IMPROVING DATA INFRASTRUCTURE FOR PERSON-CENTERED OUTCOMES RESEARCH ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
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Abstract:	Individuals with intellectual and developmental disabilities (ID/DD) continue to experience disparities in health and well-being despite improved provision of person-centered care. Patient-centered outcomes research (PCOR) translates evidence into practice for meaningful outcomes. This piece describes findings from an environmental scan and stakeholder outreach to identify and prioritize opportunities to enhance ID/DD PCOR data infrastructure. These opportunities include developing a standardized research definition; advancing data standards for service systems; improving capture of ID/DD at point of care; developing standardized outcome measures; and encouraging Medicaid data use for ID/DD research. We discuss implications of addressing data gaps for enhanced research. While the identified activities provide a path towards advancing ID/DD PCOR data infrastructure, collaborative efforts between government, researchers, and others are paramount.

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Abstract

Individuals with intellectual and developmental disabilities (ID/DD) continue to experience disparities in

health and well-being despite improved provision of person-centered care. Patient-centered outcomes

research (PCOR) translates evidence into practice for meaningful outcomes. This piece describes findings

from an environmental scan and stakeholder outreach to identify and prioritize opportunities to

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research definition; advancing data standards for service systems; improving capture of ID/DD at point

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Keywords

Intellectual and developmental disabilities; people with ID/DD; data infrastructure; patient-centered

outcomes research

Introduction

An estimated 7.4 million people in the United States have an intellectual or developmental disability

(Larson et al., 2020). Over the past 50 years, care for people with intellectual and developmental

disabilities (ID/DD) has shifted from a primarily medical, institutional model to a more holistic model

through the establishment of Medicaid home and community-based services (HCBS) waiver programs

(Spreat, 2017). While HCBS provides person-centered supports for outcomes important to recipients

(Friedman, 2020), the ID/DD community continues to experience challenges receiving equitable care.

For example, people with ID/DD lack access to high-quality health care from providers with adequate

training to meet their needs and are more likely to have unmet social needs (e.g., access to safe public

spaces, transportation, recreation, healthy foods, and social connections) (Anderson et al., 2013).

Further, there is limited evidence on which community-based interventions for this population can most

improve health and well-being outcomes as well as about the effects of social determinants of health

such as employment, satisfying relationships, and stable housing (Anderson et al., 2013).

Patient-centered outcomes research (PCOR) has potential to address this dearth of evidence. In this

piece, we use PCOR to refer to "person"-centered outcomes research because people with ID/DD often

have life-long habilitative support to facilitate community, social, and employment integration, which go

beyond clinical supports in which a person is referred to as a "patient" (Kumar & Chattu, 2018; Starfield,

2011). Facilitating PCOR that not only focuses on, but engages, the ID/DD community is extremely

important in the face of routine exclusion of people with disabilities from research (DeCormier Plosky et

al., 2022). PCOR is one avenue to address the gaps in the evidence base directly resulting from the

underrepresentation of individuals with ID/DD in research and research processes. By reflecting

preferences and the support needs of individuals, research evidence can help individuals with ID/DD and

their care teams identify the best healthcare for this population, as well as the right combination of

services and supports that affect outcomes meaningful to the person, their families, and their caregivers

(DeCormier Plosky et al., 2022).

PCOR can improve decision-making associated with meaningful outcomes for people with ID/DD by

providing evidence to address questions such as which interventions and resources are most suitable

given an individual's needs and preferences, which factors help or hinder the effectiveness of tailored

programs, and how programs or services compare in terms of benefits and risks. To ensure that PCOR

reflects the priorities and interests of people with ID/DD, members of the ID/DD community should be involved in the research process to identify the most important and meaningful PCOR inquiries. Researchers, including those funded by the Patient-Centered Outcomes Research Institute (PCORI), currently investigate these types of research questions for individuals with disabilities (PCORI, n.d.; Chung et al., 2020; Heinemann et al., 2019). One population, people with ID/DD, have a lifetime of unique health and long-term care needs, and were specifically called out in the 2019 reauthorization of the PCOR legislation.

A *Health Affairs Forefront* post in August 2022 highlighted six recommendations for improving disability data to address health and social inequities, one of which includes improving access to comprehensive data on life-long outcomes, service use, and individuals' preferences by leveraging linked, cross-sector data (Swenor, 2022, August 22). These limitations for data on the broader disability community also apply to ID/DD-specific PCOR. Johnston and colleagues (2022) also argued for inclusion of ID/DD identifiers in national surveys and linkages between national survey, Medicare, and Medicaid data as mechanisms to identify and reduce systemic health inequities experienced by people with ID/DD (Johnston et al., 2022). Linkable, individual-level data that captures information relevant to person-centered outcomes can better support PCOR inquiries to inform understanding of outcomes for people with ID/DD; however, the current infrastructure for collecting and analyzing individual-level data on people with ID/DD requires improvement.

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) manages the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) on behalf of the U.S. Department of Health and Human Services (HHS) ("Patient Protection and Affordable Care Act," 2010). The OS-PCORTF aims to build a PCOR data capacity for researchers to generate objective, scientific evidence on the outcomes and effectiveness of treatments, services, and other health care interventions

that can be used to inform policy decisions. In the December 2019 reauthorization of the OS-PCORTF, Congress identified ID/DD as a priority area of focus for PCOR ("Patient-Centered Outcomes Research Institute Reauthorization Act," 2019). Under the reauthorization, ASPE continues to collaborate with many federal agencies to improve the data infrastructure for people with ID/DD.

Given recent efforts to highlight inequities in capturing data for people with disabilities, this *Perspective* describes federal efforts to identify and operationalize five promising data infrastructure opportunities that could be leveraged to support PCOR for ID/DD in the near future. These efforts were identified through an environmental scan to assess the current landscape and identify common challenges and future opportunities to enhance data infrastructure for ID/DD PCOR (Dhopeshwarkar et al., 2021) and qualitative stakeholder input to identify priority short-term opportunities (Dhopeshwarkar et al., 2022). In what follows, we describe identified data infrastructure challenges and opportunities and discuss potential activities the federal government can support to implement these opportunities.

Data Infrastructure Challenges

Data that are valuable for ID/DD PCOR include longitudinal, person-level datasets that capture information on interventions and meaningful outcomes and can facilitate wide-reaching research through data linkages. An environmental scan conducted in 2021 described strengths and limitations of using five categories of data sources for PCOR (Dhopeshwarkar et al., 2021), as summarized in Table 1.

Table 1. Strengths and Limitations of Data Sources for Intellectual and Developmental Disabilities (ID/DD) Patient-Centered Outcomes Research (PCOR)*

Data Type and Example Datasets	Data Type Key Strengths	Data Type Key Limitations

Federal Surveys (e.g., Agency for Healthcare Research and Quality [AHRQ] Medical Expenditure Panel Survey [MEPS]; Centers for Disease Control and Prevention [CDC] National Health Interview Survey [NHIS]; Census Bureau Survey of Income and Program Participation [SIPP]; National Survey of Children's Health [NSCH])	• Availability of public use files for multiple data years • Solicit information from a large population • Federal surveys have been successfully linked to other federal data • Some federal surveys collect information on functional status or an ID/DD diagnosis	• Questions on functional limitations often included in federal surveys generally do not differentiate between ID/DD and other cognitive conditions like dementia, stroke, and traumatic brain injury • Cannot identify specific ID/DD diagnosis or severity of disability Survey administration methods and survey questions often are not designed to accommodate the communication needs of respondents with ID/DD nor cognitively tested and validated for individuals with ID/DD (Havercamp et al., 2019; Havercamp & Scott, 2015) • Surveys may use proxy responses rather than self-reported data
Federal Administrative Data (e.g., Centers for Medicare and Medicaid Services [CMS] Transformed Medicaid	• Capture information on services and supports received	• Inconsistent documentation of diagnostic codes in claims may present challenges for applying a diagnostic definition of ID/DD y

Statistical Information System [T-MSIS]; AHRQ Healthcare Cost and Utilization Project [HCUP])	• Claims-based datasets capture diagnoses through ICD-10-CM codes • Inclusion of individual identifier makes these data linkable to other data sources	• Effects of policy changes on continuity of federal administrative data • Usually lack information on people without health insurance
State-Level Data Sources (e.g., State Medicaid data and All-Payer Claims Databases [APCD]; National Core Indicators [NCI®]; Consumer Assessment of Healthcare Providers and Systems [CAHPS] HCBS Experience of Care Survey)	• Include person-level, longitudinal data with identifiers • Capture information on health care utilization and other services and supports received • Capture data on quality and outcomes of services provided	• Surveys may use proxy responses rather than self-reported data • Smaller sample sizes limit ability to focus on ID/DD subpopulations or, in surveys specific to the ID/DD population, to identify person-level data in aggregate datasets
Longitudinal Studies (e.g., National Longitudinal Transition Study 2012 [NLTS 2012]; Longitudinal Health & Intellectual Disability Study [LHIDS])	• Inclusion of longitudinal data specifically targeted to answer questions about health and other outcomes for ID/DD populations	• Lack of data following cohorts into late adulthood for to assess long-term outcomes for older adults with ID/DD • Use of proxy responses rather than self-reported data

		• Data may not be nationally representative
Other Data Sources (e.g., Special Olympic Healthy Athletes System [HAS]ⱦ)	• High data specificity related to ID/DD services, satisfaction, and health outcomes • Provides information unique from other federal and state data	• Data may not be collected consistently • Lack of global unique identifiers makes it difficult to follow individuals longitudinally

*Unless otherwise cited, information in this table is a summary of (Dhopeshwarkar et al., 2021).
ⱦData sources containing individual-level information relevant to ID/DD services and PCOR, and that do not fall into one of the previously stated categories, are limited. The authors identified the Special Olympic Healthy Athletes System dataset as one example; however, other datasets may exist.

The environmental scan also identified several data infrastructure challenges that inhibit effective data collection and use for conducting PCOR for the ID/DD population. Lack of standardization in data elements, classes, and definitions creates barriers to collecting, aggregating, exchanging, and linking data for research. A fundamental issue facing researchers is how to define and operationalize ID/DD for data collection and analysis (Havercamp et al., 2019). There is no consistent approach or criteria for defining ID/DD in surveys, administrative or programmatic data, or clinical data, with some sources using a functional assessment to determine ID/DD status and others relying on the presence of a clinical diagnosis (Havercamp et al., 2019). The variety in ID/DD definitions used in research is due to the heterogeneity of conditions, symptoms, and functional and clinical features characteristic of the ID/DD population, as well as the varied use of diagnostic criteria (e.g., DSM-5), functional status assessments, or a combination of the two to identify people with ID/DD. Administrative and programmatic data often define individuals with ID/DD based on variable service eligibility requirements across state Medicaid HCBS waiver programs, state-to-state differences in ID/DD, and disability service definitions (Dragoo, 2020) and they lack standardized outcome definitions for incident reporting systems. This further

complicates researchers' efforts to aggregate state and program datasets and make comparisons across datasets. Other challenges include difficulties in linking siloed sector-specific data (e.g., education and HCBS waiver programs) to create longitudinal datasets that are needed to generate evidence to support ID/DD youth as they transition to adulthood. Finally, inadequate standardized, harmonized, and validated data collection instruments for collecting self-reported outcome measures (Mont et al., 2022) and limited digital technologies for individuals with functional limitations make it challenging to collect information directly from individuals with ID/DD in a cognitively accessible manner. These barriers can lead to overreliance on proxy-reporting, which can result in a one-sided, caregiver-specific view of critical outcomes for PCOR, such as measures of social engagement, quality of life, and community integration (Shogren et al., 2021a).

Data Infrastructure Opportunities

We identified 23 opportunities to enhance data infrastructure for ID/DD PCOR. A technical expert panel of HHS agency representatives, convened in 2021, reviewed these 23 opportunities and prioritized 11 for ID/DD data infrastructure development projects (Dhopeshwarkar et al., 2021). In 2022, we gathered additional feedback via key informant interviews and a listening session with federal agency representatives, ID/DD and PCOR researchers, a national association of state ID/DD service providers, and individuals with ID/DD. Informants prioritized three of the 11 opportunities and identified two cross-cutting opportunities for pursuit through the OS-PCORTF. In this section, we describe proposed activities to illustrate the types of PCOR ID/DD data infrastructure improvements that can be accomplished through OS-PCORTF funded efforts for the five shortlisted opportunities. All five opportunities and activities are described in further detail in a corresponding report (Dhopeshwarkar et al., 2022).

Develop a Standardized Research Definition of ID/DD

As noted above, the lack of a standard ID/DD definition that can be used to identify the ID/DD population in research data sets is a fundamental challenge to advancing PCOR ID/DD. Further, ID/DD populations within federal and state programs vary, depending on the eligibility criteria and supports offered. These inconsistencies lead to differences in the ID/DD populations captured in administrative program data sets that are used for research. While it is likely impossible to standardize administrative definitions because of the diversity in Medicaid programs across the country, it is important that researchers using administrative data endeavor to use a consistent and transparent definition when conducting research (U.S. HHS Administration for Community Living, 2020) and share results from that research, noting where their study diverges from the standardized definition.

A consistent definition of ID/DD applied in research could help harmonize data and produce informative, generalizable evidence for both state and federal programs. Informants identified two potential stakeholder-driven activities to move towards a standardized ID/DD research definition. First, they suggested identifying relevant clinical diagnoses codes (i.e., ICD-10-CM codes) for developing a data flag to identify individuals with ID/DD in administrative and clinical datasets often used in ID/DD PCOR. Second, they called for development of a conceptual framework for defining ID/DD in the context of PCOR that provides guidance on how to consider factors such as: condition severity and presence of co-occurring conditions; appropriateness of using a diagnostic definition and/or functional definition of ID/DD; and the role of self-identification of having an ID/DD. It is imperative that the conceptual framework for defining ID/DD in the context of PCOR provide pragmatic guidance to researchers on how their study's research objectives, available data sources, and target outcomes could help them determine appropriate use of a standardized functional vs diagnostic definition for ID/DD.

Support Development and Adoption of Data Standards for ID/DD Service Systems

Individuals with ID/DD have complex care needs and often receive a multitude of specialty services across several care settings. Electronic exchange of information across service systems for individuals with ID/DD not only supports delivery of person-centered and coordinated care, but also facilitates researcher access to cross-sector data. In 2014, CMS and the Office of the National Coordinator for Health Information Technology (ONC) jointly launched the Electronic Long-Term Services and Supports (eLTSS) project to identify and enable electronic exchange of a harmonized set of 56 standard data elements commonly found on LTSS individualized service plans (Patel et al., September 12, 2019). With funding from ONC, the Missouri Department of Mental Health recently demonstrated use of the eLTSS standard by exchanging information from the state's case management system with a health information network, a supported employment provider IT system, and a primary care provider electronic health record (EHR) system (Akinnagbe, 2022). Interview informants suggested that OS-PCORTF projects could support additional resources and testing efforts to further eLTSS HL7® data standard adoption across states and to support use of LTSS data in PCOR.

Improve Identification of ID/DD at the Point of Care

Within EHR data, diagnosis codes are the primary data elements used to identify the ID/DD population. However, diagnoses are not consistently captured in EHRs, for a variety of reasons such as an individuals' hesitancy to disclose their disability due to stigma concerns or irrelevancy to the visit's purpose, the limited number of providers who are trained to assess, diagnose, and document ID/DD, and billing and payment policies that do not incentivize ID/DD documentation (O'Malley et al., 2005). Improving the ability to identify people who have ID/DD in standardized data captured at the point of care within EHRs would improve the accuracy and comprehensiveness of EHR-derived datasets for ID/DD PCOR. Furthermore, identification through point of care settings could improve identification of people with ID/DD for research, as almost 60% of people with ID/DD are not known to the LTSS system

(Larson et al., 2020) and are therefore not captured in LTSS administrative data (Rosencrans et al., 2021). Key informants identified three key activities to address this opportunity. First, they called for cross-agency collaborative efforts to build on the United States Core Data for Interoperability (USCDI) dataset to create an ID/DD-specific USCDI Plus (USCDI+) dataset. The USCDI sets the minimum interoperability requirements for certified EHR products (ONC, 2022). USCDI+ extends the utility of USCDI beyond the core interoperable datasets to support domain or program-specific datasets supporting agency-specific programming requirements (ONC, 2021). Second, they suggested partnering with developers to create open-source EHR-based tools that capture and document self-reported ID/DD via patient portals and EHR documentation templates. Finally, they suggested testing the feasibility of natural language processing and machine learning techniques to capture presence of an ID/DD from unstructured EHR data.

Develop Standardized Outcome Measures Important to the ID/DD Population

While efforts to study patient-centered outcomes for people with ID/DD are increasing, assessment of outcomes for this population has historically centered around medical outcomes and service utilization (Barth et al., 2020). Furthermore, there is little standardization of measures used to capture outcomes meaningful to people with ID/DD, limiting comparability across studies. Creating standardized outcome measures important to people with ID/DD would ensure capture of meaningful individual-level outcomes necessary for PCOR. These measures should encompass all domains of life, including health and well-being, education, employment, daily living, community integration, and social inclusion. Measures in these domains are captured through existing surveys, including those developed and reported by the NCI (Human Services Research Institute [HSRI] and The National Association of State Directors of Developmental Disabilities Services [NASDDDS], 2020) or facilitated by the National Quality Forum (NQF) (NQF, 2016); however, these measures support program-level assessments rather than

individual-level outcomes important to PCOR inquiries. Key informants called for improved

measurement of PCOR-relevant outcomes that span the life course of individuals with ID/DD. They also

identified four domains where improved individual-level data capture, data linkage to support

longitudinal assessment, and standardized measure development are needed: 1) abuse, neglect, harm,

and exploitation, 2) justice system involvement, including community re-entry after incarceration, 3)

quality of life and well-being, and 4) gainful employment and income. Measure developers should

prioritize the validation of self-reported measures used with people with cognitive impairments or

limited communication abilities, given the variability between self-reported and proxy-reported

responses, especially in subjective domains such as quality of life (Roberts and Abery, 2023; Shogren et

al., 2021a; Shogren et al., 2021b).

Encourage Use of T-MSIS Data for ID/DD Research and Support a T-MSIS Data Linkage Program

Transformed Medicaid Statistical Information System (T-MSIS) aggregates state Medicaid and Children's

Health Insurance Program (CHIP) administrative records to enable national level analyses of

beneficiaries' outcomes, service use patterns, and cost and quality of care. It is the most up-to-date

federal claims data source for Medicaid and CHIP. Key informants identified two activities to promote

use of T-MSIS data for ID/DD PCOR: 1) a guide that supports researchers in using T-MSIS data for ID/DD

research and outlines strengths and weaknesses of the data; and 2) dataset linkages with T-MSIS and

other federal datasets that can extend the T-MSIS dataset's capacity to capture important health,

services, social, and economic outcomes identified by individuals living with disabilities. Potential

linkable datasets include the Census Bureau's Survey of Income and Program Participation, the

American Community Survey (U.S. Census Bureau, 2021), the Social Security Administration (SSA)

Disability Analysis File (SSA, n.d.), and the Department of Education's Rehabilitation Services

Administration's Case Service Report (RSA-911) dataset (Center for Large Data Research and Data

Sharing in Rehabilitation, n.d.; Rehabilitation Services Administration, n.d.), which includes individual-level data on individuals participating in Vocational Rehabilitation programs across all 50 states.

While use of T-MSIS data for ID/DD PCOR is a promising opportunity, notable barriers preclude researchers' access to T-MSIS data, including high acquisition costs and a multi-step process to obtaining data access. Additionally, stakeholders have noted data quality concerns including issues with the completeness and accuracy of HCBS waiver information, race and ethnicity data, and data elements used to identify LTSS recipients (Medicaid and CHIP Payment and Access Commission [MACPAC], 2022, June; Kim et al., 2022, July 22). The proposed T-MSIS research guide may help address these challenges by encouraging broader use of T-MSIS data among researchers who then identify additional Medicaid data quality improvement focus areas.

It is important to acknowledge that while all five of these opportunities may improve access to data on individuals with ID/DD who receive services through HCBS waiver programs, these opportunities may not improve the availability of data on individuals who are not enrolled in Medicaid, those who remain on states' waitlists for services, are uninsured, or undiagnosed.

Future Direction and Next Steps

The OS-PCORTF 2020-2029 Strategic Plan (ASPE, 2022, September) identifies funding for internal HHS ID/DD projects as a priority for this decade. Through these projects, federal agencies will improve the visibility of individuals with ID/DD in data used for PCOR. As with many OS-PCORTF funded projects, the resources and tools that result from interagency efforts to improve data infrastructure often have ripple effects for research endeavors beyond the initial identified use case. The investments that are made to improve ID/DD data infrastructure have the potential to improve access to and quality of data for disability research more broadly.

The OS-PCORTF portfolio has already begun operationalizing these prioritized opportunities, funding projects that address ID/DD PCOR data infrastructure needs. For example, the OS-PCORTF-funded project, *Integrated Dataset on Intellectual and Developmental Disabilities* (iDIDD), aims to produce a de-identified, publicly accessible dataset linking Supports Intensity Scale data, Medicaid claims data, the NCI In-Person Survey, and other relevant state-level data sources, in close consultation with ID/DD stakeholders including individuals with ID/DD (ASPE, n.d.a). Data linkage methodologies utilized in this project will be disseminated to researchers and may help facilitate similar data linkages for other disability populations. A second project, *Engaging People with ID/DD to Enhance Functional Disability Representation in Point of Care Settings*, will help improve identification of people with ID/DD in administrative data systems, by developing a standardized definition of functional disability to collect disability status in provider settings (ASPE, n.d.b).

A central aim of the OS-PCORTF ID/DD priority goal, as outlined in the 2020-2029 Strategic Plan, is to promote health equity for the ID/DD population, an area where federal and community efforts align. Both experts consulted in this work and external researchers emphasized the need for data collection and analytic approaches that assess and address inequities within the ID/DD community and the need to improve accessibility of data and findings for people with ID/DD (Pendo, 2016). Collaboration with people with ID/DD, self-advocates, and researchers is a key component of this work, and will ensure that resulting data infrastructure resources and end-products are useful and reflect the values of people with ID/DD. Researchers should seek to engage members of the ID/DD community as equal partners throughout the research lifecycle. ID/DD partners can provide guidance and input on research priorities in the design and development phase (Bendixen et al., 2022), developing data collection tools and informing analytic techniques and conclusions, and disseminating findings (Hewitt et al., 2023). Partnership with the ID/DD community will enable OS-PCORTF investments to advance the field of PCOR and provide optimal care for the ID/DD population.

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