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**PATIENT-CENTERED OUTCOMES
RESEARCH TRUST FUND**

REPORT

Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities

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

By
NORC at the University of Chicago

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The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) was established as part of the 2010 Patient Protection and Affordable Care Act and is charged to build data capacity for patient-centered outcomes research. Managed by the Office of the Assistant Secretary for Planning and Evaluation on behalf of the Department, OS-PCORTF has funded a rich portfolio of projects to meet emerging U.S. Department of Health and Human Services policy priorities and fill gaps in data infrastructure to enhance capabilities to collect, link, and analyze data for patient-centered research. The OS-PCORTF portfolio includes projects that are developing and testing standards that improve data interoperability, piloting novel approaches to patient-provided data collection, using real-world data (RWD) in evidence generation, and addressing challenges to data linkages.

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ABSTRACT

This report describes insights gained from key informant interviews and an ASPE-hosted listening session on short-term opportunities for improving patient-centered outcomes research (PCOR) data infrastructure that addresses the needs of individuals with intellectual and developmental disabilities (ID/DD).

Key informants prioritized three opportunities to enhance data infrastructure for PCOR related to individuals with ID/DD for pursuit under the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF): 1) standardize the collection of ID/DD status at the point of care through development of standards and policy changes to promote their adoption; 2) address gaps in standardized outcome measures important to individuals with ID/DD; and 3) support the development of robust data linkages programs for Transformed Medicaid Statistical Information System (T-MSIS) data and other federal data sources.

Key informant interviews identified potential future activities related to all three priority opportunities, as well as two additional activities that would support all three opportunities: 1) develop a standardized definition of ID/DD; and 2) support development and adoption of data standards for ID/DD service systems.

A listening session panel consisting of ten experts raised considerations regarding the feasibility and potential impact of the ideas raised during key informant interviews, as well as additional considerations for implementing projects related to each opportunity.

Given ASPE's role in coordinating intradepartmental projects to strengthen PCOR data infrastructure, the OS-PCORTF is well positioned to engage with federal partners and the ID/DD community to implement projects that address key opportunities related to improving data infrastructure for ID/DD PCOR.

BACKGROUND

In 2017, there were approximately 7.4 million people with intellectual and developmental disabilities (ID/DD) in the United States, including approximately 5.3 million children and two million adults.¹ Historically, individuals with ID/DD have experienced health disparities related to several factors including: a lack of access to high quality medical care, inadequate preparation of health care providers to meet their needs, higher prevalence of unmet social needs, and the frequent exclusion of people with ID/DD from public health research programs.² People with ID/DD have wide ranging health concerns and needs for services and supports that allow them to participate meaningfully in their communities. Research is needed to generate evidence around the services, supports, and interventions to improve the overall health and well-being of people with ID/DD.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) coordinates intradepartmental projects on behalf of the Secretary of Health and Human Services (HHS) that build data capacity for conducting patient-centered outcomes research (PCOR). This work is referred to as the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) portfolio, and it is funded by a trust fund that Congress established in 2010 and reauthorized for ten years in 2019.³ The 2019 reauthorization legislation identified ID/DD as a new research priority for the PCORTF. As a result of the reauthorization, ASPE developed a 10-year strategic plan with four priority areas of focus. One of the priority areas of the OS-PCORTF Strategic Plan focuses on building data capacity for PCOR that informs the greatest evidentiary needs for programs, providers, and the people served by the federal health care programs.

In 2021, ASPE commissioned NORC at the University of Chicago (NORC) to conduct an environmental scan that identified 11 opportunities to enhance data infrastructure for PCOR related to individuals with ID/DD (see [text_box](#)). These 11 opportunities were fully described in a [2021 white paper published by ASPE](#).⁴ In early 2022, the

11 Priority Opportunities to Enhance Data Infrastructure for PCOR Related to Individuals with ID/DD

1. Standardize the collection of ID/DD status at the point of care through development of standards and policy changes to require it.
2. Test the feasibility of using currently accepted terminology standards and implementation specifications to collect data on function and disability.
3. Standardize quality of life (QoL) measures for the ID/DD population.
4. Support user-centered design and feasibility testing of digital technologies (e.g., smartphone apps, tablets, wearables, devices, etc.) for diagnostic and therapeutic purposes.
5. Support ongoing efforts to improve the collection and documentation of social determinants of health (SDOH) data in the electronic health record (EHR) using standard clinical terminologies.
6. Work collaboratively with states to improve the utility of Transformed Medicaid Statistical Information System (T-MSIS) data for comparative effectiveness research (CER).
7. Address gaps in standardized outcome measures important to individuals with ID/DD.
8. Support the development of a robust data linkages programs for Transformed Medicaid Statistical Information System (T-MSIS) data.
9. Support common data governance policies for creating easier access to relevant datasets, especially to perform linkages between state and federal datasets.
10. Offer support to states to facilitate capture of granular data and to develop clear data dictionaries that support application of a standard definition of ID/DD across state data.
11. Foster Opportunities to validate patient-reported outcome (PRO) measures for the ID/DD population.

11 opportunities were revisited and key informant interviews were conducted to explore three short-term opportunities that could be pursued under the OS-PCORTF. This report highlights findings from the 2022 key informant interviews and listening session conducted by NORC.

METHODS

We gathered input through three mechanisms. First, feedback form was completed by 15 federal agency representatives. The feedback form asked the federal respondents to choose the top four opportunities among the 11 areas from the previous white paper which they believed would improve data infrastructure for PCOR related to ID/DD. Second, we conducted 13 virtual key informant interviews, which also included group interviews with multiple informants. Interviews were conducted with 19 federal agency representatives, five ID/DD and PCOR researchers, and two representatives of a national association of state ID/DD service providers. Two of the interview informants were individuals with lived experience with ID/DD, providing a personal understanding of how ID/DD affects people's lives and interactions with the healthcare system. Feedback form results informed the focus of the interviews. Third, ASPE hosted a listening session with a broader set of federal and non-federal stakeholders.

The listening session was held on April 21, 2022, to share and discuss preliminary findings from the key informant interviews. The 90-minute listening session involved a moderated discussion panel with ten panelists, most of whom participated in the key informant interviews, and engagement with an audience of federal and non-federal stakeholders. The ten-member panel consisted of five federal agency representatives, four researchers including self-advocate researchers, and one representative of a national association of state ID/DD service providers. Panelists included three individuals with lived experience. A list of panelists who attended the listening session can be found at the beginning of this report.

A preliminary version of this report (which we referred to in its preliminary form as an "Opportunity Brief") was shared with the panel to guide the discussion. The panelists and audience reflected on findings from the key informant interviews about PCOR data priorities and engaged in a discussion related to the feasibility and impact of the ideas raised through the following questions:

- Of the ideas presented in the Opportunity Brief, which are the most feasible to develop into new PCOR data initiatives that can be implemented by HHS agencies and their partners through the OS-PCORTF portfolio?
 - What concrete resources (i.e., specific agency collaborations, datasets, expertise, etc.) would be needed to get started on these ideas this year?
- Of the ideas presented in the Opportunity Brief, which do you think will have the most tangible impact on improving data for research that improves understanding of the health outcomes for individuals with ID/DD and their families?
 - Which ideas do you think have the most significant downstream impacts on data infrastructure for health outcomes research?
- What other factors are important for the OS-PCORTF portfolio to consider in order to make substantial progress on building data capacity for patient-centered outcomes research within the top three opportunities described in the brief?

The OS-PCORTF portfolio generally focuses on data infrastructure for PCOR, which has an emphasis on generating evidence to inform health care decisions that occur in clinical settings. However, for people with ID/DD, there is a need for person-centered research that considers a more holistic view of an individual's health and well-being to support both clinical and non-clinical decision-making. For the purposes of this report, the term *person-centered* research is distinguished from but closely aligned with PCOR.

KEY INFORMANT FINDINGS: POTENTIAL FUTURE DATA INFRASTRUCTURE ACTIVITIES

Fourteen respondents completed the feedback form (93% response rate). Three opportunities were selected most often by all respondents and are shown in Exhibit 1. Key informant interviews focused on identifying current ID/DD data infrastructure activities pursued across federal agencies, ideas for future data infrastructure activities, and potential cross-agency partnership opportunities related to these top three priority opportunities. The findings in this report reflect potential future activities that are in the purview of the OS-PCORTF portfolio and others interested in data for ID/DD research.

Interviews with key informants revealed several potential future activities for improving data infrastructure for PCOR focused on the needs of people with ID/DD. While most of the ideas raised related to one of the top three opportunities, there were two suggestions that cut across all three opportunities. Informants described one cross-cutting data infrastructure need related to defining ID/DD that they believed was necessary to address in order to achieve meaningful improvements across all three opportunities. The second cross-cutting opportunity relates to supporting exchange of information and data across service systems for individuals with ID/DD. The following sections present the cross-cutting opportunities first, followed by the ideas that informants raised under each of the three prioritized opportunities.

Exhibit 1. Top Three Opportunities Identified among Federal Partners

Opportunity A: Standardize the collection of ID/DD status at the point of care through development of standards and policy changes to promote their adoption

Opportunity B: Address gaps in standardized outcome measures important to individuals with ID/DD

Opportunity C: Support the development of robust data linkages programs for Transformed Medicaid Statistical Information System (T-MSIS) data and other federal data sources

Cross-Cutting Opportunity: Develop a Standardized Definition of ID/DD

A common theme that emerged from key informant interviews was the lack of a standard definition for identifying the population of individuals with ID/DD in data sets used for research. Key informants noted that it can be challenging to identify individuals with ID/DD in data given the heterogeneity of conditions, causes, symptoms, functional status, clinical features, and co-occurring disorders in the ID/DD population. Additionally, there is a lack of consensus regarding whether to use diagnosis, functional status, or a combination of the two to identify individuals with ID/DD. Although the American Association on Intellectual and Developmental Disabilities (AAIDD) has put forward defining criteria for intellectual disabilities⁵ and the Developmental Disabilities Assistance and Bill of Rights Act of 2000 has done the same for developmental disabilities,⁶ these definitions have been operationalized in different ways by federal and state programs. Therefore, research data sets which are derived from state or federal program administrative data can vary in the populations they capture.

Many informants emphasized that a lack of a standardized definition for ID/DD that can be applied in research creates challenges for all three opportunities explored through the 2022 key informant interviews (i.e., capturing the ID/DD status at the point of care; developing standardized outcome measures; and leveraging the T-MSIS data effectively). Therefore, a few informants noted that, as a first step, stakeholders should jointly

identify and develop a standardized list of International Statistical Classification of Diseases and Related Health Problems-10-Clinical Modification (ICD-10-CM) codes and other criteria (e.g., minimum number of claims in which those diagnoses must be present) that could be used to develop a data flag to identify individuals with ID/DD in Medicare, T-MSIS, state Medicaid, and other data sets that capture ICD-10-CM codes. Key informants suggested that a product such as the T-MSIS Substance Use Disorder (SUD) Data Book, which provides a definition for SUD,⁷ could be a good model for an ID/DD-specific product that provides guidance to researchers on identifying individuals with ID/DD in claims or enrollment-based data. Examples of how a standardized definition for ID/DD could be leveraged are shown in Exhibit 2.

Other informants expressed the view that, rather than focusing on a specific set of codes to operationalize an ID/DD definition in claims-based and enrollment-based data, work should be done to develop a

conceptual framework that would address the many other facets of defining ID/DD for PCOR, including:

- Determining when to use a diagnostic definition of ID/DD (e.g., appropriateness of leveraging a medical model of ID/DD), a functional definition, or both. For example, one informant noted that for children eligible for services through the Individuals with Disabilities Education Act (IDEA), children must be diagnosed with an IDEA eligible condition. The condition must adversely impact learning and the children must benefit from special education services.⁸ Another informant pointed out that functional support needs are an important determining factor for adult eligibility for long-term services and supports for an individual with ID/DD, more so than a specific diagnosis, and is more useful for tracking outcomes over an individual's lifetime. Finally, an informant noted that while developmental delays are not the same thing as developmental disabilities, there may be certain scenarios in which it would be important to include children with developmental delays in the research definition of ID/DD.
- Determining if and how to consider ID/DD status determined through self-identification when operationalizing a standardized definition for ID/DD.
- Providing guidance on how the definition can be operationalized in different types of data sets, including indication of when use of case definitions or algorithms may be appropriate.
- Considering how severity of conditions and co-occurring conditions are accounted for in the application of a standardized definition to identify individuals with ID/DD in research.
- Considering if and how the definition should be operationalized differently depending on the objective of the PCOR studies.

A few key informants emphasized that the efforts to develop a conceptual framework and/or standardized definition for ID/DD should engage a variety of perspectives including federal and state agencies, individuals

Exhibit 2. Potential Application of a Standardized ID/DD Definition

- A consistent definition of ID/DD used in research studies would allow researchers and ID/DD service programs and providers to determine if study findings are applicable to the specific populations they serve.
- A standardized definition of ID/DD would aid the development and adoption of standardized outcome measures, thereby increasing the quantity and quality of data available for outcomes research in the ID/DD population.
- States could map their Home & Community Based Services (HCBS) program eligibility criteria to a common ID/DD definition to understand how the population served by their state's HCBS waiver program compares to the research definition of ID/DD.
- A data flag for identifying individuals with ID/DD in Medicare and Medicaid claims could be used to conduct stratified analyses of claims-based quality measures to understand disparities in care quality and health outcomes for individuals with ID/DD relative to the general Medicare and Medicaid populations.

with lived experience and their caregivers, advocates, researchers, and ID/DD service program directors through a collaborative consensus building process.

Cross-Cutting Opportunity: Support Development and Adoption of Data Standards for ID/DD Service Systems

Key informant discussions revealed a need for data standards to support exchange of information across service systems for individuals with ID/DD to support delivery of person-centered and coordinated care. One promising effort, which could be expanded upon to advance the capture of standardized data across Home and Community-Based Services (HCBS) provider systems, is the Electronic Longitudinal Service and Supports (eLTSS) HL7® data standard development efforts.⁹ The standard is based on the eLTSS data set developed jointly by the Office of the National Coordinator for Health Information Technology (ONC) and the Centers for Medicare and Medicaid (CMS) and supports exchange of data elements that are captured in individualized service plan (ISP) information within a state’s case management system. The eLTSS implementation guide describes how the eLTSS data elements can be represented and exchanged/shared across HCBS providers, person-centered planning coordinators (e.g., care coordinators or case managers), and clinical or institutional based providers.¹⁰ Through ONC’s Leading Edge Acceleration Project (LEAP) Grant, Missouri is testing the eLTSS standard through a use case in which ISPs for individuals with ID/DD are shared with Missouri’s supportive employment HCBS provider to match HCBS recipients with training and employment opportunities. The ISPs are also shared with primary care providers via the state’s health information exchange (HIE) networks.¹¹

A few informants believed that future OS-PCORTF efforts could develop resources to facilitate broader adoption of the HL7® eLTSS standard by states and to explore how eLTSS data could be used in person-centered research. Additionally, resources and lessons learned from a [current OS-PCORTF funded project](#)¹² that aims to make electronic health data from HIEs more accessible for PCOR could support use of eLTSS data for research if eLTSS data are integrated into HIEs.

Opportunity A: Improve Data Capture of ID/DD Status at Point of Care

Within electronic health record (EHR) data, ICD-10-CM diagnosis codes are the primary data elements that are used to identify the ID/DD population. However, these diagnoses are not systematically captured at the point of care for a variety of reasons, including individuals’ hesitancy to disclose status due to stigma concerns or because they feel the information is irrelevant to the purpose of their visit. Additionally, not all providers are trained to assess, diagnose, and document ID/DD, and billing and payment policies do not incentivize ID/DD status documentation. When diagnoses are inconsistently documented in the EHR, they are less likely to be captured in EHR-derived data sets as standardized data elements, such as ICD-10-CM codes. A snapshot of key informants’ thoughts on activities to support capture of ID/DD at the point of care is shown in Exhibit 3.

Exhibit 3. Activities to Support Capture of ID/DD Status at Point of Care

- Create an ID/DD-specific United States Core Data for Interoperability Plus (USCDI+) data set and encourage its adoption.
- Support development of mechanisms and tools for capturing and documenting self-reported ID/DD status.
- Investigate machine learning or natural language processing techniques to capture ID/DD status information in provider free text notes or other unstructured EHR data.

Develop Interoperable Data Sets Under United States Core Data for Interoperability Plus (USCDI+).

Interoperability of EHR information supports HIE between health systems, the ability for patients to access their own medical record from EHRs, and the aggregation of EHR data across systems for research. The United States

Core Data for Interoperability (USCDI) is a set of standards-based health data classes and elements released by ONC that serve as the minimum requirements for interoperability that certified EHR products must adhere to. A few informants noted that one potential activity to improve data capture of ID/DD status at the point of care is development of an interoperable ID/DD data set as part of the USCDI+, an extension of the existing [USCDI](#).¹³ USCDI+ is an ONC initiative that was launched to support the identification of domain or program-specific data sets that extend beyond the core USCDI data sets in order to meet agency-specific programming requirements.¹⁴ Currently, the Draft USCDI Version 3 has newly added data elements that could serve as a starting point for an ID/DD-specific data set within USCDI+. The relevant data elements from USCDI Version 3 fall within three health status categories: disability status, functional status, and mental health function.¹⁵ Key informants from across agencies suggested that this existing work could serve as a first step towards cross-agency coordination and thought leadership for future USCDI+ efforts to define data elements on ID/DD status within certified EHR products. The adoption of an ID/DD-specific USCDI+ data set could have downstream implications for the development and use of EHR documentation templates by EHR developers which could facilitate collection of ID/DD status by providers and could support inclusion of ID/DD status in EHR-derived data sets and registries.

Create Mechanisms and Tools to Support Capture of Self-Reported ID/DD Status at the Point of Care. A few informants noted the development of templates and tools for capturing and documenting patient-reported ID/DD status as another potential focus area for future work. For instance, one key informant shared an example of a federal grant-funded effort in which a large health system partnered with an EHR developer to create a patient portal form for capturing information from patients on necessary disability accommodations for medical appointments and then presented that information back to health care providers within the EHR.¹⁶

Use Natural Language Processing to Explore Unstructured ID/DD Data in EHRs. At least one key informant noted that ID/DD status at the point of care may already be captured in the form of free text notes, rather than structured data fields in the EHR. Therefore, an exploration of free text information in the EHR through natural language processing coupled with machine learning techniques could be beneficial for identifying people with ID/DD using unstructured EHR data. Exploring the potential of existing but untapped data could allow researchers to access rich and nuanced data without the time and expense of potentially changing provider training and behavior around capturing ID/DD diagnoses in structured data fields. Similar work has been done in an ONC-funded project at Boston Children's Hospital, which uses natural language processing to extract information on COVID-19 from clinical notes.¹⁷

Opportunity B: Create Standardized Outcome Measures Important to the ID/DD Population

Key informants agreed that outcome measures for person-centered research for individuals with ID/DD should encompass all domains of life including physical and mental health, education, employment, daily living, community integration, and social inclusion. While many of these domains are captured through existing surveys and measures developed and reported by the National Core Indicators¹⁸ or facilitated by the National Quality Forum,¹⁹ they are generally designed to support program-level assessments rather than to capture individual-level outcomes. Additionally, there are many challenges to collecting and validating individual-level outcome measures for the ID/DD population due to concerns with validity of proxy-reported measures and the diverse communication needs of individuals with ID/DD. Key informants provided feedback on this opportunity in two areas: 1) identifying areas to focus on improving the collection of standardized measures important for the ID/DD population, and 2) identifying a need for improved measurement of outcomes that span the life course (childhood, adolescence, adulthood, old age) of individuals with ID/DD.

Address Gaps in Outcome Measures. Key informants noted several domains where there is a need for focused efforts to systematically measure and track outcomes important to individuals with ID/DD. Although specific

activities to address these gaps were not identified, informants called out the following areas as priorities for broader data infrastructure efforts related to standardized data capture, data linkage, and measure development:

- Abuse, neglect, harm, and exploitation: These areas of safety were described as outcomes domains important to individuals with ID/DD that are often not reported in a standardized way across ID/DD service programs.
- Justice involvement: Measures are needed to assess outcomes for individuals with ID/DD who are involved in the justice system, including outcomes of individuals upon reentry into the community after incarceration.
- Quality of life and well-being: Multiple key informants described a need for broader indicators of well-being and quality of life that focus on strengths rather than deficiencies of individuals with ID/DD (e.g., functional measures that focus on what a person can do rather than cannot do, social participation measures that focus on involvement rather than exclusion). Key informants also stressed the need for validated data collection instruments, protocols, and tools to support the collection of information directly from individuals with ID/DD rather than their caregivers given the concerns that proxy-reported measures may not be an accurate reflection of an individual's actual experience and perceptions on quality of life.
- Employment: One key informant noted several gaps in measurement in the gainful employment literature, namely capturing consistent information related to income of individuals with ID/DD, intersection of backgrounds (e.g., considering sexual orientation, status of people with autism), and augmented alternative communication use or other disability accommodations in the workplace that support gainful employment. The Rehabilitation Services Administration's Case Service Report ([RSA-911](#))²⁰ data set collected by the Department of Education was identified as one potential federal source of employment-related data. The RSA-911 data set captures individual-level data on participants of the federal- and state-funded Vocational Rehabilitation (VR) Program. It includes information on type of disability as well as outcomes related to VR program participation up to one year after leaving the program, including attainment of employment or education credentials.

Collect Data to Support Longitudinal Outcome Measurement. Many key informants noted that there is a need for measures that can track outcomes from the point when an individual receives an ID/DD diagnosis through their entire life course. They emphasized the importance of capturing experiences of individuals as they transition from childhood to adulthood through the creation of longitudinal data sets that capture information on early intervention and special education programs during childhood and HCBS waiver services received (or not) during adulthood, along with quality of life, physical, and mental health outcomes. A few key informants cited the importance of longitudinal cohort studies that track children into adulthood and through various service systems. One informant noted that there may be opportunities to build on or expand existing studies focused on children, similar to how the Centers for Disease Control and Prevention (CDC)-funded Study to Explore Early Development (SEED), which aims to identify factors that may put children at risk for autism spectrum disorder, was expanded as part of CDC SEED Teen to focus on teenagers.^{21,22}

Many key informants reflected that supporting the collection of patient-reported outcomes (PROs) from the ID/DD population is an important opportunity related to creating standardized outcome measures important to individuals with ID/DD. They stressed the importance of investing in tools and resources to facilitate collection and validation of PROs for the ID/DD population.

Opportunity C: Encourage Use of T-MSIS Data for ID/DD Research and Support a Data Linkages Program for T-MSIS Data

T-MSIS is the most current and complete federal source for Medicaid and Children’s Health Insurance Program (CHIP) data. As described in the [2021 white paper](#),⁴ T-MSIS aggregates state Medicaid administrative records and CMS makes files available to researchers. Key informants noted that because T-MSIS is relatively new, many researchers are unfamiliar with how to leverage T-MSIS for person-centered research related to ID/DD.

Develop T-MSIS Guide for ID/DD Research. Some key informants noted that one way to encourage researchers to conduct more person-centered research for the ID/DD population would be to develop a guide to support the use of T-MSIS data for research. The guide could focus on advising researchers on the strengths and limitations of using T-MSIS data for ID/DD-focused research. In addition to including a standardized definition for ID/DD, as described earlier, the guide could identify other variables of interest for the ID/DD population that are captured in T-MSIS and the relative completeness and quality of these data across states within T-MSIS. The creation of a guide may also help identify gaps in T-MSIS data which could then be potentially addressed through targeted data quality improvement efforts with states and/or data linkages to fill gaps in information.

Support Data Linkages with T-MSIS. The OS-PCORTF has already funded a [project](#)²³ to link T-MSIS with other federal data sets including the National Death Index (NDI), National Hospital Care Survey (NHCS), and Housing and Urban Development (HUD) data. Some key informants identified additional data sets that they believed would be valuable to link to T-MSIS for ID/DD PCOR. These data sets included the Census Bureau’s Survey of Income and Program Participation (SIPP) and the American Community Survey (ACS), as well as the CDC’s Behavioral Risk Factor Surveillance System (BRFSS). One key informant noted that a linkage between T-MSIS and the RSA-911 data set (refer to the previous section) would provide insight into the other types of HCBS services utilized by individuals participating in VR programs. Several key informants also noted the value in linking T-MSIS to the Social Security Administration (SSA) Disability Analysis File to enable identification of individuals with ID/DD who do not utilize HCBS services but who do receive other disability benefits through SSA. Many key informants highlighted data linkages at the state level that could be beneficial for ID/DD PCOR, including linkages between HCBS waiver administrative data and state education data and employment data.

LISTENING SESSION FINDINGS: POTENTIAL FUTURE DATA INFRASTRUCTURE ACTIVITIES

On April 21st, 2022, ASPE held the *Opportunities to Improve ID/DD Data Infrastructure Listening Session*. The purpose of the listening session was to provide a forum to discuss potential federal opportunities for improving data infrastructure to support person-centered research to address the needs of individuals with ID/DD. The session brought together experts in ID/DD and data infrastructure who drew from their own diverse perspectives and experiences to provide input on the key informant interview findings in two areas: feasibility and impact of the identified potential future activities.

The listening session resulted in a robust discussion around the following opportunities of focus:

- Develop a standardized definition of ID/DD
- Support development and adoption of data standards for ID/DD service systems
- Improve data capture of ID/DD status at point of care
- Create standardized outcome measures important to the ID/DD population
- Encourage use of T-MSIS data for ID/DD research and support a data linkage program for T-MSIS

Panelists delved into broad themes surrounding data infrastructure needs within the aforementioned opportunities and discussed future activities that could be pursued to address these needs. The listening session concluded with an interactive activity to gain feedback on impact and feasibility from all 42 expert attendees. The following sections focus on the discussion that pertains to the purview of the OS-PCORTF, but are also relevant to others interested in building data capacity for outcomes research. The discussion below does not identify individual panelists and attributes all comments to the panel as a whole.

Feasibility Considerations for Data Infrastructure Efforts

Panelists discussed the feasibility of developing ideas identified from key informant interviews into a data initiative that OS-PCORTF could support through project funding. Panelists shared ideas on prior work which could be leveraged, important gaps that need to be filled, and actions necessary for improving feasibility of an opportunity. Panelists also pointed out interdependencies and relationships between proposed ideas under each opportunity, which could have implications for feasibility.

Develop a Standardized Definition of ID/DD. All panelists agreed that the creation of a standardized ID/DD research definition deserved particular attention. A definition would have downstream implications for effectively carrying out other data infrastructure activities, including effective use of T-MSIS for person-centered research and development of standardized outcome measures for ID/DD. Panelists described important considerations related to the feasibility of developing a standardized definition:

- The components of the definition for ID/DD depend on the research purpose. A framework for developing a standardized definition of ID/DD would need to be reflective of and responsive to a broad range of research questions, analysis methodologies, and data sources available for ID/DD PCOR.
- A panelist described the need for coded clinical terminologies for data elements specific to the ID/DD service system to support their uptake of a standardized ID/DD definition based on ICD-10-CM codes. Most case management systems do not utilize data elements based on clinical taxonomies and terminologies, such as ICD-10-CM codes. In some instances, case management systems map their standards taxonomy to clinical taxonomies and terminologies to enable data exchange; however, many systems used by service providers for the ID/DD population are not currently mapped to clinical taxonomies. Without mapping of these systems, service providers would be unable to use an ID/DD definition and other data elements based on ICD-10-CM codes, highlighting the need for new ID/DD service system data elements.
- Developing a standardized definition for ID/DD requires collaboration and coordination across research entities, as well as inclusion of and input from people with ID/DD and other ID/DD stakeholders.
- The panel suggested building on prior efforts that relate to defining ID/DD and ID/DD-relevant constructs, including a 2012 study conducted by Lin and colleagues using administrative health care data to define ID/DD²⁴ and the Keeping the Promise Report,²⁵ which sought to define “community living” and informed the 2014 Medicaid HCBS Settings Rule.²⁶
- The discussion on feasibility produced two potential project ideas related to developing a standardized ID/DD definition:
 1. Create a conceptual framework which could guide efforts for developing an ID/DD definition for PCOR. The framework could address how to ensure a research definition is reflective of various data collection methodologies, data sources, and the purpose of the research.
 2. Through consensus approaches, develop a standard definition that can generate operational definitions that align with available data.

Improve Data Capture of ID/DD Status at Point of Care. Panelists described preliminary steps needed to ensure that ID/DD status can be reliably captured at the point of care for all individuals with ID/DD:

- There are limitations in the availability of validated diagnostic instruments for adults across the full spectrum of conditions that make up the ID/DD diagnosis. For example, there are a limited number of validated instruments for assessing autism spectrum disorder in adults,²⁷ meaning that diagnosis often occurs during childhood or not at all. Training for health care providers on diagnostic instruments is limited as well. The potential lack of identification or clinical diagnosis could result in an underestimation of individuals with ID/DD for research relying on diagnostic codes.
- Diagnoses are often made outside of the health care setting, including in schools and eligibility determinations for state-funded services such as Medicaid HCBS. Therefore, ID/DD diagnosis codes for these individuals may not get captured in electronic clinical databases derived from health care EHR systems. Interoperability between the various systems that capture ID/DD diagnoses could bolster and improve the ID/DD status information that is available at the point of care.

Develop and Adopt Data Standards for ID/DD Service Systems. The panel stated that foundational work to validate existing interoperability data standards should be done prior to embarking on efforts to develop new interoperability data standards for the ID/DD service system. This work would entail testing existing standards to assess gaps and needs that could then inform the development of resources or new standards. Additionally, an attendee commented that adoption of the eLTSS standard and other Fast Healthcare Interoperability Resources (FHIR)-based application programming interfaces (APIs) among providers of social services and HCBS is limited. Without policy levers in place to incentivize uptake of FHIR-based APIs and other standards, adoption will likely remain limited, impacting the feasibility of widespread implementation and use of standards specific to ID/DD service systems. In some instances, case management systems currently work around interoperability barriers by mapping their data terminologies to clinical taxonomies. In the absence of policies requiring the use of FHIR-based standards, taxonomy mapping solutions may be a more feasible option.

Encourage Use of T-MSIS Data for ID/DD Research. While acknowledging that T-MSIS is a potentially under-utilized data source for ID/DD research, panelists expressed enthusiasm for efforts such as an ID/DD data book or guidebook to improve use of T-MSIS data for PCOR related to individuals with ID/DD. Panelists raised the following considerations for developing resources to encourage the use and linkage of T-MSIS data in PCOR for the ID/DD population:

- To leverage T-MSIS for claims-based research focused on the ID/DD population, it is important to have a standardized definition that includes a list of ICD-10-CM codes for identifying individuals with ID/DD in T-MSIS data. Developing a standardized definition also helps to avoid duplication of efforts and ensure comparability of results across studies that leverage claims-based data.
- Panelists cautioned that resources or guidebooks developed as part of a data infrastructure project should acknowledge limitations of T-MSIS that many researchers may not be fully cognizant of, including variation in availability and quality across states' contributed Medicaid data. Additionally, they noted that individuals with ID/DD not receiving Medicaid and HCBS waiver services would not be represented in the T-MSIS data. The panelists suggested consideration of linking T-MSIS with other data sets that would capture individuals with ID/DD who are unlikely to be identified in T-MSIS data, such as all-payers claims databases.

Potential for Impact of Future Data Infrastructure Efforts

Panelists were next asked to consider which of the opportunities will have the most tangible impact on improving data for ID/DD research. Panelists shared their perspectives on the opportunities which they believed would have important implications for patient-centered research for individuals with ID/DD. They also shared suggestions for specific actions that would amplify the impact of any OS-PCORTF activities pursued related to these opportunities.

Improve Data Capture of ID/DD Status at the Point of Care. The panel noted that standardizing and increasing the collection of ID/DD status of the point of care would have important impacts on data infrastructure for conducting PCOR that addresses the needs of individuals with ID/DD. Panelists mentioned specific potential implications of efforts to standardize collection of ID/DD status at the point of care:

- Standardizing the collection of ID/DD status at the point of care would improve the availability and quality of information available to researchers on individuals' ID/DD status within datasets that capture ICD-10-CM diagnosis codes, including T-MSIS data, Medicare, and all-payers claims datasets.
- One panelist noted that it would be useful to develop and disseminate conversation guides for health care providers that provide recommendations and best practice guidelines to providers about how to start conversations that could lead to diagnosis of ID/DD or capture of ID/DD status information (based on a prior diagnosis).

Develop a Standardized Definition for ID/DD. The panel noted throughout the listening session that developing a standardized research definition for ID/DD would be one of the most important activities to undertake. Developing a standardized definition for ID/DD would have significant downstream impacts on achieving the other opportunities described in the report, particularly using T-MSIS, linking other datasets to T-MSIS, developing standardized outcome measures for ID/DD, and developing data standards for ID/DD service systems. Operationalizing a common definition for ID/DD across research projects and allow for more accurate comparisons between programs and populations. For research that involves primary data collection (i.e., not using existing administrative data sources), a common definition for ID/DD would create more consistency and improve the data quality.

Create Standardized Outcome Measures Important to the ID/DD Population. Panelists noted that current outcome measures are outdated, lack cultural sensitivity, and do not capture domains that are meaningful to individuals with ID/DD. Addressing gaps in person-centered outcome measures for the ID/DD population would help researchers to better understand how individuals with ID/DD experience the services and supports they receive, their level of engagement with services, and how the services impact their lives. Panelists shared some examples of activities that could support development and use of standardized outcome measures for ID/DD:

- It is important to ensure that federal and federally-funded quality measure development efforts include and engage individuals with ID/DD throughout the measure development process. This will help researchers to understand which outcomes are most important to individuals with ID/DD. For instance, developing a resource such as a blueprint or roadmap for engaging individuals with ID/DD in the measure development process could promote and support development of meaningful outcome measures for ID/DD.
- Ongoing state-based efforts funded by the Administration for Community Living (ACL), Patient-Centered Outcomes Research Institute (PCORI), and others engaged in outcome measure development could serve as a model for efforts at the federal level to increase engagement. For example, key findings from the PCORI-funded [Compensation Engagement Guide](#),²⁸ an existing guide on how to engage people with disabilities in research, could be applied to work pursued under the OS-PCORTF.
- While a variety of quality measures exist, there is not enough standardization in terms of which measures are used to assess programs that serve individuals with ID/DD across states. States and service programs utilize varying outcome measures to evaluate their efforts, which limits the ability to adequately assess differences in outcomes between populations. Work that is currently being done by the University of Minnesota's Rehabilitation Research and Training Center on HCBS Outcome Measurement to validate, refine, and implement a national framework of HCBS measures for people with disabilities, could potentially be leveraged to further standardize outcome measures for the ID/DD population.²⁹

Attendee Input

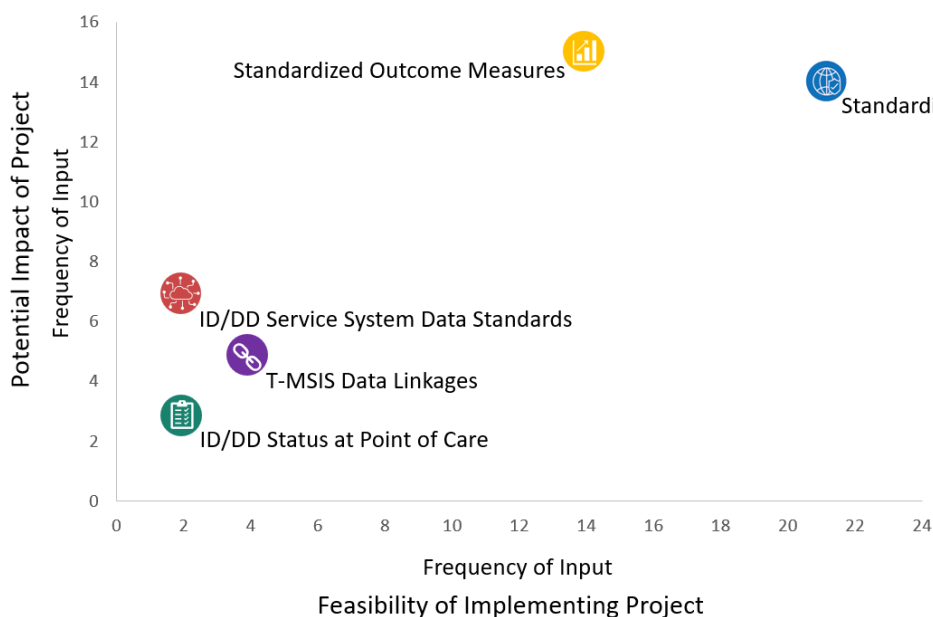
Following the panelist discussion, all 42 panelists and expert attendees provided input on which two opportunities they thought were most feasible and most impactful. Using an annotation tool on the Zoom platform, attendees selected opportunities that they thought from their perspective were most feasible to pursue. Panelists and attendees were then asked to indicate their views on other opportunities that they thought would have the greatest impact on the ID/DD population.

Results from the collective input are shown in Exhibit 4.

The top two opportunities that were selected most often across both categories of feasibility and impact were:

- Develop a standardized definition of ID/DD (Feasibility: 21, Impact: 14)
- Create standardized outcome measures important to the ID/DD population (Feasibility: 14, Impact: 15)

Exhibit 4. Listening Session Attendee Input on Feasibility and Impact of Opportunity-Related Projects



CONSIDERATIONS ACROSS OPPORTUNITIES

Engage the ID/DD Population Collaboratively in Research and Data Improvement Efforts

The key informants and listening session panelists stated that the inclusion of individuals with ID/DD throughout the research lifecycle, including any efforts to enhance person-centered research data infrastructure, was paramount. They stressed the importance of being inclusive and mitigating bias at all phases of the research. Key informants and panelists highlighted several considerations for engaging individuals with ID/DD. They noted the importance of involving individuals with lived experience in any discussions related to developing a definition of ID/DD, especially since the definition could have implications for services that are made available to them, and because the label of ID/DD is still often stigmatized. They also highlighted that individuals with ID/DD should be directly involved in efforts to address gaps in outcome measures that are important to them, and efforts should be directed towards facilitating collection of self-reported outcomes data rather than proxy-reported outcomes.

Key informants emphasized the importance of avoiding tokenism and supporting meaningful participation of individuals with ID/DD in all phases of research and data infrastructure development. Methods of support and inclusion include supporting alternative modes of communication, recognizing that people’s abilities and preferences for communication may vary day-to-day. A few panelists voiced agreement that using plain, inclusive language makes research accessible. It is important to ensure that all research findings and data infrastructure products are disseminated in ways that are accessible to individuals across the spectrum of ID/DD.

Finally, key informants stressed the need to move towards a strengths-based approach as opposed to a medical deficit model of disability when developing end products related to the opportunities identified in this report.

Capturing Demographic Data to Support Health Equity

Many key informants noted that future activities to enhance data infrastructure should ensure that a health equity lens is applied to PCOR for the ID/DD population. Informants emphasized the importance of supporting the collection and use of demographic and SDOH data to inform a more nuanced understanding of the disparities in care and outcomes among individuals with ID/DD. Assessing and comparing demographic information (i.e., race and ethnicity, language spoken) of individuals receiving services through state programs could be used as an indicator to determine whether additional work is needed to address disparities in access to services. For example, if overall state demographic data and demographic data of individuals supported by Medicaid or other systems are not parallel, this could indicate the need to identify underserved populations.

Across all efforts related to data infrastructure for the ID/DD population, panelists stressed the need to maintain awareness of who is captured in existing data sets as well as which subgroups are most likely to be excluded and why. For example, panelists noted that claims-based data sets, which make up many of the data sources used in ID/DD research, including T-MSIS, are unlikely to capture people who are not enrolled in HCBS waivers or who are not having active encounters with the health care system. Therefore, other approaches should be considered to identify individuals with ID/DD who are not captured in these data sets. Within the ID/DD population, this may mean paying particular attention to a lifespan perspective, as many of the current research and service efforts are divided by age categories.

Additionally, panelists suggested utilizing private insurance or all payer claims data as well as data available about people on the waitlist for HCBS services to identify additional people with ID/DD. However, panelists recognized the ongoing challenge of identifying individuals who are uninsured, undiagnosed, or who are not receiving services at all.

Ensure that Safeguards are in Place for Access to and Use of Data Sets

Many key informants offered several considerations regarding the access to and responsible use of data about individuals with ID/DD. They raised concerns about ethical and legal considerations that may limit activities to address the opportunities, such as laws limiting the ability to access and link certain data sets or specific data elements related to people with ID/DD (e.g., Family Educational Rights and Privacy Act protections of school and education records). However, this concern was coupled with the recognition that assurances are needed to protect the privacy and security of data in the ID/DD population. Additionally, panelists noted that it is important to consider reciprocity of data, such that those amongst the ID/DD population who contribute data to research should receive results and knowledge in return.

Administration of the OS-PCORTF Projects

During the listening session, panelists shared suggestions for successful administration of future projects to increase long-term impact of OS-PCORTF efforts. One panelist emphasized the importance of sequencing and

staging OS-PCORTF projects for ID/DD data infrastructure in a way that allows for continued progress and advancement and avoids stagnation after the initial step. For example, if a project is focused on developing a framework for defining ID/DD for PCOR, then there should also be a plan in place to operationalize the framework and demonstrate how it can be used. Another panelist emphasized the need for intentional thought within OS-PCORTF projects about how to share data and resources actively across federal agencies and new methods for facilitating communication between agencies. Finally, OS-PCORTF projects should ensure that dissemination plans include products that are accessible to the ID/DD community (e.g., plain language, visual supports).

CONCLUSION

This report highlights specific activities that address the following opportunities expressed by experts, researchers, federal partners, and individuals with lived experience:

- Develop a standardized definition of ID/DD
- Support development and adoption of data standards for ID/DD service systems
- Improve data capture of ID/DD status at point of care
- Create standardized outcome measures important to the ID/DD population
- Encourage use of T-MSIS data for ID/DD research and support a data linkage program for T-MSIS

Key informants and panelists shared many existing and ongoing efforts that target the aforementioned opportunities and assessed the feasibility and potential impact of addressing these opportunities through OS-PCORTF efforts. The OS-PCORTF portfolio coordinates intradepartmental projects that advance the data infrastructure needed for PCOR; as such, ASPE is well positioned to engage with federal partners and the ID/DD community to implement projects that address key opportunities related to improving data infrastructure for ID/DD PCOR.

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