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REPORT

Considerations for Building Federal Data Capacity for Patient-Centered Outcomes Research Related to 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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Office Of The Assistant Secretary For Planning And Evaluation

The Assistant Secretary for Planning and Evaluation (ASPE) advises the Secretary of the U.S. Department of Health and Human Services (HHS) on policy development in health, disability, human services, data, and science; and provides advice and analysis on economic policy. ASPE leads special initiatives; coordinates the Department's evaluation, research, and demonstration activities; and manages cross-Department planning activities such as strategic planning, legislative planning, and review of regulations. Integral to this role, ASPE conducts research and evaluation studies; develops policy analyses; and estimates the cost and benefits of policy alternatives under consideration by the Department or Congress.

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The Office of Behavioral Health, Disability, and Aging Policy (BHDAP) focuses on policies and programs that support the independence, productivity, health and well-being, and long-term care needs of people with disabilities, older adults, and people with mental and substance use disorders.

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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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TABLE OF CONTENTS

EXECUTIVE SUMMARY

In 2021, NORC at the University of Chicago (NORC) completed an environmental scan that explored existing data infrastructure capacity to conduct patient-centered outcomes research (PCOR) for people with intellectual and developmental disabilities (ID/DD). NORC placed emphasis on research that is person-centric, meaning focused holistically on people's physical, mental, emotional, and social health and outcomes. This report describes the current state of PCOR data infrastructure resources related to ID/DD, highlights data issues in the ID/DD research landscape that require more research, and identifies opportunities to enhance data infrastructure to improve PCOR for ID/DD.

Since 2010, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) has managed 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) Secretary. The OS-PCORTF was created to build national data capacity and infrastructure to support PCOR that provides decision-makers with objective, scientific evidence on the effectiveness of treatments, services, and other interventions used in health care. Reauthorization of the OS-PCORTF extended this research funding through 2029 and identified ID/DD as a priority topic. The results of this environmental scan are intended to inform ASPE's data infrastructure development strategy that enables PCOR for the ID/DD population.

The environmental scan consisted of three activities: (1) a review of peer-reviewed and grey literature; (2) key informant interviews with seven ID/DD data and research experts; and (3) input from a technical expert panel (TEP) that represented HHS agencies, the Department of Education, and the Department of Labor.

These activities generated a list of 23 opportunities to improve the data infrastructure for ID/DD PCOR, and thereby enhance researchers' ability to conduct PCOR. These opportunities offer ways to improve the use of data to identify people with ID/DD and to measure social service and medical interventions, as well as person-centered outcomes. In this report, the discussion of opportunities is organized to reflect OS-PCORTF's five functionalities for building PCOR data capacity: (1) use of clinical data for research; (2) collection and use of participant-provided information; (3) linking of clinical and other data for research; (4) standardized collection of standardized clinical data; and (5) use of enhanced, publicly funded data systems for research.[1]

Use of Clinical Data for Research. The opportunities within this functionality involve standardizing and increasing collection of ID/DD-related data elements in electronic health records (EHRs) to improve the quality and availability of ID/DD data for research. This includes standardizing collection of ID/DD status at the point of care, and pilot testing use of existing terminology standards for ID/DD to determine feasibility and inform design of data collection and implementation specifications for documenting functional status and disability. Furthermore, structured and standardized clinical data create a strong foundation for future efforts to support data extraction, distributed queries, and aggregation of these data for PCOR; and facilitate increased clinical data use as a supplement to other data sources (e.g., administrative and national survey data).

Collection and Use of Participant-Provided Information. The opportunities aligned with this functionality focus on improving collection and use of participant-provided data. These data offer a complementary perspective to that of clinical assessments, by providing for a more holistic picture of a person's health and functional status. Improving use of these data for PCOR will require increased attention to existing tools and measures, and in particular their appropriateness for use within the ID/DD population. For example, opportunities exist to standardize quality of life measures for the ID/DD population, validate patient-reported outcome measures, and address gaps in standardized outcomes measures important to people with ID/DD. These opportunities build on previous and ongoing efforts to improve the standardized electronic capture of patient reported outcomes (PROs) and patient-generated health data.

Linking Clinical and Other Data for Research. Many of the existing data sets available to researchers have gaps in the information they provide on the ID/DD population. Only rarely does a single data set contain information to: (1) accurately identify the ID/DD study population; (2) measure and assess interventions at the person level; and (3) understand whether important outcomes have been achieved. Linked data sets, which greatly expand the types of questions researchers can investigate, are critical for conducting ID/DD PCOR. Opportunities to enhance data linkage capacity include use of unique identifiers across federal data sources, linking ID/DD data with the Transformed Medicaid Statistical Information System (T-MSIS) data, validating linkage algorithms, and developing data governance policies and privacy-preserving solutions to data sharing.

Standardized Collection of Standardized Data. Developing and applying standards can improve the uniformity and consistency of data for PCOR and clinical care. Opportunities in this functionality represent work to improve the quality of existing data sources, particularly Medicaid administrative data. For example, to maximize the value of T-MSIS data to study the effectiveness of interventions for those with ID/DD, state reporting efforts could focus on improving consistency and completeness of home and community-based services (HCBS) service codes that are captured that would support application of the Centers for Medicare & Medicaid Services (CMS) HCBS taxonomy for classifying HCBS services. Similar opportunities exist to improve the comparability of Medicaid data, for example, by standardizing the outcome definitions collected across state Medicaid programs that serve the ID/DD population.

Use of Enhanced Publicly Funded Data Systems for Research. State and federal agencies collect data to administer, monitor, and evaluate programs and to inform policymaking decisions. The agencies' data and data systems infrastructure are not always optimized to support their use for research and evidence generation. Thus, there are opportunities to improve the utility of existing state and federal data sets and systems by facilitating data retrieval, linkage, aggregation, and use. Additionally, increasing the number of states creating and using all-payer claims databases (APCD) offers the potential to address the limitations of current single-payer administrative data sources (e.g., Medicaid, Medicare, commercial payers). State-level incident surveillance systems also represent an underutilized source of outcomes data that have potential value for PCOR researchers, but these legacy systems will need updating to successfully export to linkable, research-ready data. Finally, ID/DD researchers have identified education data as a resource to support outcomes research. Assessing the feasibility of accessing these data and their fitness for use in research could yield additional opportunities for PCOR data infrastructure development.

Given ASPE's role as a facilitator of multi-agency partnerships and enabling PCOR data infrastructure, and the PCOR Trust Fund's reauthorization until 2029, the agency is poised to continue advancing PCOR data infrastructure in significant ways. Table 1 depicts the 11 opportunities prioritized by the TEP to inform ASPE's short- and long-term planning for ID/DD data infrastructure development.

Table 1. Short- and Long-term Opportunities for ID/DD Data Infrastructure Development

	Opportunities for Building Data Capacity, by OS-PCORTF Functionality
Short-term Opportunity (Address in 2-4 years)	**Use of Clinical Data for Research** • *Standardize the collection of ID/DD status at the point of care through development of standards and policy changes to require it.* Widespread collection will require support through the development and dissemination of provider resources for documenting patient functional and disability status consistently in the EHR. Additionally, capturing relevant elements related to intersectionality begins with consistent, accurate, and complete data collection of demographic data, which should align with federal priorities to improve demographic data collection. • *Testing the feasibility of using currently accepted terminology standards and implementation specifications to collect data on function and disability.* Such testing supports the refinement and maturation of functional status standards in LOINC and SNOMED, and the HL7® FHIR® US Core R.4.0–Functional Status implementation guide to increase widespread adoption.

	Opportunities for Building Data Capacity, by OS-PCORTF Functionality
	Collection and Use of Participant-Provided Information • *Standardize quality of life measures (QoL) for the ID/DD population.* To encourage consistent adoption of standardized QoL measures, person-centered outcomes researchers need to advance and align measures to increase the consistency in outcomes measured. Leveraging existing measure repositories[2] and selecting measures that have undergone cognitive and psychometric testing will be critical to ensuring their value. • *Support user-centered design and feasibility testing of digital technologies (e.g., smartphone apps, tablets, wearables, devices, etc.) for diagnostic and therapeutic purposes.* Ensuring the availability of these tools for use by the ID/DD population will entail inclusion of the target ID/DD population in research design and implementation. This will enable researchers to study the safe and effective use of these technologies, and the selection of technologies that meaningfully reflect the preferences, values, and abilities of people with ID/DD. • *Support ongoing efforts to improve the collection and documentation of social determinants of health (SDOH) data in the EHR using standard clinical terminologies.* Standard clinical terminologies (e.g., LOINC, SNOMED, ICD-10-CM Z codes) can improve use of SDOH data for research. Researchers should identify opportunities to select the most relevant SDOH data elements to the ID/DD populations (e.g., gainful employment). **Standardized Collection of Standardized Data** • *Work collaboratively with states to improve the utility of T-MSIS data for comparative effectiveness research (CER).* To maximize the value of T-MSIS data for CER on PCOR for the ID/DD population, state reporting efforts should focus on improving consistency and completeness of Home and Community Based Services codes.
Long-term Opportunity (Address in 5-10 years)	**Collection and Use of Participant-Provided Information** • *Address gaps in standardized outcomes measures important to individuals with ID/DD.* Person-centered research for ID/DD population would benefit from standardized definitions of person-centered outcomes such as community participation. Efforts to standardize the definitions and create psychometrically tested quality measures should include developing and testing standards for appropriate use of proxy reporting and for assessing its reliability and validity when used. **Linking Clinical and Other Data for Research** • *Support the development of a robust data linkages programs for T-MSIS data.* A data linkage program can enhance the value of the datasets that are linked by enabling the generation of new knowledge to answer questions and fill gaps that were not previously possible to answer. • *Support common data governance policies for creating easier access to relevant datasets, especially to perform linkages between state and federal datasets.* Developing clearly defined administrative pathways for researchers to receive data will broaden the number of people able to conduct relevant studies and accelerate knowledge generation. **Standardized Collection of Standardized Data** • *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.* State eligibility requirements vary for receipt of services offered through Medicaid 1915(c) HBCS waiver programs. Lack of common eligibility criteria for individuals with ID/DD limits comparability of participants and program outcomes across states. The development and dissemination of data dictionaries that provide consistent definitions for data elements would enable researchers to compare data across states, regardless of differing eligibility criteria.
Both Short- and Long-term Opportunity	**Collection and Use of Participant-Provided Information** • *Foster opportunities to validate PRO measures for the ID/DD population.* Efforts need to be devoted to supporting psychometric and cognitive testing of PRO measures to ensure their validity for use within the ID/DD population.

INTRODUCTION

Since 2010, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services' (HHS), has coordinated and overseen the Office of the Secretary–Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) portfolio of projects. This funding was authorized under the Patient Protection and Affordable Care Act[3] to develop data infrastructure resources, tools, and services that generate evidence to empower patients, caregivers, and clinicians to make better-informed health care decisions. The resulting portfolio of projects brings together agencies, divisions, and offices across HHS to collaborate on shared data infrastructure. Reauthorization of the PCOR Trust Fund (PCORTF) through 2029 expanded research priorities to include intellectual and developmental disabilities (ID/DD). The reauthorization notes that research related to ID/DD should reflect a balance between long- and short-term priorities.[4]

Definition of ID/DD

Intellectual disability (ID) is characterized by significant limitations in both intellectual functioning and in adaptive behavior that originate before age 22.[i] Developmental disability (DD) is a severe, chronic disability due to a mental or physical impairment originating before age 22. DD is likely to continue throughout the lifespan, results in substantial functional limitations in major life activities, and reflects an individual's need for a combination of services and supports.[ii]

i. American Association on Intellectual and Developmental Disabilities. Definition of Intellectual Disability. https://www.aaidd.org/intellectual-disability/definition.
ii. 106th U.S. Congress. (2000). Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106–402. https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf

People with ID/DD have a wide range of health concerns, as well as unique needs and preferences—making it important to understand how to provide supports and services that allow them to participate meaningfully in their communities. Furthermore, there is a need to conduct person-centric research that is specific to the ID/DD population and considers people's health and outcomes holistically, both within and outside health care settings. Person-centered research is a growing area of interest for which formal models of study are still emerging.[5] For the purposes of this report, patient-centeredness and person-centered are distinguished in the text but treated as closely aligned.

Over the past two decades, researchers and other stakeholders have increased their efforts to: (1) estimate the prevalence of people with ID/DD; (2) better assess their health status; (3) address health disparities; and (4) create programs to enhance the health, well-being, and community participation of people with ID/DD.[6, 7, 8] Federal and non-federal groups are collaborating to improve population-level health surveillance and data sources that can be used for ID/DD research. However, additional effort is required to ensure ID/DD PCOR data is readily available to PCOR researchers. By specifically prioritizing ID/DD, the PCORTF reauthorization provides necessary resources to increase the body of patient-centered research and evidence, which is crucial to help improve the overall health and well-being of people with ID/DD.

PCOR for ID/DD Population Explores Research Questions such as:

- What types of interventions are most helpful and appropriate for individuals with ID/DD?
- What individual characteristics may influence the effectiveness of programs or other interventions aimed at improving the lives of individuals with ID/DD?
- What are the comparative benefits and risks of one program type or intervention over another for individuals with ID/DD?

PCOR evidence is needed on multiple fronts, including the effectiveness of interventions that are broadly targeted to the ID/DD population and to people with specific ID/DD conditions such as autism. To enable this dual focus, PCOR data infrastructure must allow researchers to accurately identify the ID/DD population at these levels—i.e., broadly (e.g., by eligibility for ID/DD-related services) and among specific subpopulations (e.g., by diagnoses). Comparative effectiveness research (CER) is needed to understand treatment outcomes for people with ID/DD being treated for mental health

conditions—including pediatric, transitional age, and adults with mild-to moderate ID/DD-related impairment.[9] In addition, there is a need to increase research focused on health equity, transition to adulthood, caregiver needs and wraparound support, and understanding ID/DD patient preferences and needs.[10] Developing and expanding both the data and data infrastructure necessary to support ID/DD studies is critical to researchers' ability to address these questions.

Researchers must also be able to identify and measure interventions that are critical to optimizing person-centered outcomes across the lifespan of individuals with ID/DD, such as, medical interventions, long-term services and supports (LTSS), and home and community-based services (HCBS). Additionally, data infrastructure for ID/DD PCOR must enable researchers to measure outcomes of interest to the ID/DD community related to health and well-being, as well as important factors that explain differences in measured outcomes.

The findings in this report detail challenges and opportunities for ID/DD PCOR data infrastructure, and are intended to inform ASPE's efforts to identify OS-PCORTF investments to build data infrastructure for ID/DD PCOR.

METHODS

NORC conducted a literature review, key informant interviews (KIIs), and a technical expert panel (TEP) to characterize the current ID/DD research landscape, identify high value data sources that could support ID/DD PCOR research, and identify challenges and opportunities for ID/DD PCOR data infrastructure development.

Literature Review. The literature review focused on considerations for ID/DD research, including how ID/DD is defined, interventions and services for people with ID/DD, outcomes that stakeholders have identified as important, and priority research topics. The review covered peer-reviewed and grey literature, systematic reviews, and scoping reviews, as well as resources TEP members and key informants identified. NORC also reviewed data source compendiums and industry and federal reports to highlight select "high value" data sources and described how they can be leveraged for PCOR (i.e., identify population, interventions, outcomes). The data source review process and resulting list of high value data sources was not meant to be exhaustive, given other more extensive ID/DD data source compendiums that exist, but rather it provides a view into the types of data available for ID/DD PCOR. For this report, high value data sets are defined as data sets commonly used for ID/DD research that contain longitudinal person-level data—rather than aggregated data counts--have the potential to be linked to other data sets, and that ASPE has the ability to improve. In doing so, NORC highlighted: (1) the utility of, and gaps in, these data sources for use in PCOR, and (2) opportunities to expand data infrastructure.

Key Informant Interviews. NORC conducted key informant interviews with seven experts in ID/DD research to validate and expand upon the findings from the literature review. NORC in collaboration with ASPE selected key informants based on their expertise and unique perspectives on PCOR for the ID/DD population. NORC developed semi-structured KII guides focused on data needs related to the OS-PCORTF Data Infrastructure Strategic Framework's five functionalities:[11]

(1) Use of clinical data for research

(2) Standardized data collection

(3) Linking clinical data with other data

(4) Collection and use of participant-provided information

(5) Enhancing use of publicly funded data

NORC synthesized information from the KIIs to identify challenges and opportunities to improve data infrastructure for PCOR ID/DD.

Technical Expert Panel. The TEP was composed of eight experts who work on ID/DD initiatives, including from HHS, Department of Labor, and Department of Education.[a] To ensure our research was consistent with the priorities previously identified by people with ID/DD, the TEP included a PCORI principal investigator who led engagement research with persons with ID/DD and their family members and caregivers. The TEP convened three times and provided feedback on the key opportunities to enhance data infrastructure for ID/DD PCOR identified through the literature review and KIIs. The TEP also provided feedback on actions that ASPE and other federal partners could execute in the short and long term to develop ID/DD PCOR data infrastructure.

Limitations. NORC developed research questions that focused on identifying HHS data resources and data infrastructure, specifically searching for opportunities to build on existing federal assets to support PCOR. As a result, NORC sought out informants who represented policy, program, and research perspectives, and did not speak with advocacy organizations at this stage. The report is an initial inquiry intended to inform future efforts that will explore the identified opportunities in greater depth. These future efforts may include engagement with advocacy organizations.

Report Structure. Chapters 1, 2, and 3 of the Report explore three important areas to inform a future agenda for enhancing PCOR data infrastructure for ID/DD. Chapter 1 describes considerations for person-centered research for the ID/DD population, including the evolution of ID/DD policy and practice, definitions of ID/DD, interventions to support the ID/DD community, outcomes of interest to the ID/DD population, and priority research topics for the ID/DD community and stakeholders. Chapter 2 includes available data for PCOR and CER for the OS-PCORTF to consider enriching and/or supporting. Chapter 3 identifies ID/DD PCOR data infrastructure challenges and future opportunities to develop the infrastructure.

CHAPTER 1. CONSIDERATIONS FOR PERSON-CENTERED OUTCOMES RESEARCH FOR ID/DD

PCOR research for the ID/DD population is intended to generate evidence around the services, supports, and other interventions that can help improve health and well-being outcomes for individuals with ID/DD. As mentioned above, much of this research is *patient-centered*, meaning that it focuses on interactions in the health care context in which there is a patient-provider relationship, and the effects of a particular intervention are being studied. There is a corresponding need to conduct *person-centric* research that is specific to the ID/DD population and takes a holistic view of a person's health and outcomes. This chapter explores the interventions, outcomes, and opportunities to enhance person-centered care and research for people with ID/DD.

I. Evolution of ID/DD Policy and Practice and Implications for PCOR

Over the past 50 years, supports for people with ID/DD in the United States have evolved from the medical paradigm of primarily institutional, residential supports to programs that provide services and support in non-institutional, community settings. In the 1990s, as the federal government initiated the Medicaid Waiver program, funding increased for community-based services and support for families and other caregivers to take care of individuals with ID/DD at home and in community-based settings [12] .

HCBS programs generally include a wide range of LTSS provided in the home or community, typically delivered by state disability agencies. HCBS waivers can be administered by State Developmental Disability Services or State Medicaid programs. State HCBS waiver programs vary considerably in eligibility, benefit scope, and delivery systems.[23] Additionally, each state's administrative data system reflects the state's program design and service structure, which in turn leads to varying state level ID/DD data infrastructures.[13]

Alongside the shift toward community-based settings of care for people with ID/DD came a shift away from a medical model of care to emphasize holistic person-centered care. Person-centered care recognizes that people with disabilities should have the opportunity to make decisions that enable them to lead meaningful lives.[14] However, despite this shift, implementation of a person-centered model remains an area for improvement, as researchers and research partners with lived experience with ID/DD collectively work to better understand the quality of life (QoL) outcomes most important to individuals with ID/DD and their families.[15]

Three other major factors in the ecosystem have influenced the research agenda for the ID/DD population (further defined in subsequent sections of this report):

a) Improvements in screening and diagnostic tools have made it easier to identify individuals with ID/DD at younger ages, resulting in provision of early intervention services for children—often in school-based settings.
b) Individuals with ID/DD are living longer, which necessitates ID/DD research expansion to include aging, dementia, and aging-related comorbidities.
c) The heterogeneity of the ID/DD population in conditions, etiology, symptomology, and presentation requires the development of research priorities and interventions that ensure the unique needs of specific subpopulations are empirically documented and appropriately addressed.

II. How is ID/DD defined?

NORC uses the definition of ID from the American Association on Intellectual and Developmental Disabilities and the definition of DD from the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). NORC referenced two methods when describing how individuals with ID/DD are identified within data sources: (1) functional limitations captured by clinical assessments in electronic health records (EHR), and (2) diagnosis through diagnosis codes (e.g., ICD-10, ICD-9).

Functional limitations are often recorded in administrative data sets associated with service programs to identify individuals who may have ID/DD. Defining ID/DD using functional limitations generally has a high degree of sensitivity in identifying individuals with ID/DD but has limited specificity (i.e., may capture individuals with other conditions that also impact cognition and function, such as stroke and dementia). As explored in Chapter 2, using functional limitations to define and identify the ID/DD population involves substantial definitional heterogeneity.

Diagnoses captured through ICD-10 and ICD-9 codes are also used in EHRs and administrative claims for health care services. These codes capture the specific type of ID/DD an individual is diagnosed with, as well as any co-occurring clinical conditions. Some federal agencies, such as the Department of Education, use a combination of functional assessments and diagnostic conditions to define ID/DD. State eligibility criteria for HCBS waiver programs may also combine diagnoses with assessed functional limitations.

Estimating the population of people with ID/DD poses major challenges. There were an estimated 7.4 million people with ID/DD in the US in 2017;[16] however, more recent research suggests that prevalence in the general population is much higher. Recent research estimates over 6 million people in the US have Autism Spectrum Disorder, which is a sub-population within the broader ID/DD population.[17] The challenge of estimating the prevalence of ID/DD, among other issues, makes it difficult to plan services and interventions across multiple sectors, including child and youth services, social services, aging services, education and health services. [18] The lack of reliable prevalence estimates also stymies public health surveillance for the ID/DD population.[19]

III. Interventions of Interest for the ID/DD Population

People with ID/DD have diverse needs that evolve across their lifespan. Furthermore, those with ID/DD often contend with a myriad of co-occurring conditions that contribute to the complexity of the care they require. Such individuals typically rely on a wide range of services and supports. Person-centered research is urgently needed to build an evidence base for the relative effectiveness of these interventions—both clinical therapies and community-based supports. This chapter describes common services and supports that people with ID/DD receive. Chapter 2 describes the data sets that capture information on these interventions, which can be leveraged for PCOR.

Of the estimated 7.4 million people with ID/DD in the US in 2017, approximately 1.28 million received publicly funded LTSS from state developmental disabilities (DD) agencies.[20] These services are generally funded through Medicaid 1915(c) waiver HCBS programs, although a few states authorize provision of HCBS services through Section 1115 waivers.[21] States have great flexibility in the design and administration of HCBS waiver programs (within broad federal requirements), including the services offered and who is eligible to participate in the waiver program.[22]

Most state HCBS waivers use the same functional eligibility criteria required for institutional level of care, which generally include the extent of assistance needed to perform self-care and activities of daily living (ADLs) like getting dressed and meal preparation.[23] DD-specific waivers often have additional age and diagnostic criteria specific to DD with co-occurring ID required for eligibility.[24] Individuals with ID/DD who may benefit from receiving HCBS services but do not meet eligibility requirements are sometimes tracked via HCBS waitlists.

However, states' approaches for establishing HCBS waitlists also vary, with only some states requiring those placed on waitlists to meet all waiver eligibility criteria. A national study from 2017 estimated there are 182,000 people with ID/DD on HCBS waitlists.[25]

The common goal of all HCBS programs is to facilitate successful community living with support from community-based services. Additionally, federal Medicaid HCBS regulations require person-centered planning in the provision of these services. Although the specific services included in HCBS programs vary, researchers have developed a taxonomy of 17 common HCBS services offered across state programs.[26] Exhibit 1 depicts a national-level analysis of projected spending distribution across these 17 services (111 waivers from 46 states and the District of Columbia) as offered to individuals with ID/DD, using data from fiscal year 2015. The most common Medicaid HCBS-funded services are residential habilitation, day habilitation, and personal care services/supported living services to support individuals living in their own homes. Other important "wrap-around" services include employment support, transportation support, and care management support. Most acute care services are paid for by other health insurance payers (Medicare, Medicaid, private insurance). In fiscal year 2015, for example, less than 5% of the total projected spending of Medicaid HCBS waivers was allocated for traditional acute care services in fiscal year 2015.[27]

Exhibit 1. Fiscal Year 2015 Funding Distribution across 17 HCBS Service Categories

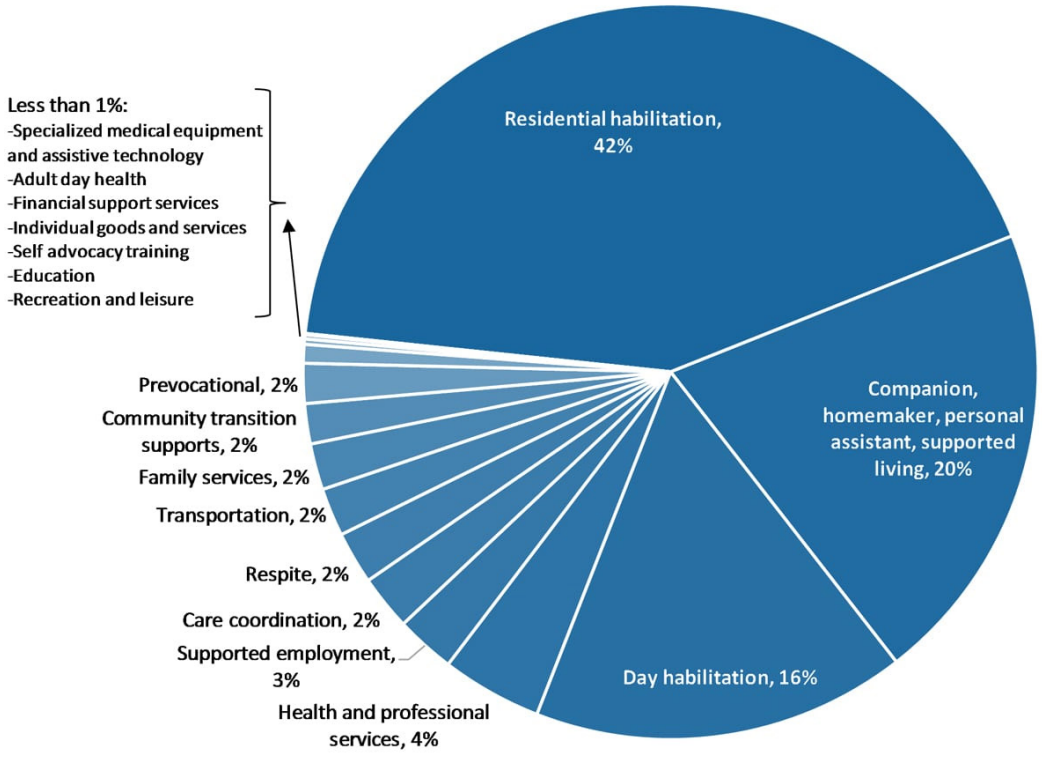


Image Source: Friedman, C. An In Depth Look at Medicaid HCBS Waivers for People with IDD. (2017). Available at: https://www.c-q-l.org/resources/articles/an-in-depth-look-at-medicaid-hcbs-waivers-for-people-with-idd/

Below is a description of the most common interventions offered through HCBS, and how they support the health and well-being of individuals with ID/DD.

Residential Habilitation, Day Habilitation, Personal Care Services, and Supported Living. Of the 1.3 million people with ID/DD who received services from state DD agencies in 2017, 60% lived with a family member, 23% in a group home or facility, 12% in their own home, and 5% with a host or foster family.[28] Residential habilitation refers to services offered in residential settings such as group homes, which promote community living for individuals with ID/DD by helping them to acquire, retain, or improve ADL skills. These skills include personal grooming, household chores, meal preparation, and social participation. Services are provided in accordance with an individual support plan (ISP) designed to help individuals achieve their personal goals for successfully living in the community. Day habilitation, personal care services, and supported living refer to a similar suite of services critical to the daily functioning of many individuals with ID/DD, which are offered to individuals living in their own homes or with families or caregivers.

Supported Employment Services and Vocational Training. Employment opportunities help adults with ID/DD earn a wage, receive employee benefits, facilitate social integration, and foster a sense of purpose and productivity. Many HCBS waiver programs fund employment services for adults with ID/DD—such as career planning, job placement support, and employment retention support (e.g., job coaching and self-advocacy training).[29] Integrating vocational training into the education system and vocational rehabilitation supports can also positively influence future employment prospects and maximize independence and self-advocacy among youth with ID/DD.[30]

Person-Centered Planning, Case Management, and Care Coordination Services. Care coordination services are key to helping individuals with ID/DD navigate the health care system, particularly since the population with ID/DD have a higher likelihood of having multiple chronic conditions, discussed in more detail later in the report. Case managers or care coordinators use a person-centered planning process to identify resources that address the needs and goals of people with ID/DD. Case managers and care coordinators also support service coordination, particularly integration of primary and behavioral health services given the high prevalence of co-occurring psychiatric disorders.[31]

Caregiver Supports. Caregiver supports are recognized as increasingly important, given that the majority of individuals with ID/DD live with a family caregiver,[32,33] and 60% of family caregivers provide more than 40 hours of support per week.[34] During the COVID-19 pandemic, caregiver support was especially important for individuals with ID/DD whose underlying health conditions, social circumstances, and in some cases limited abilities to communicate, made them especially vulnerable to infection.[35,36,37] Many adults with ID/DD lost their daily routines and structures, as well as access to community-based services outside the home—becoming, as a result, reliant on family caregivers for additional support.[38,39] Examples of caregiver supports funded through HCBS waiver programs include home-delivered meals, homemaker/chore services, caregiver counseling, and caregiver training.[40] The body of research focusing on quality of life for caregivers of individuals with ID/DD is growing, as is recognition that caregiver support interventions are associated with positive outcomes for caregivers—including better mental and physical health outcomes and reports of higher satisfaction and quality of life.[41]

Education Programs. As a result of the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973, free appropriate education must be made available to children and youth with ID/DD through public or charter school systems. Supports provided in school settings can support improved academic and social outcomes for students with ID/DD, particularly those related to communication skills, problematic behaviors, and independence.[42] IDEA Part B provides services to school-age children (3 to 21 years) who meet one or more of 13 disability eligibility categories (see text box). Part B describes how states must work with local education agencies to evaluate students for eligibility, and then use this assessment to develop individualized plans for specialized instruction, appropriate accommodations, and related services referred to as Individual Education Programs (IEPs).[43] In many cases, IEPs include Medicaid-covered services for children, such as physical and speech therapy.[44] Children who do not qualify for IDEA may still receive services through a 504 plan. Under Section 504 of the Rehabilitation Act of 1973, any child with a disability may receive a 504 plan if the child's disability interferes with their ability to learn in a general education classroom. The 504 plan addresses specific accommodations, supports, and services for the child.[45]

IDEA Part B Disability Eligibility Categories

A child evaluated as having one or more of the following:

1. Intellectual disability,
2. A hearing impairment (including deafness),
3. A speech or language impairment,
4. A visual impairment (including blindness),
5. A serious emotional disturbance,
6. An orthopedic impairment,
7. Autism,
8. Traumatic brain injury,
9. Any other health impairment,
10. A specific learning disability,
11. Deaf-blindness, or
12. Multiple disabilities,
13. Optional: Developmental delay (States may adopt developmental delay as a disability category for children aged three through nine or for a subset of that age range.)

Cognitive and Behavioral Therapy. For children with ID/DD, cognitive and behavioral therapy is largely provided in school settings. For adults, these services can be provided through Medicaid-funded HCBS waiver programs, many of which provide positive behavior supports to assist in developing adaptive skills and positive functioning. These services may include behavior support plans, counseling, therapy, and positive behavior training for support staff and family members.[46]

Special Olympics. Special Olympics is widely recognized by ID/DD researchers and advocates worldwide as an important program to support positive outcomes for children and adults with ID. Special Olympics provides research data sets and has its own portfolio of research on the impact of its programming on participants.[47] Special Olympics also provides year-round Olympic-type sports training and competition for children and adults with ID, as well as a variety of health, leadership, and community-building programs and grants. It also provides health programs and services to promote fitness, health, and wellness, and to provide inclusive health care.[48] The Special Olympics global network includes over 700,000 athletes with ID, 135,000 coaches, and 700,000 volunteers.[49]

PCOR and CER on these common and similar interventions would be of enormous value to researchers, policymakers, individuals with ID/DD, and those individuals' caregivers.

IV. Outcome Domains of Interest for the ID/DD Population

Services and support programs for individuals with ID/DD are designed to address domains of life that include education, employment, household care, daily living skills, community integration, and social inclusion. For these reasons, the outcomes that need to be assessed for this population must go beyond clinical outcomes, and be person-centered to reflect people's preferences, values and needs. This section describes the range of person-centered outcome domains researchers should consider in designing PCOR studies, drawing from the

following two organizations that have done considerable work in developing outcome measures or measurement frameworks for the ID/DD population.

The National Core Indicators (NCI) program is likely the most widely used set of performance and outcome measures for assessing public ID/DD service systems, with participation of 46 states and Washington, D.C. Table 2 displays the key subdomains of the NCI In-Person Survey and Family Survey, along with their respective value statements. The subdomain value statements provide a window into the person-centered nature of the outcomes captured through the survey.[50] The survey measures of the NCI Consumer survey were developed with involvement of key stakeholders from DD agencies and experts in outcomes research, data management, policy development, and program management. Extensive psychometric testing was also done to assure validity of all questions.[51] These four NCI survey domains and 20 sub-domains assess individual outcomes related to independence, relationships, health and wellness, access to services, and outcomes for families'/caregivers' experiences of services and supports.

Table 2. Key Domains and Subdomains of the National Core Indicators In-Person and Family Survey[52]

NCI Domains and Subdomains	Value Statement
Domain: Individual Outcomes	
Work	People have paid jobs in community-based settings or have otherwise, meaningful day activities.
Community inclusion, participation, and leisure	People participate in activities in their community and have opportunities to do things that they enjoy in the community.
Choice and decision-making	People make choices about their lives and are actively engaged in planning their services and supports.
Self-Direction	People participate in directing their own supports and services.
Relationship	People have friends and relationships and are able to maintain their friendships and relationships.
Satisfaction	People are satisfied with their everyday lives – where they live, work, and what they do during the day.
Domain: System Performance	
Service coordination	Service coordinators are accessible and responsive to people. The service plan is responsive to people's goals and needs. People participate in the service planning process.
Access	Services and supports of quality are readily available.
Domain: Health, Welfare & Rights	
Safety	People feel safe.
Health	People secure recommended health services.
Medications	Medications are used effectively and appropriately.
Wellness	People maintain healthy habits.
Respect/Rights	People receive the same respect and protections as others in the community.
Domain: Family Outcomes	
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Choice and Control	Families/family members with disabilities determine the services and supports they receive, and the individuals or agencies who provide them.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Community Connections	Families/family members use integrated community services and participate in everyday community activities.
Family Involvement	Families maintain connections with family members not living at home.
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
Family Outcomes	Individual and family supports make a positive difference in the lives of families.

In 2016, the National Quality Forum (NQF) published *Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement*. The report described characteristics of high-quality HCBS and a measurement framework for HCBS quality. Table 3 describes the 11 key domains the NQF report identified,[53] which address similar concepts to those included in the NCI domain value statements. These concepts relate to meaningful community and social participation, quality of life, autonomy in choices, protection of rights, and overall health and well-being of individuals with ID/DD. The NQF key domains also capture the experiences and perceptions of caregivers of individuals with ID/DD. The outcome domains of both the NCI and NQF frameworks include areas that are measured subjectively (e.g., feeling socially connected), which would ideally be assessed by directly asking the individual with ID/DD. NCI also includes outcomes that are objective and could be assessed by surveying caregivers or reviewing other program records (e.g., receipt of services).

Table 3. Key Domains for a Measurement Framework for HCBS Identified by the National Quality Forum[54]

Domain Name	Definition
Service Delivery and Effectiveness	The level to which services and supports are provided in a manner consistent with a person's needs, goals, preferences, and values that help the person achieve desired outcomes.
Person-Centered Planning and Coordination	An approach to assessment, planning, and coordination of services and supports that is focused on the individual's goals, needs, preferences, and values. The person directs the development of the plan, which describes the life they want to live in the community. Services and supports are coordinated across providers and systems to carry out the plan and ensure fidelity with the person's expressed goals, needs, preferences, and values.
Choice and Control	The level to which individuals who use HCBS, on their own or with support, make life choices, choose their services and supports, and control how those services and supports are delivered.
Community Inclusion	The level to which people who use HCBS are integrated into their communities and are socially connected, in accordance with personal preferences.
Caregiver Support	The level of support (e.g., financial, emotional, technical) available to and received by family caregivers or natural supports of individuals who use HCBS.
Workforce	The adequacy, availability, and appropriateness of the paid HCBS workforce.
Human and Legal Rights	The level to which the human and legal rights of individuals who use HCBS are promoted and protected.
Equity	The level to which HCBS are equitably available to all individuals who need long-term services and supports.
Holistic Health and Functioning	The extent to which all dimensions of holistic health are assessed and supported.
System Performance and Accountability	The extent to which the system operates efficiently, ethically, transparently, and effectively in achieving desired outcomes.
Consumer Leadership in System Development	The level to which individuals who use HCBS are well supported to actively participate in the design, implementation, and evaluation of the system at all levels.

The Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM), at the University of Minnesota, created a database of HCBS State Assessment Tools currently used by state agencies. This database can guide researchers and other stakeholders to programs, and their respective assessment tools and eligible age groups in states of interest.[55] The RTC/OM also hosts a repository of HCBS Outcomes Instruments with summary information on the instrument purpose, respondents, administration method and modes, instrument domains, etc. and publishes briefs on key issues in outcomes measurement.[56,57]

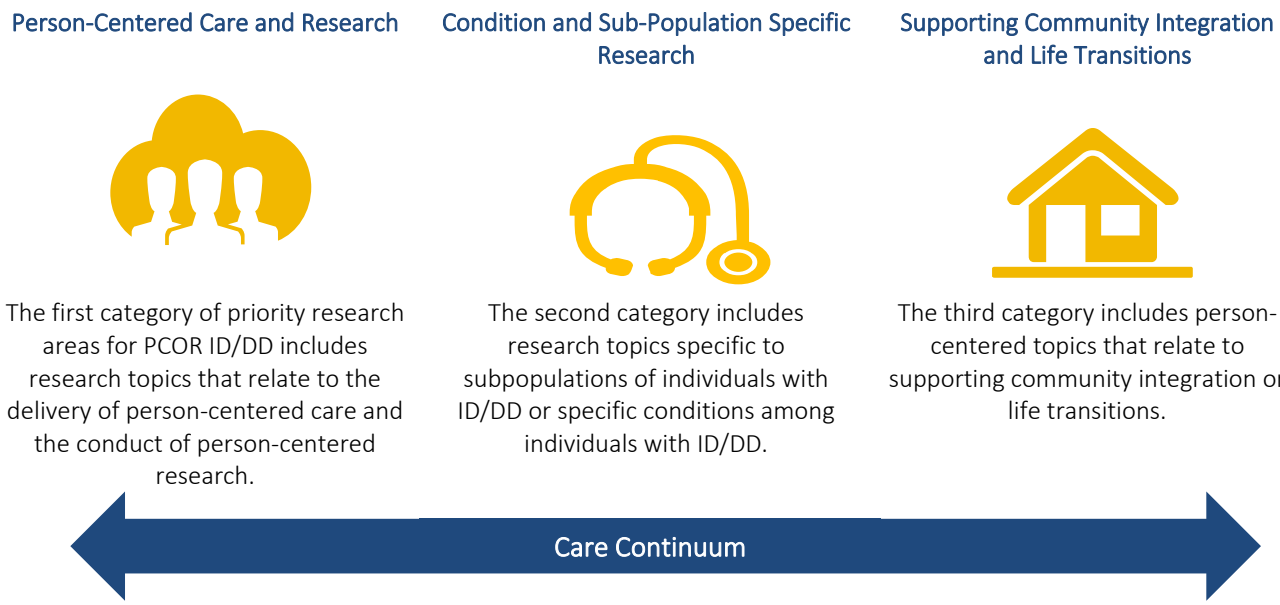
Another potential resource for researchers seeking information about tools, measures, and measure sets to assess quality of HCBS services is *Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services—Appendix III: Compendium of Measures and Tools*, a report published in 2010 by the Agency for Healthcare Research and Quality. This compendium captures tools and measures sponsored by the federal government—developed in academic and research settings, by associations or accrediting bodies, and developed and used by individual states. The compendium also evaluates the included measures across three broad categories: importance, scientific soundness, and feasibility.[58]

Providers and programs use various needs assessments and screening tools to assess individuals with ID/DD. In the context of PCOR, researchers can use these tools to measure important outcomes or covariates. Although there is no agreed-upon single assessment tool for the ID/DD population, the Supports Intensity Scale (SIS) is likely the most widely used. The SIS was developed by the American Association on Intellectual and Developmental Disabilities (AAIDD) to provide information to help care planning teams, disability service agencies, and other organizations understand the support needs of people with ID/DD. The SIS measures the supports required by an individual in 57 activities in home living, community living, life-long learning, employment, health and safety, social interaction, and protection and advocacy. It also measures support needs for 15 medical conditions and 13 behaviors commonly associated with ID/DD.[59] The Supports Intensity Scale–children's version (SIS-C) measures the relative intensity of support needs of children (ages 5 to 16) with ID/DD. Domains unique to the SIS-C include school participation and school learning.[60] Verdugo et al. conducted a systematic review in 2020 to analyze the rigor and usefulness of standardized tools for assessing support needs for people with ID/DD. Of the 86 studies reviewed, the SIS was the most frequent support needs assessment tool used. Other assessment tools identified for individuals with ID/DD included: instrument for classification and assessment of support needs (I-CAN), support needs questionnaire (SNQ), and service needs assessment profile (SNAP).[61] The American Academy of Pediatrics does not endorse use of any specific screening tool for children under age five but provides an interactive and searchable resource called the Screening Tool Finder, which provides access to a range of evidence-based screening resources.[62]

V. Research Priorities for the ID/DD Community and Stakeholders

This section describes priority research topics related to ID/DD, as identified through the literature review and KIIs and the research agendas of organizations that conduct or support ID/DD research (see Appendix B for research agenda analysis). Identified priorities are organized into three thematic categories (Exhibit 2). The first category includes research topics that relate to the delivery of person-centered care and the conduct of person-centered research. The second includes research topics specific to subpopulations of individuals with ID/DD or specific conditions among individuals with ID/DD. The final category includes topics that relate to supporting community integration or life transitions. Many of these research priorities are in line with national research priorities for the general U.S population; but others are specific to the ID/DD population.

Exhibit 2. Priority Research Areas for PCOR ID/DD



These research priorities span the care continuum from pre-medical care to medical care to post-medical care.[63]

1. Facilitating Person-Centered Care and Research

Person-centered care must incorporate a person's values and preferences. However, health care and service providers and researchers have traditionally encountered challenges engaging individuals with ID/DD —e.g., reasons include lack of training or experience communicating with individuals who have cognitive difficulties that impact recall, focus, and/or limited expressive language skills. Therefore, it is incumbent upon health professionals, care providers, and researchers to use the preferred method of communication of individuals with ID/DD (e.g., augmentative communication or picture exchange communication systems) so that their perspectives are respected and integrated into conversation. The following research topics relate to facilitating delivery of person-centered care and conduct of person-centered research.

Patient-Provider Communication Strategies and Supportive Technologies. In clinical settings, clear communication between patients and their providers is a necessary component to the delivery of person-centered care. The likelihood of communication difficulties and complex health and social factors faced by the ID/DD community requires increased effort to understand how best to support shared decision making between providers and individuals with ID/DD. Further, many providers do not understand how to communicate with individuals with ID/DD, often preferring to interact with their caregivers.[64] Technology, including health information technology (health IT), medical devices, wearables, and even mobile applications, provides an opportunity to enhance the social inclusion of individuals with ID/DD, including communication with their care providers. Research advancing the use of supportive technologies and effective patient-provider communication strategies could help individuals with ID/DD overcome the barriers they often face as they navigate the health care system.

Studies on Self-Direction. The aim of self-directed services within LTSS delivery, including some HCBS programs, is to ensure individuals with ID/DD retain control and independence over their care. Since the pandemic began, CMS has encouraged states to expand or adopt self-direction in its Appendix K: *Emergency Preparedness and Response Instructions for 1915(c) waivers*.[65] Self-direction enables people with ID/DD to decide where and with whom they want to live, what services they receive and who provides them, and whether to include friends and family supports to help them fully participate in community living.[66] The body of research around the factors associated with successful implementation of self-direction within state DD

programs is growing,[67] but additional research is needed to fully understand the outcomes for individuals who self-direct their care.[68]

Improving Person-Centered Research Methods and Including ID/DD Participants. Individuals with ID/DD are largely absent from participation in all phases and forms of mainstream health research. This makes it challenging and often inappropriate to translate research findings into practice for this population. Key informants agreed the research community must make efforts to include individuals with ID/DD in all phases of research (planning, conducting, and disseminating research), as well as all forms of research, including observational studies and experimental studies such as clinical trials.[69] In addition to increasing patient engagement in general, researchers need to consider strategies to support the participation of people with ID/DD specifically. Such strategies may include participatory research design, use of adaptive and accessible technologies for data collection, informed consent processes that support a range of health literacy and cognitive abilities,[70] and appropriate training of researchers on how to communicate and interact with individuals with ID/DD.[71] A number of research centers, such as the Nisonger Center at the Ohio State University, are investing in training researchers, including medical and graduate students, on how to conduct research with individuals with ID/DD.[72] Additionally, several active PCORI research projects are studying engagement strategies for people with ID/DD to improve communication and participation. [73,74]

2. Condition- and Subpopulation-Specific Research

People with ID/DD are more vulnerable to adverse health outcomes than individuals without ID/DD—making it critical to research better ways of supporting and providing care to the ID/DD population.

Managing Chronic Health Conditions. A plethora of research and programs are aimed at improving the quality of care and outcomes for people with multiple chronic health conditions. This field of research is especially critical for people with ID/DD, given that they have dramatically higher rates of chronic conditions than adults without disabilities.[75] Individuals with ID/DD also have higher rates of adverse health conditions in virtually every organ system,[76] and are at greater risk for hospitalization and placement in the intensive care unit.[77] Furthermore, as the population of people with ID/DD ages, researchers anticipate a substantial increase in the rates of chronic conditions and their relative impact on health.[78] A likely challenge contributing to greater adverse health outcomes and inadequate access to health services for individuals with ID/DD is the lack of widespread epidemiological and actuarial research regarding this population.[79]

Maternal Health. Disparities in maternal health is a recognized public health priority, but disparities among women with ID/DD may be overlooked when considering efforts to reduce health disparities and improve maternal health care generally. One study using data from the Nationwide Inpatient Sample of the Health Care and Cost Utilization Project estimated that 1 in 2530 deliveries were to women with ID/DD; [80] another found that women with ID/DD were significantly more likely to have preterm birth, low birth weight, and stillbirth than other women.[81] Further research and surveillance efforts are necessary to understand the causes of this disparity in care and outcomes differences and find solutions to address them. The CDC Pregnancy Risk Assessment Monitoring System (PRAMS) surveillance data described later in this report is a valuable source of data for maternal health research for the ID/DD population.

Health Disparities. Numerous published reports from multiple countries document significant health disparities for individuals with ID/DD. One literature review described a "cascade of disparities" for adults with ID/DD including: (1) higher rates of adverse health conditions, 2) less attention to care needs, 3) poorer preventive care and health promotion practices, and (4) inequitable access to health care, all of which can lead to poorer health outcomes. These disparities need to be better understood and addressed with strategies to improve data such as: increased health services research to better document disparities, improved health indicators (e.g., National Core Indicators), enhanced health surveillance, and mixed methods approaches.[82] Additional research is also needed on the intersection of race, ethnicity, and disability. Studies have shown that racial minorities

with ID/DD experience greater disparities in accessing health care, health care quality, and had worse health outcomes than white adults with ID/DD.[83,84] Finally, research that explores disparities in access to health care should also consider accessibility barriers within the built environment, particularly within health care facilities.[85]

Intervention Services for School Aged Children and Youth with ID/DD. Many young adults and children receive supports in school settings. The U.S. Department of Education reports that 7.3 million children (ages 3 to 21) receive special education services under IDEA, accounting for 14% of public school students.[86] However, little research explores the experience and impact of educational services for children and youth with ID/DD, and how services may be coordinated with other care providers.[87] Key informants mentioned that increased access to person-level education data and the ability to link education data to other data sets could contribute to greater understanding of how early intervention services and other supports in school settings can improve short- and long-term outcomes for children with ID/DD.

3. Community Integration, Life Transitions, and Aging

Research that supports meaningful participation in life and community are important to individuals with ID/DD at every stage of life. Four areas of research are critical to improving quality of life for people with ID/DD.

Community and Social inclusion. People with ID/DD experience higher rates of social isolation than people without disabilities. Their social networks are usually limited to family members and support professionals.[88,89] Loneliness for individuals with ID/DD has also begun to be closely examined. The National Core Indicators instrument, for example, includes a question about loneliness.[90] One systematic review investigating the prevalence of loneliness in people with ID/DD found an average loneliness prevalence of 44.7%[91]—over four times higher than the 10.5% prevalence of loneliness in the general population.[92]

Development of Communication, Motor, and Cognitive Skills. Speech, language, and hearing services, as well as physical and occupational therapy can improve the health, autonomy, and community participation of individuals with ID/DD.[93,94] Multiple key informants also noted the importance of assistive technology and adaptive equipment that improve gross motor skills and functional capabilities, and support the communication abilities of individuals with ID/DD. Research on the effectiveness of these services, technologies, equipment, and applications may help improve the daily lives of people with ID/DD.

Supporting Transitions to Adulthood. Additional research is critical to understand how to best support adolescents with disabilities transitioning to adulthood. The transitional phase is particularly challenging for individuals with ID/DD, as they are less likely to enter the workforce or enroll in post-secondary education compared to their peers without disabilities.[95] Children's Health Insurance Program (CHIP) eligibility requirements for children are usually different from the eligibility requirements adults must meet for Medicaid coverage, which results in some young adults losing coverage as they age out of CHIP. Youth transitioning to adulthood are generally assumed to begin taking responsibility for their own health care, but they are not always prepared, nor are their providers. One key informant noted that pediatricians may have specialized training related to providing care to the ID/DD population, unlike most adult care providers. Evidence-based provider education about caring for youth and young adults with ID/DD is a promising mechanism to support the transition of youth with ID/DD to adulthood. Notably, PCORI's recent call for research proposals related to mental health interventions for individuals with ID/DD highlights its particular interest in studies focused on pediatric and transition-age populations.[96,97]

Research Related to Aging. Service delivery systems must adapt to accommodate the growing number of older people with disabilities, particularly for family support services across the disability and aging networks.[98] People with ID/DD tend to experience age-related health outcomes (e.g., dementia) sooner and at a quicker progression than the general population;[99] yet little is known about how to promote healthy aging in this

population.[100] In an issue brief on aging among people with ID/DD, the AAIDD described a need for healthy aging research that supports interventions to prepare adults with ID/DD to reduce health risks by engaging in preventive health and health promotion behaviors. AAIDD calls for more research on age-related trajectories for specific conditions, such as the link between Down syndrome and co-occurring dementia to focus on the trajectory of an individual with this dual diagnosis. They also note that research on supporting people with ID/DD in their retirement, as well as preparation for end-of-life and palliative care, are necessary to support adults in this phase of life.[101]

CHAPTER 2. HIGH VALUE DATA FOR ID/DD PCOR

Given this report's goal of describing the types of data available to support PCOR and CER for the ID/DD population, NORC prioritized review of data sources around four criteria that align with this goal. These criteria are not mutually exclusive, but rather served as a guide to identify a subset of data sources to highlight within the vast data ecosystem:

- Longitudinal data sets that have person-level rather than aggregated data
- Common data sources used for ID/DD research
- Data sources that have potential or proven linkages to other data sources to facilitate broader-reaching ID/DD research
- Data sources that ASPE has the potential to improve, with special focus on federal and state data assets

Data sources that were identified are organized here into five broad categories: (1) federal survey efforts, (2) federal administrative data sets (Medicare, Medicaid, and SSA), (3) state administrative data sets, (4) longitudinal cohort studies, and (5) other large data sources. The data source review and resulting list of highlighted high value data sources was not meant to be exhaustive given the other more extensive ID/DD data source compendiums that exist, but rather provides a view into the types of data available for ID/DD PCOR.

For each data set, the discussion includes descriptions of the population, how individuals with ID/DD are identified in the data, key interventions and outcomes relevant to PCOR, and whether the data set has been linked to other data sets. Linkages to other data sets, either through a unique identifier or sufficient information to match patients across data sets, increase the value of data for PCOR researchers. Such linkages substantially expand the information available for PCOR and CER. Following each table are descriptions of emergent themes related to the data sets' utility and their limitations for conducting PCOR for the ID/DD population.

Beyond the five data set categories identified, several other data set types emerged from the literature and key informant interviews as potentially informative for PCOR if they could be successfully linked to health and other data—particularly in relation to other sectors of the economy (e.g., education, labor). It is important to note, however, that NORC's review did not cover assessing the feasibility of obtaining these data, capacity for data linkage with other data sources (including person-level data), or their research readiness.

I. Federal Survey Efforts

NORC identified several federal survey efforts with high potential for PCOR on ID/DD at the population level: Agency for Healthcare Research and Quality (AHRQ) data from the Medical Expenditure Panel Survey (MEPS); Census Bureau data from the Current Population Survey (CPS; co-sponsored by the Bureau of Labor Statistics), the Survey of Income and Program Participation (SIPP), and the American Community Survey (ACS); the Health Resources and Services Administration's (HRSA's) Maternal and Child Health Bureau National Survey of Children's Health; CMS' Medicare Current Beneficiary Survey (MCBS); and CDC's National Health Interview Survey (NHIS) and Pregnancy Risk Assessment Monitoring System (PRAMS). Table 4 highlights the data sources' main features followed by a discussion of their potential utility for PCOR.

Table 4. Federal Survey Efforts with High Value Data for PCOR

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
Agency for Healthcare Research and Quality (AHRQ)	Medical Expenditure Panel Survey (MEPS)[102]	A nationally representative, set of large-scale surveys of families, individuals, their medical providers and their employers; respondents are drawn from a sample of the National Health Interview Survey, annual	ACS 6-item functional assessment[103] Also includes questions that capture whether individuals have limitations in Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL)[104]	Cannot differentiate ID/DD from other conditions like dementia, stroke, and TBI. Also, cannot identify specific ID/DD diagnosis or severity.	Yes, linked to other federal survey data such as the NHIS; linked to administrative data such as Social Security Administration data, Medicare data, Medicaid data, and the National Death Index Have also been linked to other data to study the financial burden of health costs and expenditures of adults with ID/DD and families of children with autism[105] [106]
Census Bureau	American Community Survey (ACS)	Sample of U.S. households including children and adults, annual	ACS 6-item functional assessment Describes social, housing, education, and economic characteristics	Cannot differentiate ID/DD from other conditions like dementia, stroke, and TBI. Also, cannot identify specific ID/DD diagnosis or severity.	Yes, linked to other federal survey data such as the NHIS, CPS
	Survey of Income and Program Participation (SIPP)	Nationally representative, household-based continuous survey of U.S. individuals age 15 years and older, panel interviewed over 2.5 years to 4 years	ACS 6-item functional assessment 2008-2013 SIPP Social Security Administration Supplement included extensive disability and function modules, with separate items for adults and children; this supplement included items to identify adult sample members with ID/DD.[107] Assesses income, disability income, and program participation, employment status, food security, general health status, health-related costs.	Most years use the 6 disability items from the ACS, which cannot distinguish among ID/DD and other conditions Proxy response is permitted.	Yes, linked to other federal survey data such as the CPS; also, SSA administrative records

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
Census Bureau & Bureau of Labor Statistics	Current Population Survey (CPS)	U.S. individuals age 15 years of age or older; not in the Armed Forces, annual	ACS 6-item functional assessment	Cannot differentiate ID/DD from other conditions like dementia, stroke, and TBI. Also, cannot identify specific ID/DD diagnosis or severity.	Yes, linked to other federal survey data such as ACS and Community Expenditure Survey; SSA administrative records and CMS Medicare records
HRSA Maternal Child and Health Bureau	National Survey of Children's Health (NSCH)[b]	Cross-sectional, address-based survey of non-institutionalized children, annual	Physical and emotional health, factors related to child well-being (e.g., school experiences, family interactions), and presence of a DD or related diagnosis. The 2016-2017, and 2018 surveys contain the ACS 6-item functional assessment questions.[108]	Annual data are unavailable before 2016, limiting longitudinal study	No known linkages
CMS	Medicare Current Beneficiary Survey (MCBS)	A nationally representative sample of adults enrolled in Medicare, including those aged 65 and older and those aged 64 and younger with certain disabling conditions, annual	Includes data like demographics, expenditures and payments, health status and functioning over time, health behaviors, family characteristics, satisfaction with care.[c] The community health status questionnaire includes a question to identify ID/DD. Those who are Medicare eligible due to a disability are asked to specify diagnoses.	The public use files include all the same variables as the limited data set files, except those variables that could pose a disclosure risk such as dates, geographic location, and cost/payment data; they also exclude beneficiaries residing in institutional facilities.	Yes, linked to the Medicaid Analytic eXtract[109]

[b] HRSA National Survey of Children's Health integrates data from the National Survey of Children with Special Health Care Needs; the latter was fielded only three times between 2001 and 2010.

[c] CMS MCBS Survey data files include interview data augmented with limited Medicare FFS administrative data.

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
CDC	National Health Interview Survey (NHIS)	An in-person interview survey, with an adult and child questionnaire; conducted continuously -- each month's sample is nationally representative	Health status includes self-reported diagnoses, health care utilization, and health-related behaviors. Includes 6 disability questions[d] (Washington Group Short Set of Questions on Disability (WG-SS)) related to hearing, mobility, cognition, self-care, and communication using a severity scale instead of y/n; the child questionnaire asks about ID, ASD or "any other developmental delay diagnosis"[e] ACL and the National Center on Health Statistics is currently developing questions for inclusion in NHIS to better identify the population with ID/DD.[110]	Cannot differentiate ID/DD from other conditions like dementia, stroke, and TBI. Also, cannot identify specific ID/DD diagnosis or severity. The Washington Group Short Set (WG-SS) of disability questions is unique from the 6 questions used in Census Bureau surveys. The functional domains used in the WG-SS and ACS 6-item functional assessment are not mutually exclusive. Additionally, answer categories for ACS are dichotomous while WG-SS questions use an ordinal response scale. These differences may result in identification of different populations.[111]	Yes, NDI, Medicare enrollment and claims; SSA benefit history data; National Immunization Provider Records Check Survey; HUD administrative data[112], and crosswalk available to link to MEPS
	Behavioral Risk Factor Surveillance System (BRFSS)	A telephone-based survey of adults in all 50 states; sample is representative of each state's population, annual	Health conditions, health-related risk behaviors and use of preventive services. Includes two question sets related to disability: 5 questions from the ACS 6-item functional assessment, 2 questions that assess general activity limitation and use of special equipment.[113]	The two-question set may over-identify people; it is less accurate for people with transient conditions, mental illness, and sensory disorders. Cannot differentiate ID/DD from other conditions like dementia, stroke, and TBI. Also, cannot identify specific ID/DD diagnosis or severity. Data are age adjusted to facilitate state comparisons.	No, telephone number is the only unique identifier

[d] CDC National Health Interview Survey includes a six-question set to identify disability, drawing from the international standards known as the Washington Group Short Set (WG-SS).

[e] CDC is testing disability-related questions to add to NHIS 1: age of onset, learning, independent living; age of onset is being fielded in 2020; develop and test additional Identification questions to improve specificity of questions for identifying individuals with ID/DD.

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
CDC	Pregnancy Risk Assessment Monitoring System (PRAMS)	Sample of 1000-3000 women with recent live births drawn from 51 participating jurisdictions, annual	Includes 6-item Washington Group Short Set of Questions on Disability (WG-SS) functional assessment questions as of 2019. Births and maternal experiences before, during, and after pregnancy (e.g., prenatal care, health behaviors, breastfeeding).[114]	Disability data is unavailable prior to 2019. Cannot differentiate ID/DD from other conditions like dementia, stroke, and TBI. Also, cannot identify specific ID/DD diagnosis or severity. The Washington Group Short Set (WG-SS) of disability questions is unique from the 6 questions used in Census Bureau surveys.	Yes, Medicaid records, birth certificates, infant death certificates

Value of Federal Data Sources for Generating Data for ID/DD PCOR

One of the key merits of the federal surveys and data sources highlighted above is that they all have public use files available for multiple data years. Moreover, many have already been successfully linked to other sources, making them potentially linkable to additional data sets to study the ID/DD population. In particular, the CDC's NHIS has been extensively used for health research, with linkages to other data sources such as the National Death Index, Medicare enrollment and claims data, Social Security benefit data, and immunization records. These annual surveys collect data from adults, and in many cases children, representing a large swath of the population (although many exclude adults in institutions). For ID/DD populations, in addition to functional assessments of disability, several of the surveys solicit information on ID/DD diagnoses. In general, however, the sensitivity and reliability with which such surveys can identify the ID/DD population is lower than ideal, particularly in distinguishing between types of cognitive disability. Additionally, given the relatively small size of the ID/DD population, the sampling frame for most surveys does not generate a representative population sample. Further, many of the surveys use proxy response for respondents with ID/DD, often without documenting the procedure for when proxy response is accepted.

Questions Used to Identify ID/DD Population: The current questions included on most surveys do not allow for accurate identification of ID/DD separate from other conditions that involve cognitive limitations (e.g., stroke, TBI, dementia). For many years, surveys primarily included only a single question to demarcate the presence or absence of ID/DD or to specify a diagnosis, however, there has recently been a shift toward multi-question functional assessments. The NSCH and MCBS still rely on diagnosis-based reporting. But the ACS, BRFSS, CPS, SIPP, NHIS, PRAMS, and many other federal surveys use a combination of six questions to capture information related to disability and functional limitations;[115] yet, these six questions do not allow for accurate identification of ID/DD. For example, one study that compared disability prevalence rates from two data sources for adolescents with disabilities concluded that people with mental health and developmental disabilities are among those under-represented by the ACS disability questions.[116] Another study that compared the WG-SS measures to a binary impairment measure found that the WG-SS thresholds produce widely varying disability estimates.[117]

- The ACS, BRFSS, CPS, and SIPP use the same six yes/no questions about functional limitations related to (1) sight, (2) hearing, (3) mobility, (4) cognition, (5), self-care, and (6) independent living. These questions were developed for the ACS and have been adopted by the other surveys.[118]
- The NHIS and PRAMS use a different six question set known as the Washington Group Short Set (WG-SS), which uses a severity scale (rather than yes/no to presence of each disability) to assess: (1) sight, (2) hearing, (3) mobility, (4) cognition, (5) self-care, and (6) communication. The child questionnaire also includes questions about ID, autism spectrum disorder, and "other" developmental delays or diagnoses. These questions have undergone extensive cognitive testing with individuals with ID/DD to validate them for survey inclusion.[119] ACL and the National Center on Health Statistics is currently developing questions for inclusion in NHIS to better identify the population with ID/DD.
- The AAIDD National Health Surveillance Workgroup identified content gaps in national surveys and made recommendations for items to be added to the NHIS to identify people with ID/DD. The workgroup noted that, although the NHIS includes at least one item each related to self-care, communication, independent living skills, mobility, and economic self-sufficiency, it does not include items related to intellectual functioning, social skills, self-direction, age of onset, and expected duration of disability—all of which would increase the accuracy of ID/DD-related research.[120]

Key Outcomes Collected: Many of these federal health surveys include questions about demographics and disability status in conjunction with a variety of important health outcomes, social risk factors, and in some cases, payment and services data that provide a window into analyzing population health trends over time. These outcomes include, but are not limited to:

- Health status; health behaviors; health-related risk behaviors
- Physical and emotional health and well-being, including school and family experiences (for young children); family characteristics
- Healthcare utilization; expenditures; use of preventive services
- Access to care; experience of care; satisfaction with care

Limitations of the Data: In addition to a lack of high-quality ID/DD questions, researchers must take into consideration four other key limitations of these data sets when conducting research about ID/DD populations, as discussed below:[121]

Lack of a unique identifier can make data linkage more challenging, but not impossible. Data linkages can be achieved through patient matching techniques that map individually identifiable or associated variables (e.g., last name, address, date of birth) to each other and estimate the likelihood of an accurate match.[122] What is essential for many PCOR studies is the presence of person-level data that enable study of the effects of interventions on individual outcomes rather than aggregate population-level data.

Specificity and sensitivity of survey questions are a necessity for PCOR. The methods of some surveys do not allow for the disaggregation of the data to identify specific subpopulations of ID/DD. For example, questions related to cognitive limitations cannot differentiate from other conditions such as dementia, stroke, and traumatic brain injury.[123] Given the heterogeneity of the ID/DD population, data sets that do not accurately identify the ID/DD subpopulation have limited utility for outcomes research. Other research suggests two-item disability assessments have low sensitivity for transient issues, mental illness, and sensory disorders. [124] A balance must be struck between the need for inclusive questions that have a greater likelihood of eliciting an accurate response without undue burden on the respondent, versus the specificity and sensitivity needed to generate maximally useful PCOR data.

Proxy reporting versus self-reporting is a known validity issue because self-reports can differ considerably from proxy reports. There are differences in how an individual and a proxy assess and report a variety of factors based on their own perceptions; how well the proxy knows the individual also can affect response validity.[125] Often, proxies (including providers and parents) rate QoL for individuals with ID/DD lower, and based on different criteria, than the individual with ID/DD does when self-reporting QoL. This can have implications for the types of treatments physicians pursue, as many physicians are reluctant to pursue aggressive treatments for patients who they perceive to have low QoL.[126,127] Additionally, in many paper-based mail-in surveys, it is not always clear whether a respondent is the patient or a proxy; thus, the validity of a given response is unknown, as is the proportion of surveys completed by patients versus proxies.[128]

Representativeness of the population of interest presents a methodological challenge, due to mode of administration (phone, mail, in-person) and obstacles in reaching subsets of the ID/DD population. For example, the BRFSS survey is administered by random-digit telephone call, which can limit access to representative information on adults with ID/DD for two reasons. First, individuals with severe intellectual impairments typically do not answer the phone and, thus, will be excluded from the survey. Second, those with milder cognitive impairments may answer the telephone and respond to the survey but they are less likely to disclose disability status in response to BRFSS's only two disability screening questions, due to stigma or not recognizing the disability described as applying to them.[129] Landline-based surveys can further bias the sample by excluding institutionalized adults, people of low socio-economic status, homeless individuals, and people with only cellular phones.[130]

Address-based mailed surveys can limit respondent representativeness based on setting/living situation. For example, address-based surveys by their nature exclude homeless populations. In addition, not all address-based surveys include respondents in "housing units" or "group quarters" (e.g., jails, student housing, or nursing homes), limiting representation of people within certain demographic groups (age, income level, etc.).[131]

In-person interviewing is considered the most representative interviewing mode. The NHIS is regarded as the "gold standard," as it collects data in multiple phases including via face-to-face interviews.[132] The 2008–2013 SIPP exemplifies excellent comprehensiveness and granularity of the data collected. SIPP's extensive disability and function-related modules (collected 2008 to 2013) included 90 questions on health status, activity and functional limitations (ADLs and IADLs); presence of specific impairments and medical conditions; age of onset and duration; need for assistance; and conditions considered the primary reason for limitations. There were separate items for adults, children, and very young children. Unfortunately, data from these disability and function-related modules were only collected for a limited number of years.

II. Federal Administrative Data

Table 5 includes descriptions of federal administrative data with high potential for PCOR: CMS data from the Master Beneficiary Summary File (MBSF) and Transformed Medicaid Statistical Information System (T-MSIS); Social Security Administration (SSA) data from the SSA Disability Analysis File; the National Program of Cancer Registries (NPCR) from the CDC; and the Healthcare Cost and Utilization Project (HCUP) from AHRQ. NORC explored the potential for using federal education data for PCOR; however, they do not meet the project's criteria for person-level data as these data are reported in aggregate. Table 5 highlights the data sources' main features, followed by discussion of their potential utility for PCOR.

Table 5. Federal Administrative Data with High Value Data for PCOR

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
CMS	Master Beneficiary Summary File (MBSF)	Medicare beneficiaries, annual	Collects data on geographic information, demographics, and Medicare Part A/B/C/D enrollment status. The Chronic Conditions data file flags presence of one of 27 specific chronic conditions through ICD-9 and ICD-10 codes and the other conditions file expands this list to include developmental disorders, disability-related conditions, mental health, behavioral health, tobacco use, alcohol, and drug use.	Encounter and billing claims records are dependent on clinician identifying presence of an ID/DD and using the appropriate coding at the time of the encounter. Algorithms used to identify people with ID/DD in this data set are more limited in their ability to identify sub-populations.	Yes, Medicaid data and federal survey data including NHIS, CPS, and SIPP[133]
CMS	Transformed Medicaid Statistical Information System (T-MSIS)	Medicaid beneficiaries, annual	Four monthly T-MSIS Analytic Research Identifiable Files (TAF-RIF) types: inpatient hospital services, long-term care services, other services, and pharmacy claims. Claims related to intermediate care facility services for individuals with ID are contained in the Long-Term (LT) Care file. HCBS services codes are captured in the TAF Other Services File.	Key informants of this project have identified T-MSIS as a data source with a lot of potential; however, given that the data are only recently available, little has been published regarding use of T-MSIS for research for the ID/DD population.	Yes, Medicaid data and federal survey data including NHIS, CPS, and SIPP
SSA	SSA Disability Analysis File	SSA disability beneficiaries with disabilities who participated in the Supplemental Security Income or Social Security Disability Insurance programs, including children (annual)	These files contain data elements from several SSA administrative record systems including Disability Determination Service Processing File which includes the ICD-9 classification system codes for ID/DD. Disability Analysis File Restricted Access Files include benefits records including supplemental income, as well as wages, and earnings.	There are limitations of the source administrative data because these data are primarily used to determine eligibility and benefits – not for research purposes. These data are limited to information required for program administration.[134]	Yes, Medicaid data and federal survey data including NHIS, CPS, and SIPP

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
CDC	The National Program of Cancer Registries (NPCR) [135]	Includes cancer registries in 46 states and some U.S. territories, representing 97% of the U.S. population (including adult and pediatric), annual	Collects data on cancer occurrence, type of initial treatment and outcomes. People with ID/DD can be identified through linkage to Medicare data	The elderly and any diagnosis concurrent with higher incidence of cancer will be overrepresented. Together with the Surveillance, Epidemiology and End Results (SEER) program, this includes data for the entire U.S. population.	Yes, National Death Index, Medicare claims data, SEER data
AHRQ	Healthcare Cost and Utilization Project (HCUP)[136]	Includes a family of health care databases which collectively are the largest collection of longitudinal hospital data in the U.S., annual	Collects data on a range of health policy issues, including cost and quality of health services, access to health care, and outcomes of treatments at the state, national and local levels. It is possible that individuals with ID/DD would be identifiable through a diagnosis code, but it is not clear ID/DD would be identifiable through codes for episodic care.[137]	Only procedures and diagnoses that were important for payment are likely reported and chronic diagnoses are likely underreported. Only includes persons who were in a hospital, an ER, or had ambulatory surgery. The population included may have a poorer health status than the general population.	Yes, American Hospital Association (AHA) survey data[138]

Value of Federal Administrative Data Sources for Generating Data for ID/DD PCOR

The benefits of administrative data include: their broad scope, ability to identify populations with disabilities, availability for analysis, and linkability to other data sets. There are, however, three major limitations associated with all three methods used to identify the ID/DD population in administrative data: via diagnosis codes, eligibility information, and records of benefits received (rather than functional assessment of disability status), each of which is discussed further below.

Since 1973, Medicare has provided health insurance coverage for individuals under age 65 who receive Social Security Disability Insurance (SSDI) benefits. In 2016, individuals with disabilities made up 16% of the Medicare population.[139] Enrollment trends reported by CMS in 2019 showed that around 53% of beneficiaries eligible for both Medicare and Medicaid during 2012–2018 initially qualified for Medicare due to disability status.[140] Through the CMS Chronic Conditions Data Warehouse, researchers can access different Medicare data file segments—including the Master Beneficiary Summary File (MBSF), which includes geographic information, demographics, and Medicare Part A/B/C/D enrollment status; chronic conditions data; other chronic or potentially disabling conditions data; cost and use data; and the Geographic Variation Database.

T-MSIS is challenging to use, according to key informant interviews, because it is relatively new and has access requirements that include a data use agreement (DUA) with CMS and financial cost. Nonetheless, T-MSIS presents an important opportunity to analyze data of Medicaid beneficiaries at a national level. In contrast, research results from state Medicaid data analyses or state Medicaid data linked to other survey data are

limited in their generalizability to the national population of ID/DD individuals, because their samples of individuals with ID/DD are restricted to that state—and states have different definitions of ID/DD and different eligibility requirements for supportive services. Additionally, obtaining access to state Medicaid data for research can be challenging and analytic expertise often does not exist. Medicaid data also requires states to work together to develop comparable data.

T-MSIS aggregates state Medicaid administrative records and makes research-identifiable files for inpatient hospital services, long-term care services, other services, and pharmacy claims. Research-identifiable files are created by CMS and are accessible to organizations and researchers for research purposes.[141] CMS worked with states to improve the quality and completeness of T-MSIS throughout 2019 and 2020. CMS also publishes results of data quality assessments through Scorecards, so researchers can see the quality of the data they are using.[142] [143] Additionally, users can explore the quality and usability of Medicaid data in the T-MSIS Analytic Files for each state using DQ Atlas.[144] Even though key informant interviews identified T-MSIS as a data source with a lot of potential, given that the data have only recently become available, little has been published regarding T-MSIS use for research for the ID/DD population.

The SSA administers two programs for which individuals with ID/DD may qualify and receive benefits. The first is SSDI, through which individuals no longer able to work because of a physically or psychologically restrictive disability receive a monthly income benefit. The second is Supplemental Security Income (SSI), a needs-based program that provides financial support for aged, blind, and disabled adults and children with limited income and resources. The SSA Disability Analysis File (SSA DAF) is an analytical data file containing historical, longitudinal, and one-time data on beneficiaries. The data files include beneficiaries with disabilities ages 18 through retirement who participated in the SSI or SSDI programs between 1996 and the year of the file, as well as any SSI child beneficiaries who participated in the SSI program at any point from January 2005 to the file date.[145]

Questions Used to Identify the ID/DD Population: Unlike the previously described national surveys, which rely on functional assessments and self-report, the identification of the ID/DD population in administrative data is based on diagnosis codes (ICD-9, ICD-10-CM); service codes (e.g., for HCBS); and benefit records. These codes can be very useful, given their abundance in clinical and claims data; however, there are also drawbacks associated with diagnostic codes (versus functional assessments) in characterizing the ID/DD population. First, the codes themselves vary (ICD-10 is more granular than ICD-9 for ID/DD) and providers differ in how consistently they apply the codes; this creates substantial variation in the reliability of the data. Second, ID/DD diagnosis is not recorded during every encounter and may not have ever been recorded as a diagnosis for the patient, especially for individuals with mild ID/DD who do not report or do not present observable signs of ID/DD. Similarly, the reason for a visit is often unrelated to the disability, negating the relevance of including ID/DD codes for those encounters. Other drawbacks include many providers failing to ask about disabilities, and providers' tendency towards using codes that are reimbursable which may result in an incomplete picture of diagnoses and services. For those providers who discuss ID/DD with a patient, relevant information on functional status or limitations is likely to be captured only in free text encounter notes, adding detail to non-ID/DD diagnosis codes. Additionally, key informants noted that HCBS service codes are not always consistently recorded, and eligibility criteria information recorded for enrollment in HCBS waivers may not be comprehensive – states may capture the minimum amount of information necessary to enroll individuals into HCBS waivers. All these considerations can affect the quality of the data available to researchers conducting PCOR with diagnosis-coded secondary data.

Key Outcomes Collected: The MBSF, T-MSIS, SSA Disability Analysis File, NPCR, and HCUP include a wide scope of patient information. This includes demographic data, data on health conditions and healthcare services, and claims data related to intermediate care facility services for individuals with ID. When linked with other data, and even alone, these sources have abundant research uses. For example, linkages with MEPS data have been used to study service utilization,[146] access to care,[147] and experiences of care[148] for individuals with disabilities.

Other Limitations of the Data: As mentioned above, encounter and billing claims records are dependent on clinicians identifying the presence of an ID/DD and using the appropriate coding at the time of the encounter. While some coding is done by professional coders,[149] in many case coding is done by clinicians and in a haphazard manner.[150] Inconsistencies and/or inaccuracies in ID/DD coding at point of care occur for multiple reasons: the clinician does not correctly diagnose an ID/DD; the clinician does not correctly code it; or the clinician intentionally fails to code it due to fear of stigma.[151] In addition, the codes used in billing reflect the presenting clinical event that precipitated the encounter; if the presence of ID/DD was not relevant to the presenting clinical condition, the code related to ID/DD is unlikely to be captured in the encounter record. Algorithms can be used to review longitudinal claims records to identify individuals likely to have ID/DD, by taking into consideration the combination of clinical diagnoses and services received. But such algorithms can be limited in their ability to identify subpopulations.

III. State-Level Data Sources

NORC's review identified four state-level data sources with high value for PCOR (Table 6). State Medicaid data and all-payer claims database (APCD) both contain information on health and service utilization. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and the Community-Based Services (HCBS) Experience of Care Survey can be used voluntarily by states for to evaluate their HCBS programs, or as part of a value-based care programs evaluation. The Surveillance, Epidemiology and End Results (SEER) data source, an NIH/National Cancer Institute (NCI) registry, aggregates information from participating states regarding cancer incidence, prevalence, and mortality. The National Core Indicators is useful for assessing the quality and outcomes of Developmental Disability (DD) services provided to individuals with ID/DD and their families.

Table 6. State-level Data Sources with High Value Data for PCOR

Data Custodian	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
State Medicaid and DD Agencies	State Medicaid Data	Individuals receiving Medicaid services; individuals receiving services from state DD agencies	State Medicaid data include data related to: • Enrollment in waiver and other state disability programs • Eligibility criteria met • Demographics • Service utilization • Health Assessments	Social risk factor and health indicator data available in DD administrative data vary by state and in some cases, data may exist in older legacy systems (DOS), or even in archived paper records. Eligibility requirements vary by state. No common definition for capturing an ID/DD case is used across states. These data may underrepresent ID/DD populations, most of whom (~60%) do not receive services through their state DD agencies or HCBS.	Yes, linked to Medicare files (e.g., North Carolina) or linkages between DD agency and Medicaid data (Ohio) or other internal state data (California)[152]

Data Custodian	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
CMS	CAHPS HCBS Experience of Care Survey	Individuals who are frail and elderly, adults with disabilities, and individuals with ID/DD who use HCBS services (annual)	Includes three cognitive screening questions and nine questions to identify relevant HCBS services to probe on. Core questions include communication with providers and case managers, choice of services, medical transportation, community inclusion and empowerment, personal safety, and getting needed services.[153]	The annual survey is voluntary among state Medicaid programs.	Yes, claims data on Medicare and Medicare-Medicaid dually enrolled Beneficiaries; and the Medicare Health Outcomes Survey[154]
HSRI and NASDDDS	National Core Indicators	Individuals with ID/DD age 18 and over who receive support services from state DD agencies and their families (annual)	Performance and outcome measures to assess the quality and outcomes of Developmental Disability (DD) services provided to individuals with ID/DD and their families. Employment, rights, service planning, choice, health and safety, and community inclusion	Only individuals with ID/DD receiving state services are included and many states have different inclusion criteria.	Yes, a current ASPE project will link the National Core Indicators In-Person Survey, Supports Intensity Scale, Medicaid claims, and other relevant state-level data sources. Linked datasets have been established in research study at Virginia Commonwealth University[155]
States	All Payers Claims Databases	Individuals who have received health care services (medical, pharmacy, and dental claims) in the APCD states, funded by private or public insurance	State-level estimates for identifying ID/DD prevalence. The data support analysis and assessment of health care utilization by insurance type (public, private, dual enrollment), demographics, geography and can be used to identify health disparities.	Claims data may underrepresent the population with ID/DD. These data exclude the uninsured.	Yes, specific source depends on state APCD. For example, some states (e.g., Colorado, Maine) include identifying information in their APCD which allow for linkage[156]

Data Custodian	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
National Institutes of Health (NIH), National Cancer Institute (NCI)	Surveillance, Epidemiology and End Results (SEER)	People diagnosed with cancer during the year, follow-up data on all previously diagnosed patients until their deaths (annual) People who live in an area served by one of the 20 participating registries	Cancer incidence, prevalence, and survival; health status and functioning People with ID/DD can be identified through linkage to Medicare data	Proxies may be used for individuals with ID/DD. Inclusion criteria varies by participating registry. The elderly and any diagnosis concurrent with higher incidence of cancer will be overrepresented.	Yes, Medicare claims data, Medicare Health Outcomes Survey,[157] National Death Index, NPCR[158]

Value of State-Level Data Sources for Generating Data for ID/DD PCOR

The state-level administrative data (APCD, State Medicaid and DD agency data) lend themselves to population-level analyses. The inclusion of person-level, longitudinal data with identifiers in these datasets has allowed some states to link them with other data sources to complete the picture within that state. These datasets support analysis and assessment of health care utilization by insurance type, demographics, and geography, and can be used to identify health disparities. Given that these datasets are not based on program- or condition-specific samples, ID/DD research conducted with these data are more likely than CAHPS HCBS and SEER to be generalizable to the state ID/DD population.

The CAHPS HCBS Experience of Care Survey for Medicaid programs can be used voluntarily by states for their HCBS programs, or as part of value-based care programs. It is the first cross-disability survey of HCBS beneficiary experiences with long-term services and supports—with nine questions to identify HCBS services received that could be used to assess the relationship between outcomes and services.[159] HCBS waitlists can serve as possible sources of data for researchers looking to establish a control group of individuals with ID/DD who are eligible for but do not receive HCBS services, although this will vary by state given their varying approaches to establishing waitlists.

SEER encompasses multiple databases available for research, with extensive data on cancer incidence, prevalence, and longitudinal patient outcomes, as well as additional information on health status and functioning. While SEER does not collect ID/DD-related information, the extensive data it does collect—including Census-tract information and demographics—mean SEER data can be linked to other databases to identify ID/DD individuals. In addition, linkages between SEER and CAHPS, and SEER and the Medicare Health Outcomes Survey (MHOS) have been used to create databases whose data researchers can access by request.[160]

Questions Used to Identify ID/DD Population: State Medicaid and APCD datasets represent individuals who are receiving Medicaid and/or disability-related services. No common definition of ID/DD exists across states, however, and the states' widely varying eligibility criteria create heterogeneity in the population receiving services and the concomitant data. Likewise, the CAHPS HCBS Experience of Care Survey is designed for adults who use Medicaid HCBS services, including older adults and adults with disabilities, including ID/DD. The CAHPS HCBS uses three cognitive screening questions and nine questions related to specific services received and

addresses five disability populations including persons with ID/DD.[161,162] As noted, SEER can be linked to other data sets to study cancer in ID/DD individuals, but does not contain ID/DD-identifying data elements.

Key Outcomes Collected: The administrative data collected by state Medicaid agencies, the APCDs, and the HCBS include enrollment in waiver programs, eligibility criteria met, demographics, service utilization, health assessments, and social risk factors. The HCBS Experience of Care Survey employs a 69-item questionnaire intended to gauge individuals' experiences (not satisfaction) with HCBS.[163] SEER collects information on cancer incidence, prevalence, and survival, as well as health status and functioning over time.

Limitations of the Data: SEER is a robust data source; however, it has many of the same problems as other data sources in having reporting biases. For example, older adults and those with health conditions that lead to higher incidence of cancer are over-represented compared to the larger ID/DD population. In addition, SEER uses proxy responses and self-reported responses, which (as also noted) often result in different responses.

The National Core Indicators

The NCI is a voluntary program jointly coordinated and managed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The effort, which is primarily state funded, allows member state agencies to gather a standard set of performance and outcome measures to assess the quality and outcomes of DD services provided to individuals with ID/DD and their families. Washington, DC and 46 states participate, drawing random samples from their respective populations eligible for services. Data are available to participating states; the public, in the form of state-level reports and publications; and researchers by request.[164, 165]

Questions Used to Identify ID/DD Population: The NCI collects data from individuals with ID/DD ages 18 and older who receive support services from state DD agencies and their families based on state eligibility criteria.

Key Outcomes Collected: The NCI contains performance and outcome measures to assess the quality and outcomes of DD services for employment, rights, service planning, choice, health and safety, and community inclusion. Key informants noted that the methodology used for the Adult In-Person Survey results in higher validity and reliability than many other national surveys for two major reasons. First, the survey questions have gone through multiple rounds of review and validation testing, although not all have received inter-rater reliability scores.[166] Second, the surveys include in-person interviews with the adult with ID/DD for questions that require personal experiences, allowing proxy respondents for less personally sensitive questions.

Limitations of the Data: The NCI encompasses data only from a random sample of individuals receiving services, and the different eligibility criteria across states creates sample heterogeneity.[167] Also, the relatively small sample size limits the ability to focus on specific ID/DD subpopulations and issues.

Social risk factor and health indicator data available in administrative data sets from Medicaid and DD agencies vary widely state to state, which creates multiple issues for PCOR. First, the method required to identify people with ID/DD in claims data (ICD-9/ICD-10 codes) results in an underrepresentation of the population with ID/DD. This inaccuracy is worsened by the data sets' exclusion of the uninsured. Medicaid and HCBS eligibility requirements vary by state (as do definitions of ID/DD and data captured in case management records), creating variability that can make cross-state comparisons difficult. In some states, eligibility criteria can also result in individuals with ID/DD falling in and out of eligibility over their lifespan—for example, Medicaid eligibility in some states is based on both diagnosis and income, meaning that not every adult who becomes eligible for Medicaid based on ID/DD was eligible as a child, even if the diagnosis remained constant.[168] Given variation in state eligibility policies, estimates are that only a fraction of eligible children (anywhere from 15% to 67%) with special health care needs receive Medicaid/CHIP services state to state.[169] Finally, HCBS administration of CAHPS is voluntary among states, meaning the sample proportion of the ID/DD population varies by state However, the

HCBS can be administered using a combination of phone or face-to-face interviews, which is known to increase the validity of the responses gathered.[170] Research using data sets from Medicaid and commercial claims, with algorithms to identify the ID/DD population within those claims, are being explored as a strategy—to overcome the limitations of a single data set and help produce more accurate data on ID/DD prevalence within states.[171,172]

State-level Education Data

State-level education assessment data, including alternate assessment data, is a source of individual data about school-aged children. Although these data are only publicly reported in aggregate form, they may be extremely valuable for research activities since ID/DD are classifications that are included. Additionally, states all adhere to a common set of data specifications since states collect and submit these data in aggregate form to the Department of Education EDFACTS Data Collection.[173]

IV. Longitudinal Studies

Several federally funded, longitudinal studies produce data sets that may be useful for secondary analyses for ID/DD PCOR. Table 7 features three longitudinal studies with high potential for PCOR among people with ID/DD: the Traumatic Brain Injury Model Systems (TBIMS), which is the world's largest TBI longitudinal database[174]; the National Longitudinal Transition Study 2012 (NLTS 2012), which focuses on the understudied period of transition of children with ID/DD to adulthood; and the Longitudinal Health & Intellectual Disability Study (LHIDS), which focuses on health and function, health behaviors, and sociodemographic characteristics of adults with ID/DD.

Table 7. Longitudinal Studies with High Value Data for PCOR

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at the Administration for Community Living (ACL)	Traumatic Brain Injury Model Systems (TBIMS)	Individuals admitted for inpatient acute rehabilitation for traumatic brain injury who agree to participate in data collection	Demographics, pre-injury history, long-term medical outcomes including illness and mortality, long-term social outcomes, daily living outcomes, employment outcomes, degree of disability associated with TBI, and resources required	Data trend toward individuals with moderate to severe traumatic brain injury, given the inpatient acute rehabilitation setting.	No, but work is currently in progress to do so
U.S. Department of Education, National Center for Special Education Research (NCSER)	National Longitudinal Transition Study 2012 (NLTS 2012) (previous study is the NLTS-2)	Students receiving special education services in high school as they transition from high school to adulthood	Vocational, social, personal, and educational experiences of children receiving special education services as they transition to early adulthood	Children are 13 to 21 years of age when enrolled. Collection of school records data is currently underway. Phase II duration which includes administrative records collection is September 2015 to September 2022	No known linkages

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
Special Olympics International	Longitudinal Health & Intellectual Disability Study (LHIDS)	Adults with disabilities who take part in the Special Olympics and agree to participate in data collection for a five-year period	Prevalence of five health behaviors (physical activity, smoking, alcohol intake, dietary habits, and oral hygiene) and their impact on health and function; impact of musculoskeletal biomarkers across time on health and function; the impact of health behavior changes on psychosocial well-being and community participation	The survey is completed by primary caregivers and support staff rather than adults with ID/DD themselves.	No known linkages

Value of Longitudinal Data Sources for Generating Data for ID/DD PCOR

The data sources in this category encompass three distinct types of data and sources—one condition-specific resource (Traumatic Brain Injury), one from special education, and one from a subset of Special Olympics athletes. Their shared feature is that they contain longitudinal data specifically targeted to answer questions about health and other outcomes of ID/DD populations. While they have not been linked to other data sets, the data (available by formal request) has been used effectively in myriad research studies.

Questions Used to Identify ID/DD Population: All three data sets in this category are specific to the ID/DD population. As of December 2019, TBIMS had information on 17,317 individuals admitted for inpatient acute rehabilitation for traumatic brain injury, who fall into the category of having ID/DD based on age of injury. The database is representative of over 150,000 adults in the U.S. with severe TBI that requires hospitalization and inpatient rehabilitation. TBIMS includes data on individuals up to 30 years post-injury, so far.[175] NLTS 2012 includes a nationally representative sample of students ages 13 to 21 receiving special education services when Phase I of the study began in 2012-2013 from approximately 12,000 youth and their parents (10,000 of these students are with IEPs representing the federal disability categories). Phase II of NLTS 2012 will follow students in high school and beyond capturing information from school district records and postsecondary enrollment information (to be completed in 2022). Data will be linked to with the 2012-2013 survey data.[176]. LHIDS follows a cohort of 1700 to 2000 adults with disabilities over a five-year period.

Key Outcomes Collected: Data in the TBIMS database cover demographics, pre-injury history, long-term medical outcomes including illness and mortality, and long-term social outcomes—including depression and anxiety, community integration outcomes, daily living outcomes, employment outcomes, degree of disability associated with TBI, and resources required.[177] The students in the NLTS2 were followed to understand their vocational, social, personal, and educational experiences as they transitioned to early adulthood. The findings from this study are generalizable to the students in the study's age group who receive special education services in the U.S. for each of the disability categories in use for students in the NLTS2.[178] The LHIDS aims to understand the prevalence of five health behaviors (physical activity, smoking, alcohol intake, dietary habits, and oral hygiene) and their impact on health and function; the impact of baseline musculoskeletal biomarkers across time on health and function; and the impact of health behavior changes over time on psychosocial well-being and community participation for adults with ID.[179]

Limitations of the Data: The TBIMS is not fully representative of the TBI (or ID/DD) population, given that it is drawn from a sample of patients receiving treatment for acute brain injury who are therefore likely to have

moderate to severe cases of TBI and impairment. As for accessibility for PCOR, researchers can request access to the data by submitting a formal request, which is reviewed by the National Data and Statistical Center at the University of Washington and TBIMS Research Committee. If approved, a DUA is put in place giving researchers access to the data—but for only two years, after which re-approval is required.

The NLTS2, the study that preceded NLTS 2012, follows a limited cohort over a 10-year period. Children were 13 to 16 years of age when enrolled and 21 to 25 years of age at the time of final data collection in 2009. Their transition to adulthood was captured, but there is no follow-up data available to assess longer term health outcomes and access to services. The data collection ceased in 2009, and the years since then have brought increasing awareness of and specificity to different types of ID/DD.

The LHIDS captures data from a large cohort on a health behaviors and function but is limited because the study used proxies rather than self-reports.

An additional data source (not shown in the table because it is forthcoming) is the Environmental Influences on Child Health (ECHO) program developed by NIH, which includes longitudinal data to study the effects of environmental exposures on child health. Data for this longitudinal study may include developmental screening measures that would allow for identification of participants with DD.[180]

V. Other Large Data Sources

NORC identified an additional data source of high value for PCOR due to the availability of individual-level data for ID/DD research (Table 8): the Healthy Athletes System (HAS) from the Special Olympics, which is the largest data set on individuals with ID/DD in the US.

Table 8. Other Large Data Sources with High Value Data for PCOR

Agency Sponsor	Data Source	Population, Frequency	Variables of ID/DD and PCOR Interest	Key Limitations and Other Considerations	Current Linkages
The Special Olympics	Healthy Athletes System (HAS)	Individuals with ID/DD participating in the Special Olympics (annual)	Screening data on history of physical exam, vision/eye health, audiology, dentistry, prevention and nutrition, emotional health, physical therapy, and podiatry	Lack of unique identifiers challenges longitudinal tracking of individuals in the database and external data linkages. Data are not always collected consistently by volunteers. Data only includes information on athletes.	None; but opportunities exist to link with EHR and administrative data if sufficient PII is available for linkages.[181]

Value of Other Large Data Sources for Generating Data for ID/DD PCOR

The HAS include data on individuals with ID/DD and their families, with large sample sizes and wide scopes. These attributes give them high potential for linkage and high data specificity related to ID/DD services, satisfaction, and health outcomes.

The Healthy Athlete System

The HAS database has been developed jointly by the Special Olympics and CDC. It is the largest data set on people with ID in the country, improving researchers' ability to analyze the problem of health inequality.

Multiple key informants identified HAS as an important data source for understanding the physical and emotional health of individuals with ID/DD. [182, 183] These data are available to researchers by request and successful completion of an Institutional Review Board (IRB) review.

HAS uses screening data from across the Healthy Athletes disciplines (history of physical exam, vision/eye health, audiology, dentistry, prevention and nutrition, emotional health, physical therapy, and podiatry), which yields extensive screening and assessment data.

Limitations of the Data: HAS collects data only from Special Olympic athletes, which is recorded in person by volunteers who may not always collect it consistently. The assessments within each discipline have been refined over time, providing some longitudinal data reflecting similar outcomes across years, but with assessment questions for a given data point that may have changed over time and lack of unique identifiers that makes it difficult to follow athletes longitudinally. Thus far, HAS data has not been linked to external data sets, and the absence of unique identifiers makes such linkage difficult; however, depending on other data elements that are collected in HAS there could be potential to link to this dataset to facilitate PCOR.[184]

CHAPTER 3. CURRENT STATE OF DATA INFRASTRUCTURE AND FUTURE OPPORTUNITIES

The KIIs enabled NORC to explore the current state of data infrastructure for conducting PCOR specific to the ID/DD population, as well as opportunities to strengthen that infrastructure. The sections that follow summarize key challenges with the current state of data infrastructure for ID/DD PCOR and describe opportunities for its enhancement. The TEP reviewed and validated the list of opportunities and provided input on the top five priorities for both short-term and long-term action. Short-term opportunities are those the TEP members felt should be prioritized for action within the next 2 to 4 years; long-term opportunities are those TEP members felt should be prioritized for action within the next 5 to 10 years. Eleven total opportunities were identified by two or more TEP members as either short-term or long-term priorities; these are indicated in parenthesis at the end of the paragraph describing the opportunity. The remaining twelve opportunities were prioritized by fewer than two TEP members. The discussion is organized by the five functionalities from the OS-PCORTF Data Infrastructure Strategic Framework described earlier in the report.

I. Use of Clinical Data for Research

Clinical data stored in EHRs can be used to identify the study population, assess clinical treatments and interventions received, and measure health outcomes of interest. Clinical data are also a rich source for understanding and researching the progression of a person's clinical experience with an ID/DD condition. This includes, importantly, the study of co-occurring medical conditions, risks factors, and the "Fatal Five" outcomes (i.e., the top five conditions linked to preventable deaths in persons with ID/DD: aspiration, bowel obstruction, dehydration, seizures, and infection/sepsis).[185] Clinical data are also useful supplements to administrative claims data. In addition, clinical data enable researchers to further the study of health disparities by comparing outcomes among the ID/DD population with those of the general populations.

Challenges to Using Clinical Data for Research

Using clinical data for PCOR comes with five major challenges: (1) inconsistent collection of ID/DD status; (2) the limited use of standardized terminology to capture functional status and disability; (3) the use of unstructured data fields to capture ID/DD status; (4) limited availability of ID/DD status data in distributed research networks; and (5) resource intensive methods for extracting EHR data for research.

Challenge 1: Varying ID/DD Status Data Collection Practices. Diagnosis codes are the primary data elements used to identify the ID/DD population and clinical outcome(s) of interest within the EHR. However, ICD-10-CM codes for ID and DD are not captured consistently in the EHR. In the case of many patients, for example, an initial diagnosis may have occurred early in life, but not documented in subsequent encounters. Therefore, a longitudinal review of records is required to determine if a diagnosis of ID/DD is present. Additionally, the documentation of ID/DD is likely to be poor or fragmented for several reasons. First, milder forms of ID/DD less likely to be captured than the more serious cases. Second, many individuals do not disclose ID/DD diagnosis to all their treating providers due to stigma, leading providers to under-record ID/DD. Third, providers are particularly unlikely to ask if patients have ID, for example, when they are changing from one doctor to the next or are receiving care in emergency rooms or urgent care facilities.

Challenge 2: Limited Use of Standardized Terminology for Functional Status and Disability. The Office of the National Coordinator for Health Information Technology (ONC) Interoperability Standards Advisory has identified standards (LOINC, SNOMED) and implementation specifications (HL7® FHIR) for representing patient functional status and disability in the EHR.[186] However, the standards are not yet widely adopted, and the HL7 FHIR implementation specification for functional status is only just emerging and requires additional testing. Likely reasons for low adoption rates include EHR vendors not ready to adopt the standard, implementation guides with specifications that require additional testing, and health systems not prepared to capture the data.

Challenge 3: Resource-intensive Requirements to Using Unstructured EHR Data for PCOR. Standardized clinical data are an important data source for PCOR. However, because of the limited use of standard terminologies, important intervention and outcomes data are often documented as unstructured data in the EHR (e.g., free text provider notes). Converting this unstructured narrative data to research-ready data requires resource intensive (often manual) processes.

Challenge 4: Limited Availability of ID/DD Data in Distributed Research Networks. Distributed research networks offer a rich source of data to researchers to conduct PCOR and CER, through a shared data infrastructure of millions of patient clinical records of participating health care providers. The resulting networks can be queried to provide utilization and outcomes data on subpopulations of interest (e.g., specific ICD-10 codes) so researchers can conduct observational research. However, while functional status may be captured in the EHRs of participating clinical sites, these data elements may not be included in the research networks' common data models (CDMs), thus limiting the availability of these data.

Challenge 5: Difficulty Accessing Clinical Data from Disparate Data Sources for Research. Variable EHR capture of ID/DD data introduces challenges for researchers using multiple data sources, and for distributed research networks extracting and aggregating relevant clinical data from numerous clinical sites. For example, one study of people with autism spectrum disorder demonstrated that different EHR data query methods yielded substantially different results, depending on how diagnoses were entered in the record.[187]

Opportunities to Enhance ID/DD Clinical Data Capacity for PCOR

Findings from the literature review and key informant interviews indicated five major opportunities to improve the use of EHR data for research. Advancing the use of ID/DD data element standards will lay the foundation for future efforts to support data extraction and standardization, distributed queries, and data aggregation of EHR data for PCOR.

Opportunity 1: Standardize the Collection of ID/DD Status at the Point of Care. Supporting ID/DD status data collection requires: (1) increased awareness around the importance of documenting this information at the point of care; (2) capturing relevant elements for intersectional status (e.g., race, ethnicity, sex, sexual orientation); (3) workflow documentation and enhancements to ensure these data are recorded in the patient's medical record in a standard way; and (4) provider training resources, particularly among providers that care for the adult ID/DD population. These training resources should include guidance for asking about disability status in a respectful manner, and for documenting ICD-10-CM codes consistently. Use of standardized demographic data begins with consistent, accurate, and complete data collection, which should align with federal priorities to improve demographic data collection. Supporting the short-term goal of improving the use of standard clinical terminologies for functional and disability status requires a parallel focus on the standardized collection of ID/DD. Of note as of August 2021, CDC and ONC are working to identify priority data elements for potential inclusion in United States Core Data for Interoperability (USCDI) version 3, and these recommended elements could inform efforts to standardize collection at the point of care (Short Term).

Opportunity 2: Support the Pilot Testing and Use of Terminology Standards and Data Exchange Implementation Specifications for Functional Status and Disability. Pilot testing can support continued refinement and maturation of the function status standards (LOINC and SNOMED) and the HL7® FHIR® US Core R.4.0–Functional Status implementation guide to the point of widespread adoption. These functional status standards will improve the long-term, consistent collection of functional status and disability information in EHRs, interoperability of this information across settings, and availability of the data for research. Pilot testing was identified as a short-term opportunity given ongoing federal efforts through the 21st Century Cures Act emphasis on data interoperability (Short Term).

Opportunity 3: Develop and Pilot Natural Language Processing (NLP) Techniques to Extract Information from Narrative Text into Standard Coded Data for Surveillance and Research Purposes. NLP offers a solution for mining the clinical record, particularly for data that may not be consistently represented as standardized data elements. A promising application of NLP could be to mine free text fields (e.g., provider notes) where patient experiences of care are often documented. NLP can also help identify individual patients with ID/DD using EHR-captured genetic data captured (primarily applicable to the study of rare diseases).

Opportunity 4: Assess the Feasibility of Integrating ID/DD Data Elements into Existing CDMs (e.g., PCORnet, Observational Medical Outcomes Partnership ((OMOP) to Support PCOR. Harmonizing ID/DD data elements to a CDM would allow researchers to use EHR data more easily from multiple clinical sites to conduct both observation and clinical trials.

Opportunity 5: Develop and Test Standard Methods for Identifying and Extracting ID/DD Data from EHR and Administrative Claims Data Sets. Developing and piloting tools such as standardized data access queries and extract, transform, load (ETL) software to support standardized data abstraction to a CDM can increase the data available to researchers for CER.

II. Collection and Use of Participant-Provided Information

Patient-reported outcomes (PROs) offer a complementary perspective to that of clinician assessments, and may provide greater insights into health status, function, symptom burden, adherence, health behaviors, and QoL. Measures that assess individual experiences are important outcomes for ID/DD PCOR. Additionally, patient-provided information has been recognized as bolstering the collaborative nature of shared-decision making between people with ID/DD and their health care providers.

Awareness of the role of social determinants of health (SDOH) data in patient health outcomes, as well as the disproportionate effect SDOH have on different populations, is growing. SDOH data collection not only can lead to increased patient referrals to supportive services, but also can enable researchers to study population-level trends that have both health and cost implications.[188,189] Ongoing work to further standardize SDOH data elements (e.g., transportation, social isolation) will improve the quality of the data captured. And more consistent capture of self-reported SDOH using standard terminologies (e.g., LOINC, SNOMED, ICD-10-CM) will improve use of these data for research.

Challenges to Using Participant-Provided Information for Research

Several initiatives are ongoing to improve collection and use of PROs, patient-generated health data (PGDH),[190,191,192,193,194] and SDOH data.[195,196,197] Many of these initiatives focus on addressing challenges to the collection and use of these data across settings and populations. Within these broader challenges are challenges specific to the ID/DD population: (1) lack of standard QoL measures for those with ID/DD; (2) lack of validated PRO instruments for use within the ID/DD population; (3) gaps in outcome measures important to people with ID/DD; (4) few emergent fields of research and use of digital technologies for the ID/DD population; and (5) limited use of standard SDOH data elements in EHRs.

Challenge 6: Standard QoL Measures. A plethora of QoL measures and instruments are in use by researchers studying the ID/DD population. However, there is no consensus around which outcomes should be measured and which tools to use. Researchers often develop their own QoL measures on a study-by-study basis. Lack of common outcomes measures impedes researchers' ability to compare experiences of care across states or populations, which is essential to drawing reliable conclusions about the effectiveness of different interventions.

Challenge 7: Validated PRO Instruments. Given that the cognitive abilities of people with ID/DD vary greatly, researchers must consider this diversity when selecting a PRO instrument—especially measures that rely on attention span, working memory, long-term memory, judgment, and interpretation. Standardized PRO instruments for measuring person-centered physical, mental, and social health, such as PROMIS or NeuroQOL are currently validated for use by people with ID/DD. Using instruments that have not been validated for the ID/DD population is likely to reduce the reliability and validity of the data used to generate PCOR evidence for this population.

Challenge 8: Gaps in Outcome Measures. Many of the outcomes used in ID/DD research to date are limited to measuring the absence of negative outcomes (e.g., emergency department admissions, hospitalizations). Standardized definitions of person-centered outcomes (such as social relationships and sense of belonging) are required for effective PCOR.

Challenge 9: Emergent Study of the Use of Digital Technologies for PRO/PGHD Data Capture. Digital technologies used to collect PROs/PGHD, including remote monitoring devices and patient-focused health apps, are widely available. And there is promising research that digital technologies can be used by people with ID/DD to collect PROs and PGHD. However, existing literature and the KIIs warn that researchers must be careful to ensure that the use of digital tools mitigate, rather than worsen disparities (i.e., digital tools devoid of user-centered design principles may exacerbate existing health disparities, because the tools may be inaccessible or unusable among some people with ID/DD, due to disease burden, lack of access to technology, among similar obstacles).

Challenge 10: Collection of Standardized SDOH Data in EHRs. Historically, SDOH data are not routinely collected or documented using standardized terminologies (e.g., LOINC, SNOMED, ICD-10-CM) in the EHRs at point-of-care. Instead, they have been collected through a combination of screening tools and assessments, free text notes, and ad hoc solutions, limiting providers' and researchers' ability to use SDOH data to understand how social and environmental context affects an individual's health. This information is particularly relevant given that many services and supports for the population with ID/DD are provided in the home and/or community.

Opportunities to Improve Collection and Use of Participant-Provided Information for PCOR

Providing a holistic picture of a person's health and functional status requires improving collection and use of participant-provided data. The NORC study identified five opportunities to enhance data capacity for collecting and using these data, all of which build on previous and ongoing efforts to improve the standardized electronic capture of these data.

Opportunity 6: Standardize QoL Measures for the ID/DD Population. To encourage consistent adoption of standardized QoL measures, person-centered outcomes researchers need to advance and align measures to increase consistency in outcomes studied. Leveraging existing measure repositories[198] and selecting measures that have undergone cognitive and psychometric testing will be critical to ensuring their value. Disability research has already recognized the importance of disassociating the complex relationship between functional status and QoL when developing and validating these measures. Research into the use of standard QoL measures should continue to support these findings and build upon this seminal work to develop a functional-neutral measure of health-related QoL (Short Term).[199]

Opportunity 7: Foster Opportunities to Validate PRO Measures for the ID/DD Population. PRO measure development comprises well-established and rigorous methods for testing measure validity, including cognitive testing and validity studies. Efforts need to be devoted to supporting psychometric and cognitive testing of PRO measures to ensure their validity for use within the ID/DD population. Because of the availability of existing PROs, a limited number of which have been validated for the ID/DD population, this opportunity represents

longer-term enhancements. Ongoing work by an Administration for Community Living (ACL) subcommittee is conducting cognitive testing to evaluate new NHIS survey questions aimed at identifying the ID/DD population. Experts indicated this work could serve as a model for additional efforts to validate questions and instruments with people with ID/DD **(Short and Long Term)**.

Opportunity 8: **Address Gaps in Standardized Outcomes Measures Important to People with ID/DD.** Person-centered outcomes that would benefit from standardized definitions include community participation (e.g., social relationships, sense of belonging, self-determination). The DD Act highlights the importance of including people with DD and their families in the design of and participation in services and support that meet their needs.[200] Importantly, key informants emphasized a need for efforts to adapt existing data collection efforts to capture data directly from the patient, rather than relying so extensively on the use of proxy reporting, given the variability in responses between self-report and proxy report (e.g., QoL). Efforts to standardize these measures should include development of standards for assessing the reliability of proxy reporting, given the perception of the person with ID/DD may differ significantly from that of a proxy or clinician. Finally, engaging with both youth and adult populations with ID/DD will help to ensure measures developed for use at the federal, state, and local level are person-centered throughout the age spectrum. Novel research to refine and test emotional well-being concepts may offer insights for ID/DD researchers interested in extending this concept work to the ID/DD population. Additionally, several active PCORI research projects are studying engagement strategies for people with ID/DD to improve communication, which can inform future efforts to engage them in research to further identify measurable person-centered outcome measures.[201,202] As much of the work in this area is just beginning, and the development and validation of new measures is time and resource intensive, this opportunity will require incremental progress that will contribute to long-term advances **(Long Term)**.

Opportunity 9: **Support User-Centered Design and Pilot Testing of Digital Technologies (e.g., smartphone apps, tablets, wearables, devices,) for Diagnostic and Therapeutic Purposes.** Ensuring these tools can be available and used in meaningful ways by the ID/DD population entails: (1) inclusion of the target ID/DD population in research that studies the safety and effective use of these technologies, and importantly, (2) selection of digital technologies that meaningfully reflect patient preference, values, and abilities. Research and implementation efforts in these areas are now in the early stages. When a digital tool is being developed, studied, and brought to market, researchers should be careful to clearly communicate which populations these tools have been tested with, given the wide heterogeneity in the ID/DD population. One key informant suggested the potential of lessons learned from aging researchers who have tackled similar issues to inform these efforts. Given the priority placed on communication, use of digital technologies that facilitate communication is a specific area in need of research, which aligns with the charge of the Interagency Committee on Disability Research (ICRD). Authorized by the 1973 Rehabilitation Act, the ICDR promotes coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs—including programs related to assistive technology research, as well as research that incorporates the principles of universal design **(Short Term)**.[203]

Opportunity 10: **Support Ongoing Efforts to Improve the Collection and Documentation of Self-reported SDOH Data in EHRs Using Standard Clinical Terminologies.** Standard clinical terminologies (e.g., LOINC, SNOMED, ICD-10-CM Z codes) can improve use of SDOH data for research. Researchers should identify opportunities to identify which SDOH data elements are most relevant to the ID/DD populations (e.g., gainful employment). Initiatives such as the Gravity Project offer a model and opportunity for ID/DD researchers to engage in ongoing standardization efforts.[204] Additionally, the ACL Health Equity Road Map work group is developing and supporting implementation of a 10-year road map for ID/DD health surveillance. This roadmap will identify data gaps on disparities in health and access and utilization of health care, of which collection of SDOH data is critical. Given the extensive work in this area, investments focused on exploring which SDOH data elements to prioritize for ID/DD research is a short-term opportunity **(Short Term)**.

III. Linking Clinical and Other Data for Research

Data set linkages, which greatly expand the types of analyses researchers can conduct, are critical for conducting person-centered outcomes research for the heterogeneous ID/DD population, which covers varying conditions, etiology, severity of functional limitations, and services and supports they receive. Many of the existing data sets available to researchers interested in conducting PCOR for the ID/DD population have gaps in the information they provide. It is rare that a single data set contains information to: (1) accurately identify the ID/DD study population; (2) measure and assess interventions at the person level; and (3) capture outcomes of importance. Researchers often need to combine data sets to get the full picture of a particular individual's experience. For example, Medicaid claims data for adults with ID/DD who used HCBS services, NCI data, and data from the Supports Intensity Scale are being linked to study the association between Medicaid expenditures and health outcomes.[205] Now that this study has demonstrated that this type of data linkage is feasible, future studies should focus on scaling these data linkages, especially for longitudinal study. The OS-PCORTF is addressing this need through the Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person Centered Outcomes Research pilot project, which expands this work through creation of publicly accessible, de-identified, linked data sets for up to six states. This linked data set will enable researchers to analyze relationships, socio-demographic information, need for home and community-based services, service utilization, service expenditures, and person-centered outcomes prior to and during the COVID-19 pandemic for people with ID/DD[206]—filling an important information gap about the relationship between individual and service characteristics, outcomes, and Medicaid ID/DD service expenditures.

Challenges to Linking Clinical and Other Data for Research

Use of data from multiple data sources for PCOR can be enhanced by addressing the following common challenges researchers encounter in linking disparate sources: (1) dearth of high-value data sets linked to T-MSIS data; (2) low adoption of validated linking algorithms; (3) limited use of unique identifiers across high-value data sets; (4) lack of resources that identify the fitness-of-use of various high-value data sets for linkage; (5) limited ability to link condition-specific registries with EHR data; and (6) lack of common data governance polices for requesting access to linked state and federal data sets.

Challenge 11: Dearth of High-Value National Data Sets Linked to T-MSIS Data. Most linkages with Medicaid data have occurred at the state level. These linked data sets are often performed for study-specific purposes, which can be valuable for state program planning, but create siloes with limited reusability for other researchers.

Challenge 12: Adoption of Validated Linking Algorithms. Many states lack the data analytic capacity to support linking of their state program administrative data. States' record-matching capacity is generally limited, as are policies that support such linkages.

Challenge 13: Limited Use of Unique Identifiers across High-Value Data Sets. Unique identifiers are a key data element for linking data from multiple sources. But many of the high-value data sources for ID/DD PCOR, as well as for other populations, do not use common identifiers. Even public agencies (e.g., NIH), may not use common identifiers across their data sets. Without common identifiers, researchers must use more complex linking methodologies to combine these data sets, which inevitably results in some data loss.

Challenge 14: Lack of Resources that Identify the Fitness-of-Use of Various High-Value Data Sets for Linkage. Researchers often lack information to assess the overall quality and fitness-of-use of data elements and variables (e.g., race or other demographics) across federal or state data sets, even those that are commonly linked. Data quality information is needed to enable researchers to make informed decisions about which data sets among those with the same or similar data elements are the best for data linkage. Including quality information in updates to existing ID/DD data compendiums would be valuable in this respect.

Challenge 15: Limited Ability to Link Condition-specific Registries with EHR Data. A wealth of ID/DD condition-specific registries exist that are designed for research purposes, making them a potentially valuable untapped resource for studying health outcomes in people with ID/DD. Administrative and survey data sets can be leveraged to identify the overall population of people with ID/DD; but clinical registries are needed to study specific sub-populations or conditions within the ID/DD spectrum. Registry use is limited, however, in that they are usually stand-alone systems that neither are linked with other sources of patient outcomes nor incorporate data extracted from clinical records.

Challenge 16: Confusing and Difficult to Navigate Data Access Policies. Putting in place appropriate consent protections and data use agreements to access and link data for research can be difficult. Furthermore, several informants described challenges, both real and perceived, to accessing education records due to the Family Educational Rights and Privacy Act (FERPA). A limited understanding of the laws and regulations that govern access to education records may be discourage researchers' use of existing ID/DD data. In response to the ambiguity, variability, and confusion around state and federal laws governing secondary use of data for research, ONC commissioned the development of a legal and ethical framework to guide PCOR researchers. The framework describes key laws researchers should be aware of, ethical considerations, and different research scenarios in which these laws and considerations apply.[207] This is particularly relevant to ID/DD research conducted on subpopulations with diminished capacity to consent to study participation or release of health information.

Opportunities to Support Data Linkages

Many linkage efforts are occurring at the state-level, which often involve partnerships between universities and state agencies. These linkages represent emerging work in the field of ID/DD research. This work demonstrates the value of linked data sets, precisely because they allow for identification of the ID/DD population, the interventions, and the outcomes—each critical for PCOR, however informants noted that many states still lack the data-analytic capacity to support linking their state program administrative data. Increasing state capacity to perform data linkages could be enhanced through: (1) developing standardized tools for conducting linkages, and (2) policies that support data linkage and record matching.

Opportunity 11: Support Development of a Robust Data Linkage Program for T-MSIS Data. A data linkage program can enhance the value of T-MSIS data by making linkages between T-MSIS data and other federal administrative and population-based surveys. Claims data available through T-MSIS are a valuable data source for studying utilization and certain outcomes of Medicaid-funded services and supports, including HCBS. Linkages between T-MSIS data and other federal data assets can enable researchers to examine other factors that impact outcomes important to patients. These linked data sets should be accessible to researchers with appropriate access requests. The following federal data assets were identified as high priority for linking T-MSIS data to:

- Social Security Administration benefit records (e.g., SSI, SSDI)
- National Health Interview Survey
- National Health and Nutrition Examination Survey
- Medical Expenditure Panel Survey
- Survey of Income and Program Participation
- American Community Survey

The expansive nature of such an endeavor makes development of a data linkage program a long-term investment opportunity. In preparation, short-term investment can be pursued to initiate such a data linkage program, including strategic planning activities and data capacity assessments (Long Term).

Opportunity 12: Promote Testing and Use of Validated Linking Algorithms. States' capacity to perform data linkages could be enhanced through development and dissemination of privacy-preserving data linkage algorithms. Given that some states rely on state-university partnerships to enhance their analytic capacity, dissemination of validated algorithms through the State-University Partnership Learning Network (SUPLN) could be a promising avenue to support cross-state efforts.

Opportunity 13: Promote Use of Unique Identifiers within State and Federal Data Sets to Facilitate Data Linkages for Research. Global Unique Identifiers (GUIDs) are a type of unique identifier that requires a coordinated approach to ensure consistent adoption. Informants indicated a need at the federal level to fill this role of coordinator across agencies to harmonize existing GUIDs. At the state-level, data access and linkage would be improved by efforts to ensure data interoperability across state sources (e.g., Medicaid, DD agency data). Opportunities might exist to use an HHS master patient index number to support enterprise data warehouse/system approaches; or to consider methodologies for privacy-preserving linkages.

Opportunity 14: Develop and Pilot Test Data Exchange Standards for Bi-directional Exchange and Linkage between EHRs and Condition-specific Registries. Registries could be enhanced through linkages to clinical data, which would give researchers more comprehensive understanding of long-term outcomes (e.g., co-occurring conditions, chronic conditions, the "Fatal Five" conditions).

Opportunity 15: Develop Resources that Enable Researchers to Understand the Quality and Fitness-for-Use of Different Data Sets that Can Be Linked for ID/DD Research. Researchers would benefit from resources such as "data quality report cards" that can help them determine which data set will provide the most accurate and appropriate information for their research needs. For example, one data source may provide a more reliable source of race/ethnicity data than another; and some data sets provide more timely information on health care utilization than others (e.g., emergency department visits captured in hospital claims versus incident management systems).

Opportunity 16: Support Common Data Governance Policies for Accessing Data to Perform Linkages between State and Federal Data Assets. It can be challenging to put in place the DUAs and proposals appropriate for researcher access. Developing clearly defined administrative pathways for researchers to request data access would help facilitate more efficient data access, in particular access to Department of Education data and better understanding of the permitted disclosures of personally identifiable information under FERPA. Coordination with the Department of Education could also facilitate access, with consent, to student records. Given the breadth of such an inter-governmental effort, development of supportive data access policies is a long-term opportunity (Long Term).

IV. Standardized Collection of Standardized Data

Using standard data collection processes and well-specified data terms and elements supports more efficient data use, access and exchange, aggregation, analysis, and linkage. Differences across states—in both the administration of the programs that serve the ID/DD population, and the data systems those programs use—result in downstream challenges with data variability and lack of standardization. As noted, two of the most commonly cited challenges to using administrative data for ID/DD and other research—from public and private health plan data to education data—are lack of standardized definitions for identifying people with ID/DD and varying definitions and eligibility criteria across state DD and Section 1915(c) programs, in addition to education services offered under the IDEA.

CMS is in the process of implementing a taxonomy of HCBS services to create a common description of ID/DD services. [208] This taxonomy will address some of the challenges described above regarding varying service and eligibility definitions, as well as improve the standardization of state-reported data. CMS also intends to

integrate the HCBS taxonomy into its electronic system for HCBS waiver applications, which will make waiver applications, claims data, and waiver expenditures more consistently identified across HCBS.

Challenges to the Standardized Collection of Standardized Data

Gaps in data standards pose three major challenges to data availability for PCOR: (1) lack of standard ID/DD service definitions; (2) lack of standard outcomes definitions across Medicaid programs serving the ID/DD population; (3) lack of standard "caseness" definitions across state Medicaid agencies; and (4) inaccurate cause of death coding.

Challenge 17: Lack of Standard State Medicaid ID/DD Service Definitions. Programs that provide supports and services for people with ID/DD are generally funded through Medicaid HCBS waiver programs. T-MSIS data represent a critical national-level data asset for studying health care utilization and HCBS. However, T-MIS data comparability across Medicaid data is hampered by state differences in the Medicaid-provided services to people with ID/DD.

Challenge 18: Lack of Standard Case Definitions ("Caseness"). State eligibility requirements vary for receipt of services offered through Medicaid Section 1915(c) HBCS waiver programs, as do state eligibility criteria for children's special education services offered under the IDEA. Lack of common eligibility criteria for people with ID/DD limits comparability of participants and program outcomes across states, with commensurate limits on researchers' ability to determine whether research findings from state data are generalizable to the broader population of people with ID/DD. Additionally, as one informant noted, not all states conduct a comprehensive assessment to determine Medicaid eligibility. Some states, instead, use only the initial eligibility criteria applicable to beneficiaries irrespective of any health or other condition. This lack of specificity, in turn, limits researchers' ability to use Medicaid data to identify and study subgroups of the Medicaid population.

Challenge 19: Lack of Standard Outcome Definitions for Incident Reporting Systems. Just as CMS requires HCBS 1915(c) waiver programs to provide assurances around abuse, neglect, and exploitation, similar reporting structures and standard definitions exist across states for these outcomes. However, other types of incidents (e.g., planned versus unplanned hospitalization) are less standardized. Absence of consistent definitions creates barriers to both the interoperability and comparability of these data.

Challenge 20: Inaccurate Death Record Data. Mortality data are an important outcome in PCOR. However, within the ID/DD population, inaccuracies in how the underlying cause of death is coded can obscure identification of preventable causes of death. Among the U.S. population, 20 percent of decedents with ID,[209] and 21 percent of decedents with Down syndrome,[210] had their disability coded as their underlying cause of death, for example, which effectively hides the direct causes of death for many in these groups.

Opportunities to Standardize the Collection of Standardized Data

Developing and applying standards can greatly improve the uniformity and consistency of data for research and clinical care. The following four opportunities represent work to improve the quality of existing data sources, particularly *Medicaid* administrative data.

Opportunity 17: Work Collaboratively with States to Improve the Utility of T-MSIS Data for Comparative Effectiveness Research. To maximize the value of T-MSIS data for CER on PCOR for the ID/DD population, state reporting efforts could focus on improving consistency and completeness of HCBS service codes that are captured which would support application of the CMS HCBS taxonomy for classifying HCBS services. Adoption of that taxonomy will address the challenges described above regarding variability in service and eligibility definitions, improve standardization of state-reported data, and make it easier to assess state-level variation in HCBS service types.[211] Ongoing efforts to improve data reporting at the state level could be considered for

inclusion in T-MSIS data quality continuous improvement efforts. Given the availability of an existing taxonomy, this work represents a short-term opportunity **(Short Term)**.

Opportunity 18: **Work with States to Develop and Implement a Standard Definition of ID/DD Caseness across States.** Multiple informants identified a need to develop and disseminate data dictionaries that provide consistent definitions for data elements that would enable comparisons across data sets. This includes recording all eligibility data fields—particularly fields that capture diagnostic codes for ID/DD people enrolled in HCBS programs.

Opportunity 19: **Support and Provide Guidance to States around Standardizing Outcomes Definitions Collected across Medicaid Programs Serving the ID/DD Population.** State incident reporting systems offer one data source for studying health outcomes for people with ID/DD. While definitions across states for some outcomes are standard, opportunities exist to standardize definitions for other outcomes (e.g., whether to report an emergency department visit that did not result in hospitalization) across state Medicaid agencies. This opportunity spans a spectrum of outcomes that includes neurodevelopmental, clinical, QoL, and health care utilization outcomes—particularly in state DD and HCBS data. Given the level of coordination needed to attain consensus for standardized outcome definitions across states, this work represents a long-term opportunity **(Long Term)**.

Opportunity 20: **Coordinate with CDC to Propose Updated Guidance for Coding Cause of Death for Individuals with ID/DD.** Working with states to disseminate guidance for, and uptake of, coding ID/DD on the death certificate as a condition *present* at the time of death, rather than miscoding ID/DD as the underlying cause of death would greatly improve the validity of mortality data for people with ID/DD. Improvements in cause of death coding, as noted, would also promote the study of preventable death (i.e., the Fatal Five).

V. Use of Enhanced Publicly Funded Data Systems for Research

State and federal agencies collect data to administer, monitor, and evaluate programs and to inform policymaking. However, these data and the data systems that support these programmatic functions are not always optimized to support their use to generate new evidence. Enhanced funding for this functionality would enhance these federal data sets and systems for research by facilitating data retrieval, linkage, aggregation, and use. This section ends Chapter 3 by describing needs and opportunities to enhance these publicly funded data systems.

Challenges to Using Publicly Funded Data Systems for Research

Use of administrative data can be improved by addressing the following three challenges: (1) limitations to single sources of health plan data; (2) varying levels of state incident surveillance system capabilities; and (3) the availability of person-level special education data.

Challenge 21: **Limitations to Single Sources of Health Plan Data.** ID/DD research relies frequently on convenience samples of service recipients.[212] Studies using these data may not capture a representative sample, limiting their generalizability. APCDs offer the potential to address the limitations of current single-payer administrative data sources (e.g., Medicaid, Medicare, commercial payers alone). However, APCDs are not yet widespread.

Challenge 22: **Varying Levels of State Incident Surveillance System Capabilities.** State Developmental Disability reporting systems vary in their sophistication, with some states retrofitting legacy systems and others still referring to paper records to retrieve archived data.

Challenge 23: Availability of Person-Level Education Data. State and federal education data represent a significant segment of the services and supports provided to children and youth with ID/DD. At the federal level, IDEA ensures special education and related services (i.e., early intervention) are available. Multiple informants stated that linkages between education data and clinical data would be extremely helpful for studying outcomes, with one informant describing these potential linkages as the "Holy Grail" for PCOR in ID/DD. It is becoming increasingly clear that the most meaningful outcomes of medical interventions for children are educational outcomes, but there is no way to link the data on, for example, early childhood, special education, regular education, health, and school health services. These data are only available currently at the aggregate level, limiting their utility to conduct longitudinal studies directly linking receipt of a specific service to a specific outcome.

Opportunities to Enhance the Use Publicly Funded Data Systems for Research

Findings from the literature review and KIIs point to three opportunities to enhance the capabilities of publicly-funded data systems—all of which will require involvement from multiple stakeholders, and some of which is already under way.

Opportunity 21: Support Federal Efforts to Promote the Use of All-Payer Claims Databases (APCDs) to Conduct PCOR. Using data from multiple payers improves researchers' ability to identify the ID/DD population, and to provide a more complete picture of the health care services rendered. Twenty-three states have existing or planned APCDs.[f] Given the significant stakeholder commitment and the supporting policy frameworks necessary to implement APCDs, universal APCD coverage across the U.S. will require a long-term resource commitment.

Opportunity 22: Support Efforts to Modernize States' Incident Surveillance Systems. Since CMS requires 1915(c) programs to provide assurances around abuse, neglect, and exploitation, there are similar reporting structures and standard definitions across states for these outcomes. However, the reporting systems themselves vary in their sophistication, with some states lacking electronic reporting. For example, one informant described interest in assessing the quality of states' incident surveillance systems by using other data sources, such as emergency department visits and Medicaid claims data, to validate the reporting. Modernizing these systems is a long-term goal that will increase the availability of these important outcomes data for assessing the effectiveness of HCBS interventions.

Opportunity 23: Make Person-level Education Data Available to Researchers. Access to person-level education data would provide researchers with opportunities to understand how service provision in educational settings can support positive outcomes for youth with ID/DD. Additionally, privacy-preserving linkage of education data to other data sets would provide a fuller picture of the experience of children with ID/DD. Given the priority ID/DD researchers place on accessing education data to support outcomes research, this represents a potential short-term opportunity around which planning activities can begin. The National Center for Education Statistics Common Core Data Project to link state education data and Census data represents early work in the field that could serve as a model for future projects and feasibility assessments of person-level linkages.

[f] APCD (All-Payer Claims Database) Council, Interactive State Report Map, accessed June 4, 2021.

CONCLUSION

The Report identified 23 opportunities for HHS to expand PCOR data infrastructure for people with ID/DD to improve person-centered research. Across the 23 opportunities identified, five overarching themes are identified:

- Data that identify the ID/DD population more consistently and in a more granular (i.e., more detailed individual-level data) manner is a priority.
- Potential data linkages offer a promising approach given PCOR requirement for richer and more complex sources of data.
- Interoperability challenges apply to research with the ID/DD population, as with other research areas.
- Next steps are likely to result in incremental progress on availability of these data for PCOR.
- Major opportunities are longer term and require multiple stakeholder involvement.

A summary of the short- and long-term opportunities is presented in Table 9.

Table 9. Short- and Long-term Opportunities for ID/DD Data Infrastructure Development

	Opportunity for Building Data Capacity, by OS-PCORTF Functionality
Short-term Opportunity (Address in 2-4 years)	**Collection and Use of Clinical Data for Research** • *Standardize the collection of ID/DD status at the point of care through development of standards and policy change to require it.* • *Testing the feasibility of using currently accepted terminology standards and implementation specifications to collect data on function and disability.* **Use of Participant-Provided Information** • *Standardize quality of life measures (QoL) for the ID/DD population.* • *Support user-centered design and feasibility testing of digital technologies (e.g., smartphone apps, tablets, wearables, devices, etc.) for diagnostic and therapeutic purposes.* • *Support ongoing efforts to improve the collection and documentation of social determinants of health (SDOH) data in the EHR using standard clinical terminologies.* **Standardized Collection of Standardized Data** • *Work collaboratively with states to improve the utility of T-MSIS data for comparative effectiveness research (CER).*
Long-term Opportunity (Address in 5-10 years)	**Collection and Use of Participant-Provided Information** • *Address gaps in standardized outcomes measures important to individuals with ID/DD.* **Linking Clinical and Other Data for Research** • *Support the development of a robust data linkages programs for T-MSIS data.* • *Support common data governance policies for creating easier access to relevant datasets, especially to perform linkages between state and federal datasets.* **Standardized Collection of Standardized Data** • *Offer support to states to facilitate capture of granular data and develop clear data dictionaries to support application of a standard definition of ID/DD across state data*
Both Short- and Long- term Opportunity	**Collection and Use of Participant-Provided Information** • *Foster opportunities to validate PRO measures for the ID/DD population.*

Given ASPE's role in facilitating multi-agency collaboration and enabling PCOR data infrastructure—and that the findings in this report encompass a diverse body of potential work—ASPE is well poised to leverage these

findings related to ID/DD PCOR data infrastructure gaps and opportunities. The next phases of work for ASPE will center around: (1) prioritization, (2) strategic planning, and (3) engaging partners to inform future decisions on OS-PCORTF investment.

Within each data infrastructure functionality, projects already conducted by OS-PCORTF awardees have contributed numerous technical solutions to shared data infrastructure that benefit multiple agencies and support multiple data strategies—which demonstrates the impact ID/DD-targeted investments could make. In addition, opportunities exist to continue to support inter-agency cooperation as PCOR work on ID/DD expands. For example, increasing access to and interoperability of HHS data, expanding CDMs to include ID/DD data, investing in data linkages that link and enrich ID/DD data sources, and/or pilot testing and implementing ID/DD-related data standards would make significant contributions to the volume of ID/DD data available for PCOR, its research readiness, and ease of access.

NORC's work has identified strategic opportunities for PCOR data infrastructure (Appendix D), as well as data sources (Tables 4-8), ID/DD stakeholders and their research priorities (Appendix B), other compendiums of ID/DD data (Appendix C), and multiple HHS workgroups and initiatives convening around ID/DD data efforts (Appendix E). Together, these resources provide ASPE with a strategic view and ground-level information as to the needs and activities under way on behalf of ID/DD-focused research. Raising awareness of these findings among federal partners, engaging in conversations with partners, and facilitating discussions of HHS-level strategy as part of the active workgroups, are all areas in which ASPE could meaningfully contribute to expand ID/DD PCOR data infrastructure.

Since 2010, ASPE has managed the OS-PCORTF, providing inter-agency funding for projects that advance the data infrastructure needed for PCOR. Given the shared interest among federal agencies in ID/DD research and the recognized need to improve, expand, and enrich its data sources, these findings highlight OS-PCORTF opportunities and HHS-level opportunities across the five PCOR data infrastructure functionalities: (1) use of clinical data for research; (2) collection and use of participant-provided information; (3) linking clinical and other data; (4) standardized collection of standardized data; (5) use of publicly funded data sources. Within these categories, this report identifies nearly two dozen opportunities to develop ID/DD-related PCOR data infrastructure—where ASPE and partners could individually and collectively pursue their strategic priorities for improving the data available for ID/DD research, as well as the evidence base that supports health decision-making, and ultimately the health outcomes of the large, diverse, and underserved ID/DD population.

APPENDIX A. GLOSSARY OF ABBREVIATIONS

Acronym	Description
AAIDD	American Association on Intellectual and Developmental Disabilities
ACL	Administration for Community Living
ACS	American Community Survey
ADL	Activities of Daily Living
AHRQ	Agency for Healthcare Research and Quality
APCD	All-Payer Claims Database
ASPE	Office of the Assistant Secretary for Planning and Evaluation
BRFSS	Behavioral Risk Factor Surveillance System
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CDC	Centers for Disease Control and Prevention
CDM	Common Data Model
CER	Comparative Effectiveness Research
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare & Medicaid Services
CPS	Current Population Survey
DD	Developmental Disability
EHR	Electronic Health Record
FERPA	Family Educational Rights and Privacy Act
FHIR®	Fast Healthcare Interoperability Resources
GUIDs	Global Unique Identifiers
HAS	Healthy Athletes System
HCBS	Home and Community Based Services
HCUP	Healthcare Cost and Utilization Project
HHS	U.S. Department of Health and Human Services
HL7	Health Level Seven International
HRSA	Health Resources and Services Administration
HSRI	Human Services Research Institute
ICD-10	International Classification of Diseases 10th Edition
ICD-9	International Classification of Diseases 9th Edition
ID	Intellectual Disabilities
ID/DD	Intellectual and Developmental Disability
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Programs (or Plans)
IRB	Institutional Review Board
ISP	Individual Support Plan
IT	Information Technology
LHIDS	Longitudinal Health & & Intellectual Disability Study
LOINC	Logical Observation Identifiers Names and Codes
LTSS	Long Term Supports and Services

Acronym	Description
MAX	Medicaid Analytic eXtract
MBSF	Master Beneficiary Summary File
MEPS	Medical Expenditure Panel Survey
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCHS	National Center for Health Statistics
NCI	National Core Indicators
NHIS	National Health Interview Survey
NIH	National Institutes of Health
NLP	Natural Language Processing
NLTS2	National Longitudinal Transition Study-2
NLTS 2012	National Longitudinal Transition Study-2012
NPCR	National Program of Cancer Registries
NQF	National Quality Forum
NSCH	National Survey of Children's Health
ONC	Office of the National Coordinator for Health Information Technology
OS-PCORTF	Office of the Secretary Patient-Centered Outcomes Research Trust Fund
PCOR	Patient Centered Outcomes Research
PCORI	Patient Centered Outcomes Research Institute
PGHD	Patient Generated Health Data
PPI	Patient Provided Information
PRAMS	Pregnancy Risk Assessment Monitoring System
PRO	Patient-Reported Outcome
PROMIS	Patient-Reported Outcomes Measurement Information System
QoL	Quality of Life
SDOH	Social Determinants of Health
SEER	Surveillance, Epidemiology and End Results
SIPP	Survey of Income and Program Participation
SIS	Supports Intensity Scale
SIS-C	Supports Intensity Scale-Children's version
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TBIMS	Traumatic Brain Injury Model Systems
TEP	Technical Expert Panel
T-MSIS	Transformed Medicaid Statistical Information System

APPENDIX B. RESEARCH AGENDA PRIORITY CATEGORIES

NORC assessed research agendas for 24 different organizations and centers that conduct research on topics specific to improving the quality of life for people with ID/DD to identify key topics that have been prioritized by stakeholders. These organizations included branches with a disability specific research agenda from within three federal agencies - National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and the Administration for Community Living (ACL). NORC also reviewed the ID/DD research agendas of national research organizations including the Patient-Centered Outcomes Research Institute (PCORI) and the Human Services Research Institute (HSRI) as well as the American Academy of Developmental Medicine & Dentistry (AADMD). NORC reviewed the research agendas of all the NICHD funded Intellectual and Developmental Disabilities Research Centers (IDDRCs) and three of the 67 University Centers for Excellence in Developmental Disabilities (UCEDDs). The three were selected for review because of their affiliation with several key informants and are included as examples, noting that UCEDD research priorities and scope vary by center. The results are in Table 1, Appendix C, which organizes the information by the most frequently cited research agenda priority for the ID/DD population to the least. Appendix C, Table 2 presents the definitions of categories used for coding the research priorities for each of the selected organizations and centers.

1) Aside from studies that seek to better understand environmental, cellular, and genetic factors associated with ID/DD and screenings to better detect and diagnose ID/DD, research priorities for the population are tied closely to helping to improve the quality of life for people with ID/DD through physical health, mental health, and social and emotional services, supports and therapies.
2) NORC discovered that of these 24 organizations, the most cited research agenda priorities included neural, cognitive, and behavioral sciences; physical and mental health; child development; molecular, cellular, and structural basis; risk factors, causal pathways, and prevention; and social and behavioral interventions and services. Sixteen of the organizations represented in Table 1 are NIH funded, which could explain the larger focus on basic science research.
3) Topics such as family research and supports, social inclusion and community living, transitions to adulthood, transitions to aging, access to quality health care, and health disparities are notably indicated as research priorities of many disability-focused research branches within federal agencies including NIH, CDC, and ACL. Additionally, like ASPE, reauthorization of the PCOR Trust Fund has expanded PCORI's research priority topics to include person-centered care and shared decision making, and research data infrastructure for ID/DD. So, while these topics may have been less explicitly cited in research agendas of IDDRCs and UCEDDS, funding from federal agencies and PCORI for programs and research related to these topics could influence the research portfolios of the organizations that receive federal funding in the future.

Table 1. ID/DD Specific Research Agenda Priorities from Identified Organizations and Centers

Organization Name	Neural, Cognitive and Behavioral science	Physical and Mental Health	Child Development	Molecular, Cellular and Structural Basis	Risk Factors, Causal Pathways, and	Social and Behavioral Interventions and	Development of Drugs, Devices, Therapies	Family Research and Supports	Public Awareness, Education, Policy	Health Care Provider and Researcher	Screening and Early Diagnosis	Transitions to Adulthood	Social Inclusion and Community Living	Health Disparities	Access to Quality Health Care	Education Services	Transitions to Aging	Pregnant Women with ID/DD	Person-centered Care and Shared Decision	Research and Data Capacity for PCOR on
American Academy of Developmental Medicine & Dentistry (AADMD)									x	x			x	x	x					
Baylor College of Medicine Intellectual and Developmental Disabilities Center**	x				x	x	x													
Center on Human Development and Disability, University of Washington**			x	x	x															
Children's Hospital Intellectual and Developmental Disabilities Research Center, Harvard Medical School**	x		x	x			x				x									
Children's Hospital of Philadelphia, University of Pennsylvania**		x	x	x	x	x		x		x										
Del Monte Institute for Neuroscience**	x			x	x	x														
Human Services Research Institute (HSRI)		x				x		x				x	x	x			x		x	
Intellectual and Developmental Disabilities Branch (IDDB) of Eunice Kennedy Shrive National Institute of Child Health and Human Development at NIH	x	x	x	x	x		x				x	x					x	x		
Kansas Intellectual and Developmental Disabilities Research Center**	x	x		x	x															
Kennedy Krieger Institute Intellectual and Developmental Disabilities Research Center**	x	x	x	x	x								x							
National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC	x	x	x		x				x		x	x		x	x			x		
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at ACL		x				x	x	x	x			x	x		x		x			x
Ohio State University, Nisonger Center*	x	x	x	x		x	x	x	x	x	x				x	x				

Organization Name	Neural, Cognitive and Behavioral science	Physical and Mental Health	Child Development	Molecular, Cellular and Structural Basis	Risk Factors, Causal Pathways, and	Social and Behavioral Interventions and	Development of Drugs, Devices, Therapies	Family Research and Supports	Public Awareness, Education, Policy	Health Care Provider and Researcher	Screening and Early Diagnosis	Transitions to Adulthood	Social Inclusion and Community Living	Health Disparities	Access to Quality Health Care	Education Services	Transitions to Aging	Pregnant Women with ID/DD	Person-centered Care and Shared Decision	Research and Data Capacity for PCOR on
Patient-Centered Outcomes Research Institute (PCORI)		X				X		X		X		X		X					X	X
Rose F. Kennedy Intellectual and Developmental Disabilities Research Center**	X	X	X	X		X		X		X						X				
UC Davis MIND Institute**	X	X	X	X	X	X	X	X	X		X									
UCLA Intellectual and Developmental Disabilities Research Center**	X	X	X		X		X		X	X						X		X		
UNC Intellectual and Developmental Disabilities Research Center**	X	X	X	X	X	X					X									
University of South Carolina, Center for Disability Resources*	X					X	X	X	X			X	X				X		X	
Vanderbilt Kennedy Center for Research on Human Development**	X	X		X	X	X	X				X									
Virginia Commonwealth University, Partnership for People with Disabilities*	X	X	X			X		X	X	X			X			X				
Waisman Center, University of Wisconsin-Madison**	X	X	X	X	X	X	X				X									
Washington D.C., Children's National Medical Center**	X		X	X	X					X										
Washington University in St. Louis Intellectual and Developmental Disabilities Research Center**			X	X	X				X	X	X									

* University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD)
** Intellectual and Developmental Disabilities Research Center (IDDRC)

Table 2. Definitions for Research Priorities Identified Across Research Organizations

Term	Definition
Access to Quality Health Care	Research on access to health care, improving quality of health care people with ID/DD receive
Child development	Studies on the development of children with ID/DD including physical growth as well as intellectual, language, emotional and social development
Development of Drugs, Devices, Therapies	Research on medical treatment for ID/DD including therapeutics, devices, pharmacologic treatments.
Education services	Research on understanding the education services children and adolescents with ID/DD receive. Research on understanding early intervention services for infants and toddlers with ID/DD.
Family Research and Supports	Research on how family relationships and the broader family environment influence developmental outcomes for people with ID/DD; also, research on supports for families of those with ID/DD.
Health Care Provider and Researcher Training	Research on how to better train clinicians on how to provide quality treatment for people with ID/DD or understanding ID/DD in general; research on developing training for researchers, graduate students, and medical students on how to conduct research with people with ID/DD or understanding ID/DD in general.
Health Disparities	Research focused on health disparities within the ID/DD population (racial/ethnic, socioeconomic, gender, etc.) as well as disparities between the ID/DD population and general population.
Inclusion and community living	Research on inclusion and community living of people with ID/DD including supporting social inclusion and independent living.
Molecular, Cellular and Structural Basis	Research to understand the molecular, cellular, structural basis of ID/DD; research that identifies specialized biomarkers; genetic research
Neural, Cognitive and Behavioral science	Research to understand the neural, cognitive, and behavioral science of ID/DD
Person-centered Care and Shared Decision Making	Research on supporting self-directed and person-centered care of people with ID/DD including shared decision making with their providers (clinical or service providers).
Physical and Mental Health	Research on the physical and mental health of people with ID/DD including research on comorbid conditions of ID/DDs.
Public Awareness, Education, Policy Translation	Research on factors that improve understanding and awareness of conditions of interest; efforts to translate research findings into policy or broader dissemination to the public.
Risk Factors and Causal Pathways	Research on risk factors and interactions related to potential causal pathways associated with ID/DD conditions of interest. Research on prevention of ID/DD.
Screening and Early Diagnosis	Research on developmental screening; early identification of developmental disabilities
Social and Behavioral Interventions and Services	Research on non-medical interventions; social interventions such as HCBS.
Transitions to Adulthood	Research on improving child or adolescent health or wellbeing for a better transition to adulthood. Research on understanding the transition period to adulthood.
Transitions to Aging	Research on improving middle adult health or wellbeing for a better transition to aging. Research on understanding the transition to aging.
Uniform Disability Identifiers	Work that creates and implements uniform concepts, language, and methods for identifying the number and characteristics of people with disabilities

APPENDIX C. COMPENDIUMS OF DATA SOURCES RELATED TO THE ID/DD POPULATION

Much work has been done to describe data sources that are available to study the population of people with ID/DD in the U.S. The table below lists some key compendiums and provides an overview of their purpose and associate data sources.

Compendium (Publication Year)	Source	Brief Description
Compendium of Health Data Sources for Adults with Intellectual Disabilities (2011)	University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research (CDDER) Human Services Research Institute (HSRI)	This compendium provides an overview of national, state, or regional surveillance efforts and data sources that capture health information of adults with ID/DD in the U.S. The compendium reviews 101 data sources and ranks their potential for informing health surveillance of adults with ID/DD. There are 38 studies, surveys, and data sets the compendium identified as high potential sources. The compendium identified sources with moderate and low potential as well and studies in other countries.[213]
Compendium of Health Data Sources for Parents with Disabilities in the United States (2017)	The National Research Center for Parents with Disabilities, Brandeis University	This compendium is a summary of nine national data sources that capture health information related to parents with disabilities in the U.S. There are nine data sources that were selected based on methods of identifying parents in the data set with ID/DD, parent status, and including health information.[214]
Compendium of Federal Data sets Addressing Health Disparities (2019)	Data Workgroup of the Interdepartmental Health Equity Collaborative (IHEC)	This compendium consists of 250 federal publicly available data sets and related data resources that include information on health equity; it is not definitive or exhaustive. It includes several data sets that include people with ID/DD, and other data sets specific to that population. The 250 data sets identified in this compendium originate across federal agencies and can be used to conduct research related to socioeconomic factors and the social determinants of health.[215]

APPENDIX D. SUMMARY OF ID/DD DATA INFRASTRUCTURE OPPORTUNITIES BY FUNCTIONALITY

Functionality 1: Use of Clinical Data for Research	• Opportunity 1: Standardize the collection of ID/DD status at the point of care through development of standards and policy changes to require it (**Short Term)** • Opportunity 2: Testing the feasibility of using currently accepted terminology standards and implementation specifications to collect data on function and disability **(Short Term)** • Opportunity 3: Develop and pilot natural language process (NLP) techniques to extract narrative text into standard coded data for surveillance and research purposes • Opportunity 4: Develop and test standard methods for identifying and extracting ID/DD data from EHR and administrative claims data sets • Opportunity 5: Assess the feasibility of integrating ID/DD data elements into existing CDMs (e.g., PCORnet, OMOP) to support PCOR
Functionality 2: Collection and Use of Participant-Provided Information	• Opportunity 6: Standardize quality of life measures (QoL) for the ID/DD population (**Short Term)** • Opportunity 7: Foster opportunities to validate PRO measures for the ID/DD population **(Short and Long Term**) • Opportunity 8: Address gaps in standardized outcomes measures important to individuals with ID/DD **(Long Term)** • Opportunity 9: Support user-centered design and feasibility testing of digital technologies (e.g., smartphone apps, tablets, wearables, devices, etc.) for diagnostic and therapeutic purposes **(Short Term)** • Opportunity 10: Support ongoing efforts to improve the collection and documentation of social determinants of health (SDOH) data in the EHR using standard clinical terminologies **(Short Term)**
Functionality 3: Linking Clinical and Other Data for Research	• Opportunity 11: Support the development of a robust data linkages programs for T-MSIS data **(Long Term)** • Opportunity 12: Promote testing and use of validated linking algorithms • Opportunity 13: Promote the use of unique identifiers within state and federal data sets to facilitate data linkages • Opportunity 14:4 Develop and pilot test data exchange standards for bi-directional exchange and linkage between EHRs and condition-specific registries • Opportunity 15: Develop resources that allow researchers to understand the quality and fitness-for-use of different data sets that can be linked for ID/DD research • Opportunity 16: Support common data governance policies for creating easier access to relevant datasets, especially to perform linkages between state and federal datasets **(Long Term)**
Functionality 4: Standardized Collection of Standardized Data	• Opportunity 17: Work collaboratively with states to improve the utility of T-MSIS data for comparative effectiveness research (CER) **(Short Term)** • Opportunity 18: Support and provide guidance to states around standardizing outcomes definitions across Medicaid programs that serve the ID/DD population • Opportunity 19: 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 **(Long-Term)** • Opportunity 20: Coordinate with CDC to propose updated guidance for coding cause of death for people with ID/DD
Functionality 5: Use of Enhanced Publicly-Funded Data Systems for Research	• Opportunity 21: Support federal efforts to promote the use of all-payer claims databases (APCDs) to conduct PCOR • Opportunity 22: Support efforts to modernize states' incident surveillance systems • Opportunity 23: Make person-level education data available to researchers

(Short Term) - Identified as a short-term priority (2-4 years) by two or more TEP members
(Long Term) - Identified as a long-term priority (5-10 years) by two or more TEP members

APPENDIX E. SUMMARY OF CURRENT FEDERAL INTERAGENCY WORKGROUPS RELATED TO ID/DD DATA AND RESEARCH

Coordinating Group / Subgroups		Participating Agencies / Groups	Purpose
ACL Working Group on ID/DD Data Steering Committee	Health Equity Road Map	ACL, CDC, NCHS	Develop (and support implementation of) a 10-year road map for ID/DD health surveillance, informed by stakeholders including researchers, people with lived experience of disability, families. The roadmap will also Identify data gaps on disparities in health and access and utilization of health care.
	NHIS Cognitive Interview Evaluation of Questions to Identify Adults with ID/DD	ACL, CDC, NCHS	Evaluate questions taken from, or adapted from, survey questions designed to elicit whether respondents have an ID/DD
	Federal Interagency Workgroup on ID/DD Administrative Data	ACL, ASPE, NIDILLR, CDC –NCBDDD, NIH - NICHD, CMS OMH	Establish a routine work group that facilitates collaboration and information exchange among subject matter experts and leaders in the ID/DD space across federal agencies. The work group activities focus on how the respective agencies intend to use administrative data, which includes assessing availability and feasibility of use.
ICDR (Interagency Committee on Disability Research)[216]	General Committee	NIDILLR, RSA, OSERS, ODEP, Secretary of Defense, ACL, Secretary of Education, Secretary of Veterans Affairs, NIH, NIMH, NASA, DoT, HIS, Indian Affairs NSF, Small Business Administration	Authorized by the 1973 Rehabilitation Act, the ICDR promotes coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs—including programs related to assistive technology research, and research that incorporates the principles of universal design.
	ICDR Statistics Subcommittee	TBD	This committee will focus on available opportunities for data analysis.

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