years.^{19, 20}

We [the state] collect all the data, even down to the assessment data...We’re the source of truth. All referrals come from us to [the FMS entity], and what they do with that referral comes back to us immediately the next day. So, we have daily, weekly, and monthly reports...The data is readily available.

– State Medicaid agency informant

Some states maintain data on self-directing participants in **state-operated case management systems**, which assist Medicaid-eligible individuals with accessing needed services. In 2022, CMS released the HCBS Quality Measure Set that includes some measures that are collected within case management systems.²¹ Among the measures included in the measure set, the HCBS-10 measure assesses the rate of offer and take-up of self-directed services among HCBS recipients. The measure consists of two rates – one that identifies the percentage of eligible HCBS participants offered the option to self-direct services in the last 12 months, and the second is the percentage who opted in to self-direct services in the last 12 months.²² Some key informants believed that enactment of the CMS *Ensuring Access to Medicaid Services* rule (Access Rule) in April 2024²³ may improve state collection of standardized quality measures like HCBS-10 and state data management systems as a whole.

States have flexibility in selecting an EVV model that best suits their Medicaid program. States working with external EVV vendors that are not integrated with FMS entity systems recommended the **external EVV system** as a reliable source of data on direct care workers providing aide services (e.g., Medicaid personal care services [PCS] and home health care services [HHCS]). Because EVV systems are mandated to collect service provision and utilization data for PCS and HHCS, they could serve as a supplement to FMS data on aide demographics, family relations, duration of client employment, and living arrangements. However, EVV systems face challenges related to engagement and data accuracy. One

CMS official advised caution when using EVV identifiers to identify direct care workers, as states often enroll the rendering providers rather than the billing providers, and this practice may vary across states.

Database Development and Implementation Considerations

CMS informants identified the need for multiple reliable self-direction identifiers to enable potential linkage with T-MSIS. To link an auxiliary database to T-MSIS, CMS informants made it clear that multiple identifiers with high data quality will be needed to reduce the likelihood of errors and mismatches, should linkage be under consideration. Therefore, pilot states should be selected based on the type and quality of the identifiers from both FMS entities and in their T-MSIS submissions.

FMS entities collect multiple personal identifiers for participants, including SSN, EIN, and DOB, which enables linkage with T-MSIS. Given that SSNs are generally unique and remain unchanged, they are considered the most reliable identifier.

Comparatively, state-issued Medicaid IDs or MMIS IDs may be less reliable identifiers due to variation in state practices using multiple IDs. In some states, an individual is assigned multiple IDs when they change their address, eligibility status, or they switch Medicaid programs. Consequently, using state-issued IDs in T-MSIS may result in multiple IDs for a single person, depending on the state.

Key informants acknowledged that program diversity across and within states can present database design and development challenges, such as navigating multiple data sharing authorization procedures. **Therefore, CMS and FMS informants recommended starting the pilot database with a few states that have a single or small number of FMS entities and MCOs or states with a centralized self-direction program to minimize the complexity of including self-direction programs with different data element requirements.** Such an approach would also limit the number of data use agreements (DUAs) needed (see below for more information on considerations related to data sharing and governance). To reduce reporting burden on FMS entities and states in the database roll out, informants recommended clearly delineating the pilot phase from subsequent phases focused on scaling the database. If data reporting changes are anticipated when going from the pilot database to the expanded national database, it will be important to prepare FMS entities for each phase so that they do not become overburdened with changes in scope.

FMS entity and state Medicaid agency informants noted several considerations for data sharing:

- **FMS contracts with states and MCOs will dictate data sharing permissions and authorizations.** FMS entities noted that while they maintain data on workers and participants, data are owned by the state, or in the case of MLTSS, by the MCO. As such, FMS entities emphasized that they need state or MCO permission to share data for research purposes. Most FMS entities also noted that in states

The best way to identify Medicaid beneficiaries is to use a combination of SSN and state ID or a different personal identifier (e.g., date of birth, gender). The more information you have, the more likely it is you are able to create a higher probabilistic match.

– CMS informant

with MLTSS, an additional step of establishing data sharing agreements between states and MCOs may be needed to enable sharing FMS and MCO data with ASPE.

- **To reduce the administrative burden on FMS entities, state agencies could serve as an intermediary for sharing FMS data.**

Instead of a direct data transfer from the FMS entity to the data recipient (e.g., ASPE), a less cumbersome and burdensome process might include FMS entities sending the requisite self-direction data to their state Medicaid agency, which in turn can share the data for database development purposes. Interviewed states

noted that they could specify data sharing with a third party (e.g., ASPE) for the purpose of the proposed database in future contracts with FMS and MCOs if not currently allowable.

- **FMS entities would need additional funding or resources to support direct data sharing.** If transferring data directly to the data recipient (that is, not using the state as an intermediary), FMS entities noted that they would need to build

secure data file exchange systems to automate data transmission, which would require additional funding. Some informants suggested implementing a two-tier payment structure for FMS entities tasked with gathering and providing data. The first payment tier would cover the data preparation, while the second payment tier would be issued once the received data has been verified for cleanliness and completeness.

- **Establish robust data governance processes.** State and FMS informants also emphasized that appropriate data governance and sharing processes need to be in place to ensure data security and privacy. FMS entities and states noted that data sharing processes, at a minimum, must comply with the federal Health Insurance Portability and Accountability Act (HIPAA) and include safeguards for data privacy and compliance. Additionally, state informants noted participation in the potential database would need to be reviewed and approved by state leadership and their legal team.
- **Gain support from all Medicaid HCBS stakeholders.** Some FMS and state informants noted that MCOs may be hesitant to permit data sharing due to concerns about MCO identifiability, so, it would be important to provide necessary reassurances around data privacy and security to MCOs to secure buy-in. Additionally, FMS and state informants noted that they would need to check the requirements to notify HCBS participants and workers of participation in the proposed database and explain the use of the data for research. The process may include discussing how participant and worker information could be handled within the database. HIPAA allows states to use and share data with researchers that is regularly collected for program administrative purposes (such as data necessary to process Medicaid claims payments or for quality assurance monitoring) when the

If the [self-direction program] sponsor is the state, county, or MCO, they will have veto power [for any data sharing]. [...] Most of our experience is sharing data back with the sponsor so it makes it easy. In one instance with this pilot that we're doing [...], we're sharing data with a research entity out of [university], and it's at the behest of the state, and the state gave that research organization carte blanche to use whatever data we were able to provide them, so it was very open.

– FMS informant

So long as our costs are covered, and we can get contractors to help us with the work, we're happy to take on causes or research that benefits the segment. We believe in self-direction, and we're willing to put in some managerial time to prove the point.

– FMS informant

purpose for doing so is to carry out program oversight functions and improve program performance. Doing so does not require obtaining permission from Medicaid program participants. Data use agreements must be put in place as well as other safeguards to protect personal identification once data linkages have been made and the data de-identified to conduct the research.

- **Navigating distinct FMS entity timelines for updating data.** FMS informants noted that data updates may not always be feasible on a predetermined schedule. For example, one FMS entity noted that service plan information is made available as plans are authorized and reauthorized. Therefore, updates to service authorizations are provided inconsistently, leading to potential gaps in service delivery. Additionally, as with T-MSIS data, older data will be more complete than more recent data.

CMS informants noted the importance of determining, during the initial planning phase, where the database will be housed and how external users can access it. The organization that will host the data may depend on which federal agency has the original authority to collect self-directed data from FMS entities or state agencies. One informant recommended that the database be housed in a virtual environment that researchers can access with permission, rather than allowing the transfer of physical data files to external users. In addition to adhering to standard data governance and privacy practices, one CMS informant noted that the organization responsible for maintaining the eventual database should take additional precautions to ensure the security and privacy of participant and worker data. This could include policies and penalties around terms of use and DUA violations for researchers accessing the database. Additionally, simple precautions and settings can be included in the database environment to protect data security, such as disabling cut-and-paste features and split tunneling to enable access to multiple network connections while accessing the database. User authentication and geography-based rules can also be implemented to monitor who can access the data and where they are located. Finally, given the possibility for re-identification, access could be granted in a tiered manner, with some variables only available in restricted-use files, or restricting identification of small-area geographies.

Discussion

Overall, the FMS, state Medicaid agency, and CMS informants participating in interviews saw value in the proposed database and the usefulness of leveraging FMS-collected data for the database.

I can't tell you how thrilled I am that somebody is working on this project. It's been a desire - we've been trying to get attention more on this comparison for some time.

– FMS informant

Pilot Database Development Next Steps

Below, we describe key next steps for designing and developing the pilot database.

Determine the appropriate scope for pilot iteration. An important first step in designing and developing the pilot database will be determining its scope, including selecting states and FMS entities for participation, the desired individual-level identifiers for linkages to T-MSIS, and other key variables to characterize the direct care workforce providing aide services to self-directing HCBS participants.

Determine the approach for standardizing data elements across disparate states and FMS entities. As a next step, it will be necessary to explore how to best align data definitions and elements across disparate state and FMS data sources to enable the database to support multi-state CER on patient-

centered outcomes, once the database is linked to T-MSIS and other data sources. One FMS informant suggested relying on existing standardized data, like payroll information, and building out processes to transform remaining data to create standardized variables within the proposed database.

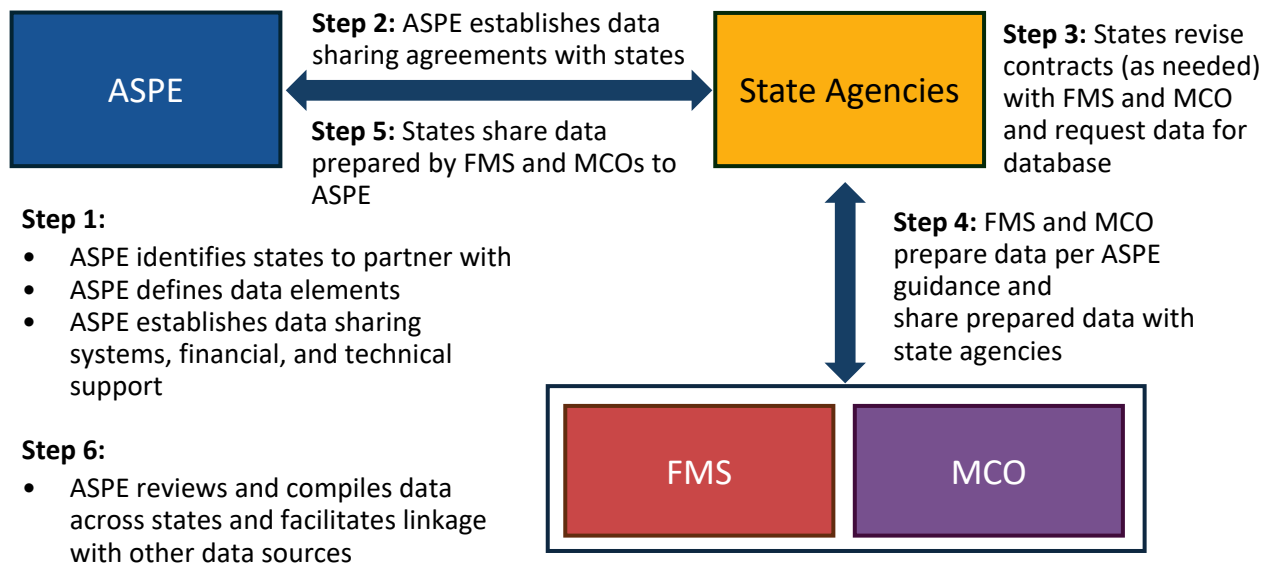
Determine the data sharing approach and stakeholders involved.

Determining the best approach for transferring FMS data to federal partners who would perform the data compilation is a key planning consideration. To minimize states’ burden, informants agreed that the most efficient process may be one where FMS entities and MCOs send participants’ individual identifiers and data on participant and worker demographics and characteristics to states, and then the state transmits data to ASPE (**Exhibit 2**). Recently, CMS introduced new rules²⁴ requiring payers to use application programming interfaces (API) and store sensitive data within its authorized environments. If linkage for the auxiliary database is pursued with T-MSIS then requirements within this rule need to be considered in the future.

CMS could probably perform the T-MSIS linkages if the identifier data we need are there. CMS has finder file specifications that specifies the variables we need, so we can provide that. Then we link data in the Enterprise Cross reference. CMS typically performs straightforward linkages for researchers. If there’s a lot of imputation or very complicated algorithms for determining a population, CMS would require a contractor to perform the linkage.

– CMS informant

Exhibit 2. Potential Data Sharing Approach for Pilot Database



Potential Long-Term Solutions to Integrating Data with T-MSIS

Informants agreed that the proposed database, once linked to T-MSIS and other data sources, could promote timely PCOR with the Medicaid self-direction HCBS population. However, as a long-term solution, CMS informants suggested working with states to reduce existing T-MSIS reporting barriers so that individual-level data on self-direction program participation is consistently reported in T-MSIS. Additionally, new variables for direct care workers could be added to T-MSIS using CMS’ current processes for adding variables. If this approach were taken, T-MSIS could potentially become the

centralized database for self-directing as well as traditional HCBS Medicaid beneficiaries. ASPE could partner with CMS to identify key priority variables that could be included within T-MSIS. One CMS informant said that reporting directly to T-MSIS would be preferable to an auxiliary database as a long-term solution, given the resources needed to standardize FMS data across states and FMS entities and to plan for longitudinal data updates

Implications for Research and Policy

The findings of this report align with HHS and OS-PCORTF Strategic Plan goals to advance data

capacity for PCOR studies that improve person-centeredness. The proposed database addresses two goals outlined in the OS-PCORTF Strategic Plan: build data capacity for PCOR that informs the needs of federal health programs, providers, and the people served by these programs; and expand longitudinal data resources that enable PCOR to advance evidence generation.²⁵

The proposed database would enable researchers to access longitudinal data on self-directing Medicaid HCBS participants to improve understanding of outcomes for this population, compared to participants receiving traditional Medicaid HCBS. Broadly, informants identified questions and outcomes of interest pertaining to both the direct care workers serving the Medicaid HCBS self-direction participants and the participants themselves. Potential topics of PCOR studies raised by informants are described in **Exhibit 3**.

We want this data to be able to prove that self-direction leads to improved outcomes, like staying out of the hospital or fewer bed sores than people in facilities. These are things that we can't get our hands on. We know they're there. We're just grasping at air. Those are the things we are trying ourselves to figure out how to track.

– State Medicaid agency informant

There are things that have been successful for getting states to voluntarily report data, but it's much harder than if you can get it into something that already exists and that's required for them to report into.[...] [Directly submitting self-direction data to T-MSIS is] not just an issue of getting that data element quality fixed but also getting other data elements added to T-MSIS. It's possible, T-MSIS is not static, but it is a process to make those changes and get states to report it.

– CMS informant

Potential participant outcomes of interest include assessing differences in authorized services used, continuity of care, and quality of life and health outcomes. The proposed database would also facilitate PCOR to understand the impact of direct care workers' characteristics on outcomes for self-directing HCBS participants. Importantly, one informant noted that it will be necessary to collect data on all workers, not just workers serving self-directing participants, to enable CER on how worker characteristics are associated with beneficiary outcomes.

Exhibit 3. PCOR Study Examples

Topic	Description
Worker Characteristics' Impact on Participant Outcomes	<ul style="list-style-type: none"> Compare differences in worker characteristics by program design, e.g., age, union status, average length of worker employment, utilization, rate of pay, family member involvement, and live-in status, and their impact on participant outcomes. Assess impact of worker turnover on participant outcomes.

Topic	Description
Participant Health Outcomes	<ul style="list-style-type: none"> ■ Assess differences in health outcomes and adherence to preventive care between self-directing and non-self-directing HCBS participants. ■ Assess differences in authorized services used and continuity of care outcomes.
HCBS Utilization	<ul style="list-style-type: none"> ■ Compare costs on an apples-to-apples basis between self-directing and non-self-directing individuals, including Medicaid clinical outcomes costs beyond long-term care, such as adherence to preventive care, falls, emergency department visits, hospitalizations, incident reports, and acute care claims. ■ Compare utilization of how authorized HCBS hours differ between self-directed care and agency-directed care, and the extent to which workforce availability and scheduling flexibility impacts the delivery of authorized hours in each model. ■ Analyze differences in care plans in managed care versus fee-for-service, by acuity.
Participant Program Satisfaction	<ul style="list-style-type: none"> ■ Understand why participants opt out of self-direction when given the choice. ■ Consider the insights from in-depth interviews conducted by the National Committee for Quality Assurance (NCQA) to gauge satisfaction levels, although the data may not be as clean or comprehensive.

Informants underscored that database linkage to T-MSIS will enable research solely on claims-based outcomes. As such, additional data sources will need to be linked to the database for researchers to assess person-centered outcomes that go beyond outcomes available in claims data, such as quality of life, program satisfaction, and care experiences, among others. In light of this consideration, informants suggested linking administrative data to experience of care surveys (e.g., National Core Indicators® [NCI], Consumer Assessment of Healthcare Providers and Systems [CAHPS], Council on Quality and Leadership Personal Outcome Measures) to better understand participant perspectives on the care they receive and outcomes meaningful to them. However, it is important to note that these surveys only capture a sample of participants; therefore, PCOR focused on nonclinical outcomes would be available only for a subset of the HCBS population. One informant also suggested linking to state electronic incident reporting systems to understand participant experiences with adverse outcomes. States and health care organizations are required to report both actual and potential harmful incidents through these systems. These electronic systems would capture data on the prevalence of abuse, neglect, exploitation, or other outcomes affecting self-directing HCBS participants.

Additional Data Sources for PCOR Besides T-MSIS

- *NCI Intellectual & Developmental Disabilities (IDD) and Aging & Disabilities (AD) Surveys*
- *CAHPS Survey*
- *Council on Quality and Leadership Personal Outcome Measures Survey*
- *Electronic Incident Reporting Systems*

Limitations of this Study

This report focused on the perspectives of a select number of large FMS entities (serving 11 or more states), state Medicaid agencies, and CMS staff knowledgeable about T-MSIS. Therefore, the findings are not generalizable to smaller FMS entities or other states operating self-directed HCBS programs, given

the diversity of FMS models and self-direction programs. This report does not include the perspectives of other relevant partners, including researchers, Medicaid HCBS self-directing participants and their direct care workers, and MCO representatives. Inclusion of these additional perspectives, especially those of researchers, would be important to facilitate prioritization of data elements for inclusion in the proposed database. Additionally, in focusing on available worker data collected by FMS entities, these findings may not capture paid family members serving as direct care workers for self-directing participants, as paid family members qualify for tax exemption in some states.

Conclusion

As self-direction HCBS programs continue to expand across the nation, it becomes increasingly important to compare outcomes and worker characteristics between self-directed HCBS participants and those in traditional HCBS programs. This comparative research necessitates the development of a database that records individual identifiers for self-directing participants and details on the characteristics of their hired aides. This database can be potentially linked to data sources such as T-MSIS to support CER. Such a database could significantly inform larger national and state efforts aimed at addressing direct care worker shortages for this population and program design.

In our interviews, FMS entities indicated their readiness to provide a comprehensive range of data on self-direction programs, participants, and direct care workers. However, the discussions also underscored concerns and considerations related to database architecture and data linkage. These considerations include the need for standardized definitions of data elements to reduce variability across different FMS entities and programs; strategies to address potential gaps in longitudinal or non-payroll data that may be unique to specific states or programs; and the incorporation of multiple identifiers to ensure accurate linkage of the database to data sources such as T-MSIS.

Looking ahead, this feasibility study serves as a foundation in informing the selection of key stakeholders, resource planning, and considerations pertaining to database design and record layout or potentially expanding data elements within the T-MSIS itself. As a next step in pilot database development, ASPE should explore the feasibility and specifics of linking the auxiliary data to T-MSIS.

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Appendix A. FMS Models

The table below is adapted from the SCAN Foundation’s Community Living Assistance Services and Supports Technical Assistance Brief.¹ Note that individual programs may customize the roles performed by FMS entities and participants. These are general guidelines of typical roles and components.

Role	Fiscal/Employer Agent	Agency with Choice	Fiscal Conduit
Employer of Workers	Participant	Co-employment shared between Agency and Participant	Participant
Payroll Duties Performed By	Fiscal Employer/Agent	Agency	Participant
Compliance with Employment Rules Maintained By	Fiscal Employer/Agent	Agency	Participant
Sets Worker Rate of Pay	Participant	Agency (participant may have input)	Participant
Sets Worker Schedule	Participant	Agency (participant may have input)	Participant
Pays Nonemployee Goods/Services Providers	Fiscal Employer/Agent or Participant	Agency or Participant	Participant

Appendix B. State Selection Criteria

Criterion	Description
Enrollment in MLTSS	Where enrollment in MLTSS is mandatory or voluntary but robust
Growth in self-directed program enrollment (as per LTSS Scorecard methodology)	<ul style="list-style-type: none"> • Large increase in self-direction rate per 1,000 adults with disabilities • Restrictive self-direction model or poor growth/slow uptake per 1,000 adults with disabilities
Established ID/DD self-direction program	Where the ID/DD population is well represented within the self-direction program.
Cash and Counseling Demonstration participant	A participant in either the original or replication demonstration measuring the impacts of consumer-directed personal assistance.
Type of FMS model	<ul style="list-style-type: none"> • Agency with Choice (AwC) • Fiscal/Employer Agent (F/EA) • Other

¹ Murphy MG, Selkow I, Mahoney KJ. Financial Management Services in Participant Direction Programs. The SCAN Foundation CLASS Technical Assistance Series Brief #10. 2011. Accessed July 2024. Available at https://www.thescanfoundation.org/media/2019/07/TSF_CLASS_TA_No_10_Financial_Management_Services_FINAL.pdf

Criterion	Description
Number of FMS entities within the state	<ul style="list-style-type: none"> • 1 – 3 • 4 – 9 • 10+ <p><i>Note: Per discussion with ASPE and ASD, states with >3 vendors will be excluded from consideration altogether.</i></p>
Currently participating in database endeavors	<p>For example, the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) project, Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person-Centered Outcomes Research.</p>
Quality of T-MSIS data (as per Outcomes Based Assessment methodology)²	<ul style="list-style-type: none"> • Meets OBA targets: The state passes on critical priority criterion, high priority criterion, and expenditures. • Does not meet OBA targets: The state fails on high priority and/or expenditures but passes on the critical priority criterion. • Does not meet OBA targets: The state does not meet the target for critical priority criterion.

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Appendix C. Key Informant Discussion Guides

Exhibit B1. Federal Informant Discussion Guide

1. I want to start by having you briefly introduce yourself. Please tell us your name and about your role within CMS.
2. To your knowledge, what types of data are currently captured in T-MSIS that could enable comparing outcomes (e.g., health, quality of life) and service utilization between self-directed and traditional HCBS users (i.e., those receiving professionally managed home- and community-based services)?

I would now like to ask you about considerations for creating a database (ideally, one that spans multiple states) containing individual-level identifiers for self-directed HCBS users, and characteristics of the direct care workforce providing these services, and potentially linking such a database to T-MSIS.

3. Discussions we have had with sources knowledgeable about self-direction services indicate that we would need to obtain the personal identifiers for self-directing HCBS users from individual states, and/or MLTSS plans, and/or FMS entities that perform payroll and related functions and (where applicable) manage individual budget financial transactions on behalf of self-directing program participants. Currently, it appears that FMS would be the best source of both the personal identifier and worker data. This might also be the least burdensome for states if they only had to grant permission to the FMS to provide these data.
4. What are the implementation considerations for such an endeavor to create this database?
5. What are the most important data-related considerations for states when providing the requisite information for this database (i.e., identifiers for self-directed HCBS users, and information on direct care workers that serve them)?
6. What are key requirements for enabling linkages between this database and T-MSIS data?
7. Looking, say, 5+ years into the future, will there be changes in how researchers use or conduct research from T-MSIS data that should be accounted for in the creation of the self-direction identifiers database, or in its linkage with T-MSIS? In what ways?
8. We've talked about the creation of a separate database for identifiers of self-directed HCBS users and their direct care workforce, that in turn can be linked to T-MSIS. Do you have ideas for alternative ways to capture information on the self-directing population and their workers that does not involve the separate creation and linkage of an auxiliary database? If so, what would that process look like?

Just a few more questions before we wrap up.

9. Given HHS' priorities in improving outcomes for people with disabilities and addressing the national workforce shortage of LTSS providers, what kinds of enhanced data on the self-directing HCBS population could support research that addresses these priorities?
10. We will be talking to representatives from several states, including state Medicaid agencies, FMS organizations, and MCOs, to gain their perspective on the feasibility of such a database. Do you have any suggestions for important focus areas or topics to discuss with these stakeholder groups, as it relates to appending T-MSIS data with additional data on self-directing HCBS beneficiaries?
11. Is there anything else you would like to share with us on this topic, or is there anyone else you would recommend we speak with on this topic?

Exhibit B2. FMS Entity Informant Discussion Guide

1. I want to start by having you do a brief introduction of yourself, and hearing about your role within [name of FMS entity].
2. Based on our understanding, [name of FMS entity] is currently assisting self-directing Medicaid participants across several states [name states]. Would you agree, and can you briefly describe the type or types of FMS models you deploy across these states? For example, do you provide Fiscal/Employer Agent (F/EA) or Agency with Choice (AwC) services and, in which states if you provide different models in different states or programs within states?

We would now like to better understand the types of data that you routinely collect on Medicaid HCBS self-directing participants, and the hired aides providing services to them.

3. I want to now ask you about the types of personal identifiers that [your FMS entity] collects for Medicaid HCBS self-directing beneficiaries that you work with. We have been told by CMS staff who work on T-MSIS that Medicaid numbers for program participants are not always correct and that they would prefer to have as many identifiers as possible for self-directing program participants as possible to ensure accuracy. In particular, they would like to have SSNs for self-directing program participants, and we've also been told that some states have begun issuing unique provider identifiers to individual providers of aide services for anti-fraud purposes.
4. I'd like to now ask you about other types of information on participants that is collected.
5. I want to now pivot to asking you about the types of information [your FMS entity] collects on workers (i.e., the aides hired by self-directing participants).
6. How are these data that we just talked about maintained?
7. What role do state agencies and managed care organizations (MCOs) play in collecting personal identifiers for Medicaid HCBS self-directing beneficiaries and any information about their direct care workers?

As we mentioned at the top of the discussion, it appears that FMS entities are a promising source of both personal identifiers for the HCBS self-directing participant and direct care worker data. Leveraging what you collect might be the most efficient way to obtain this data across multiple states.

8. What permissions or approvals would be required, and from whom, to enable you to share, with us, the data you collect on self-directing Medicaid HCBS participants and direct care workers?
9. Assuming the necessary permissions or approvals are secured, would [your FMS entity] be willing to participate in this database (that is, serve as a data provider for it)?
10. If given permission from the required entities, how do you foresee providing this data to ASPE for the purpose of preparing a report in this area?

Just a few more questions before we wrap up. We will be speaking with representatives from 4-6 state agencies for Medicaid HCBS services to understand their level of interest in such a database, and how willing they would be to participate in it/provide approvals to FMS entities for sharing data.

11. Thinking about the states that [your FMS entity] works with, are there specific ones that you would recommend we contact for this conversation?
12. We talked today about the types of data that [your FMS entity] collects on self-directing participants and their hired aides. Following today's conversation, we'd like to send you a form that lists, with more specificity, the data indicators within three categories (program characteristics, program

participants, and program direct care workers) that are of most interest for this database. Would you be willing to complete the form to check off which indicators are available, and not? We'd ask that you return your responses to us within about 2 weeks.

Exhibit B3. State Agency Informant Discussion Guide

1. I want to start by asking you to briefly introduce yourself. Please tell us your name and role within [State Agency Name].
2. Before we dive into questions concerning this potential database, can you briefly describe your state's self-direction program(s) or waiver(s)? We understand [insert few sentences on the state's program]. Would you agree and/or would you like to add anything?
3. Based on the feasibility research we have done so far, we think the best source of the self-direction data we seek – especially the data on characteristics of self-directed workers – is likely to be the financial management services (FMS) entities that perform accounting/payrolling/and tax filing for self-direction programs. However, we are also interested in learning about other potential state sources of data. Within your state's Medicaid claims/encounter data/billing system, is it possible to distinguish between HCBS beneficiaries who self-direct and those who do not? If yes, can you explain the types of data flags or indicators that are available for this?
4. Does your state directly collect any (other) data on HCBS beneficiaries who self-direct services and/or their direct care workers (e.g., demographics, eligibility, other characteristics)?

As noted before, we understand that FMS entities, being as they are the payroll agents for self-directed beneficiaries, collect quite a bit of data on self-directing participants (including demographic information and beneficiary SSN numbers) as well as data on their hired workers.

5. To what extent does your state agency require FMS entities to submit data on self-directed HCBS users and direct care workers? For example, is there any data on beneficiaries and workers that you or Managed Long-Term Services and Support (MLTSS) plans in your state require FMS entities to submit for claims billing and reimbursement purposes?

Currently, it appears that FMS entities are the most promising source of both the personal identifier and worker data for self-directed HCBS beneficiaries. This might also be the least burdensome approach for states if they only had to grant permission to the FMS to provide these data.

6. Assuming the FMS entity in your state is willing to participate in this future database (i.e., be a data provider for it), how feasible would it be for your state agency to grant permissions or approvals for them to participate? We don't anticipate that participation in the database would occur prior to late 2025 or early 2026.
7. In your view, what would enable or facilitate your state's future participation in this database? And by participate, what we mean is providing the necessary approvals for FMS entities to share data and the eventual linkage of this data to T-MSIS.

Just a few more questions before we wrap up.

8. We understand that CMS requires each state agency to operate a continuous quality assurance and improvement system which can be used to monitor performance measures and individual outcome measures.

9. Finally, from the perspective of your state’s HCBS program for self-directed beneficiaries, what is the level of interest in being able to compare outcomes and service utilization between self-directing and traditional Medicaid HCBS users?

Those are all the questions we had for you today.

10. Is there anything else you would like to share with us that we have not covered?
11. [Only ask if State collects data on HCBS self-directed beneficiaries and/or their workers] We talked today about the types of data that your state collects on self-directing participants and/or their hired aides. Following today’s conversation, we’d like to send you a form that lists, with more specificity, the data indicators within three categories (program characteristics, program participants, and program direct care workers) that are of most interest for this database. Would you be willing to complete the form to check off which indicators are available, and not? We’d ask that you return your responses to us within about 2 weeks.

Appendix D. Post-interview Data Element Form

Data Elements of Interest for a Future Database on Self-Directed Beneficiaries, Providers, and Services

The federally managed Transformed Medicaid Statistical Information System (T-MSIS) – which houses administrative data on the Medicaid program – lacks systematic collection of individual identifiers for self-directed Home and Community-Based Services (HCBS) users and data on their workers, creating a gap in such data availability at a national level. The absence of such national data hinders researchers’ and policymakers’ ability to conduct multi-state comparisons of outcomes between self-directed beneficiaries and traditional HCBS users.

To address this gap, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and NORC at the University of Chicago (NORC) are collaborating to better understand the needs, challenges, and feasibility of establishing a future database (national or multi-state) that would include individual identifiers for the self-directing HCBS beneficiary population, as well as data on their direct care workers.

We had a conversation with you on <insert date> about this potential database. At that discussion, we mentioned sharing with you a data form, your responses to which will help us understand more granularly the data that you have and would be potentially able to share. Please see below for instructions on how to complete this form.

Instructions for Completing the Form

The table below is categorized into three data domains: Self-Directed Services (SDS) program characteristics, SDS program participants, and SDS program direct care workers.

- In the response columns, please indicate with an “X” whether your FMS entity a) collects the data element and could share it in the future, b) collects the data element but could not share it in the future, or c) does not collect the data element.
- In the last column under “Notes,” please indicate any additional information you would like to share about that data element, including whether a data element is only available for some states in your network but not all.

Please feel free to share this form with any of your colleagues who you think would be best positioned to complete the form.

Data Elements Relevant to Patient-Centered Outcomes Research for Self-Directed HCBS Users

Data Element	Data Element	Data Element Description	Collected And Can Be Shared	Collected But Cannot Be Shared	Not Collected	Notes
SDS Program Characteristics	Medicaid Funding Authority	How the state administers and jointly funds Medicaid within broad federal rules. States may have a 1915 (c) waiver, a Personal Care Services (PCS) plan, or other types of Medicaid authorities.				
	Employer Authority only or Budget Authority	The program may allow participants to self-hire and manage their own staff (employer authority) and decide how the funding is allocated (budget authority).				
	FMS Model	States principally use two FMS models to implement SDS: the Fiscal/Employer Agent (F/EA) model or the Agency with Choice (AwC) model.				
SDS Program Participants	MSIS Identification Number	A state-assigned unique identification number used to identify a Medicaid/CHIP enrolled individual. This value may be a social security number (SSN), a temporary SSN, or state-assigned eligible individual identifier.				
	Social Security Number	An individual's SSN.				
	Medicaid Card ID	The Medicaid Card ID is a state-assigned unique identifier that states should report with all Medicaid and CHIP beneficiaries. This should be the identifier that is used in the state's Medicaid Management Information System (MMIS).				
	Age	An individual's age in years.				
	Date of Birth	An individual's date of birth.				
	Sex	Either individual's biological sex or their self-identified sex.				

Data Element	Data Element	Data Element Description	Collected And Can Be Shared	Collected But Cannot Be Shared	Not Collected	Notes
	Race	A code indicating the individual's race either in accordance with requirements of Section 4302 of the Affordable Care Act classifications Race Code clarification.				
	Ethnicity	A code indicating that the individual's ethnicity is Hispanic, Latino/a, or Spanish ethnicity of a Medicaid/CHIP enrolled individual.				
	Primary Language	A code indicating the language that is the individuals' preferred spoken or written language.				
	Rural/Urban Residence	A code indicating the individual's residence as defined by the United States Census Bureau (Census) and the Office of Management and Budget (OMB).				
	Start of SDS Participation	The date the individual began self-directing their services.				
	Previous SDS Participation	Whether the individual previously received agency aide services before your FMS.				
	Use of Representatives	Whether the individual has designated a representative to assist them in managing their self-directed services and budget.				
	Representative Option Requirements	Whether the representative is a) related to the SDS participant (and if so, the type of family relation), or b) authorized to sign off on timesheets for their aides.				
	Budget Authority or Employer Authority	Whether the SDS program participant has employer authority or budget authority.				

Data Element	Data Element	Data Element Description	Collected And Can Be Shared	Collected But Cannot Be Shared	Not Collected	Notes
	Determining Hourly Wage Rate	Whether the SDS program participant can negotiate hourly wages for workers, or the wage rate is fixed by the state or a union contract.				
	Number of Workers Employed	How many workers are employed by each SDS participant at a time.				
	Gaps in Employed Workers	Months during the past year when the SDS participant did not employ (pay) any workers.				
	Turnover Rate	Number of SDS participants who had direct care workers leave their employment in the past year.				
	Maximum Monthly Benefit - Hours	If applicable, the number of authorized aide hours the SDS program participant I can receive per month.				
	Maximum Monthly Benefit - Budget	If applicable, the authorized monthly budget amount the SDS program participant can receive.				
	Maximum Monthly Benefit Usage	Reported amount of benefit used since joining the SDS program, per month.				
SDS Program Direct Care Workers	Social Security Number	Direct care worker's SSN.				
	National Provider Identifier	National Provider Identifier (NPI) is the nationally recognized provider identifier assigned by the Center for Medicare & Medicaid Services (CMS).				
	Tax Payer ID	Federal Employer Identification Number (FEIN).				
	Age	The worker's age in years.				
	Date of Birth	The worker's date of birth.				
	Sex	Either the worker's biological sex or their self-identified sex.				

Data Element	Data Element	Data Element Description	Collected And Can Be Shared	Collected But Cannot Be Shared	Not Collected	Notes
	Race	A code indicating the worker's race either in accordance with requirements of Section 4302 of the Affordable Care Act classifications Race Code clarification.				
	Ethnicity	A code indicating that the worker's ethnicity is Hispanic, Latino/a, or Spanish ethnicity.				
	Citizenship Status	Type of citizen (by birth, naturalized, or non-citizen/immigrant/green card holder).				
	Education Level	The worker's highest level of education.				
	Family Relation to SDS Participant	Whether the worker is related to the SDS program participant, and, if so, the type of family relation (legally responsible individual [e.g., spouse, parent], or legal guardian). <i>Note to FMS's: at a minimum this should be available if the worker is subject to special tax rules based on the family relationship.</i>				
	Worker(s) Living Arrangement	Whether the worker is living in the same household as the SDS participant or not.				
	Number of SDS Participants Served	How many SDS program participants the worker serves at one time.				
	Length of Time Employed	How long the worker has been working for the SDS program participant.				
	Number of Hours Worked	The number of hours workers work for SDS program participants (mean, median, percentages).				
	Hourly Wage Rates	The rate of pay for the worker (range, mean, and median).				

Data Element	Data Element	Data Element Description	Collected And Can Be Shared	Collected But Cannot Be Shared	Not Collected	Notes
	Pay Increases	Whether the worker has received pay increases since starting to work for an SDS program participant.				
	Overtime Pay	Whether the worker has received overtime wages since starting to work for an SDS program participant.				
	Benefits	The types of benefits that the worker receives (if any) (e.g., paid time off, health insurance).				
	Completion of Aide Training Requirements	Whether the worker has completed voluntary or mandatory training requirements.				
	Completion of Advanced Aide Training	Whether the worker has some kind of advanced aide training and the type of training received (e.g., paramedic training).				
	Criminal Background Check (Required or Voluntary)	Whether the worker has been subjected to a criminal background check (required or voluntary).				
	Status of Criminal Background Check	Whether the worker a) passed the background check or b) did not pass but allowed to work under waiver requested by the SDS participant.				