Risk Adjustment for Payment of Healthcare and Home- and Community-Based Service Sectors:

The Case for People with Intellectual and/or Developmental Disabilities (IDD)

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GOAL OF THIS WORK

In this work, we discuss the concept of risk adjustment for payment of healthcare and home- and community-based services (HCBS) and why it is important for individuals with intellectual and/or developmental disabilities (IDD).

Risk adjustment practices can help identify individuals with IDD as a distinct group in the first place and also allocate more resources to those service providers caring for people with IDD so that, ultimately, people with IDD receive the right services. We discuss current strategies for risk adjustment; explain why, when designing for payment for services, such practices do not work well for people with IDD; and consider potential ways to strengthen these practices.

Given the importance of a wide array of services for people with IDD, we consider both healthcare and home- and community-based services.

EXECUTIVE SUMMARY

Risk adjustment practices for payment of healthcare and home- and community-based services (HCBS) can be designed and applied to promote equity in a society that is trying to be more inclusive and supportive of people with intellectual and/or developmental disabilities (IDD).

The main recommendation from this work is to develop new risk adjustment methods that align with the social model of disability, in which a person's abilities are a function of their environment as well as their health condition. Ideally, such methods should use diverse sources of data that fairly represent people with IDD, should be affordable and easy to use, and should reflect people's changing needs.

SECTION I reviews modern concepts and definitions of disability which have been developed and implemented internationally. These models center disability upon the interaction between the person and the environment, rather than focusing narrowly on a health condition and its medical treatment. Using modern social concepts of IDD leads to recognition of the shortcomings of healthcare-oriented risk adjustment approaches. It also leads to imagining new approaches—methods that recognize IDD as an important factor in a person's health and life outcomes, that capture information about a person's functional ability as well as their health status, and that support payment that reflects the needs of people with IDD.

SECTION II discusses why risk adjustment is important for people with IDD. It first reviews the statistical base of risk adjustment as a method that accounts for how a person's characteristics (e.g., age) may relate to health outcomes (e.g., when heart disease develops) or healthcare spending (e.g., cost of delivering care for a stroke). It thereafter highlights how risk adjustment does not, in and of itself, create effective ways for paying service providers and points out that both risk adjustment and its real-life application in payment approaches must be evaluated to confirm that they have their intended effects and do not create negative unintended results.

This section closes with a description of some of the common data points used in healthcare risk adjustment, warns against unintended results of risk adjusted for health care, and provides background on risk stratification strategies used in home- and community-based services.

SECTION III highlights how existing data sources, including those used in healthcare risk adjustment, under-identify IDD, thus limiting understanding of how IDD relates to variation in health spending. It describes the current reliance on diagnostic codes in healthcare claims data for risk adjustment and ways in which the practice can cause people with IDD to be undercounted; it also notes that HCBS programs currently cover far fewer people with IDD than could benefit from those supports.

This section suggests areas for exploration to improve identification of people with IDD in healthcare data sources, a theme that is expanded in Section IV.

SECTION IV lays out a series of principles to guide future work to make healthcare risk adjustment and HCBS risk stratification work better to assure that people with IDD receive the appropriate services to support best health and participation in society. It discusses ways to improve identification of people with IDD and their functional abilities by using a broader range of data sources, including information (e.g., people's socioeconomic context and their receipt of supports) and new analytic methods (e.g., artificial intelligence). It encourages more standardization and payment for HCBS, using a five-tier indicator of support levels.

Finally, this section highlights the potential for combining healthcare risk data with HCBS support levels to give a more holistic view of people with IDD when building and using risk adjustment methods.

ABBREVIATIONS

ACO: accountable care organization

ACS: American Community Survey

ADDMN: Autism and Developmental Disabilities Monitoring Network

AHRQ: Agency for Healthcare Research and Quality

CCI: Chronic Condition Indicator

CDC: Centers for Disease Control and Prevention

HCBS: home- and community-based services

IDD: intellectual and/or developmental disabilities

NHIS: National Health Interview Survey

UN: United Nations

US: United States

VBP: value-based purchasing

WHO: World Health Organization

I. FRAMING DISABILITY IN THE CONTEXT OF ENVIRONMENT AND SOCIAL SITUATION

A. Applying the International Framework of Functioning to Concepts of Disability

Although this work addresses risk adjustment for healthcare and HCBS payment within the US context, our analysis is grounded in disability concepts and definitions articulated in the 2001 WHO International Classification of Functioning, Disability, and Health[1] and the 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities.[2] The WHO and UN articulate that, "Persons with disabilities include those who have long-term physical, mental, intellectual, and/or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[3] Note that the WHO and UN disability concepts and definitions highlight impairments that interact with the context in which people live, not diagnoses. Diagnoses are critical for identifying problems and guiding treatment for people with IDD in the same manner as for those without IDD, but they do not directly measure functional ability or contextual factors.[4]

Considering disability as an interaction between the person and his/her environment rather than only as a medical condition makes it more apparent that the service sectors of healthcare and HCBS are both key parts of the environment that can be structured to help, or harm, people with disabilities.[5] Rather than focusing on curing or "fixing" disabilities, systems of care and payment that capture a person's functional ability and the degree to which their environments support them may better help people with disabilities live their lives on an equal basis with others, by rewarding providers for improving their health.

Another feature of the WHO and UN work on disabilities that is highly relevant to this work is the call for the "equalization of opportunity," which asks nations to address whether, "persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society."[6] Equalization of opportunity is relevant to risk adjustment for payment of healthcare and HCBS services because the failure to fully capture all the dimensions of IDD in typical healthcare and HCBS data both reflects, and results in, inequitable opportunity for people with IDD—it makes them less "visible" and hampers efforts to predict and finance appropriate levels of services to meet their needs.[7]

B. How Can This Framework Apply to IDD?

We use the WHO and UN definitions of disability and focus on impairments that affect cognition and developmental trajectories. The identification of childhood-onset IDD is featured because, for those with access to medical care in the US, healthcare data systems may be most enriched with IDD-relevant diagnoses in the first two decades of life, when parents and school systems first note children as potentially having lifelong developmental issues.[8] There have also been recent efforts to use claims-based algorithms for identifying children with disabilities and clarifying functional ability.[9] In the future, methods for identifying childhood-onset disability may be adapted to better identify acquired IDD in adult populations.

II. RISK ADJUSTMENT FOR HEALTHCARE AND HCBS PAYMENTS

One way to start designing and applying risk adjustment practices so that they include and support people with IDD is to recognize the ways in which this population has been, and continues to be, excluded, underrecognized, or undertreated in healthcare and HCBS sectors.

First, one must recognize that healthcare often mirrors societal biases and misconceptions about people with IDD.[10] Numerous studies have illustrated how often healthcare providers avoid, overlook, or undertreat people with disabilities. If frontline providers do not recognize people with IDD, their needs and services will not be recorded in the data systems upon which payment-related risk adjustment is based. If insurers cannot tell who has IDD in their claims data, then their payment rates cannot reflect the needs and complexity of people with IDD.

The structural issues go further. The diagnostic codes recorded when patients receive care from clinicians are organized according to body systems, which limits appreciation of conditions that affect the whole person (like IDD). Codes describing human development or intellectual ability also constitute a small fraction of the overall number of codes. Moreover, although tens of thousands of diagnostic codes attempt to capture the range of possible health issues a person might have, these codes generally lack information about condition severity and thus may allocate resources imperfectly because they do not reflect that people with a given condition may have different levels of need. In the US, codes related to how well people are functioning in life have not been implemented.

A. Risk Adjustment Is a General Statistical Method Applied to Payments in Healthcare and HCBS

Risk adjustment is a general statistical method that accounts for how characteristics of people may relate to need for, or spending for, services.[11] In healthcare and HCBS payment, the characteristics examined usually include demographic and clinical factors (e.g., age, sex, and diagnostic codes).

Risk adjustment is critical for appropriately paying insurers or care providers that serve patients with different levels of complexity. Without such adjustments, insurers or providers receiving an unadjusted payment will tend to serve less complex patients and avoid more complex patients.[12]

The explanatory value of a risk adjustment algorithm is most frequently judged by the R-squared statistic, a number that reflects how much of the observed variation in the outcome is predicted by the characteristics of the observations that are used in the risk adjustment algorithm. A perfect risk adjustment algorithm explains all the variation in outcomes and has an R-squared of 1.0, whereas a completely imperfect algorithm explains no variation and has R-squared of zero.

Currently, in healthcare and HCBS payment, age, gender, and diagnoses make up most of the characteristics included in risk adjustment models, which perform unimpressively with R-squared statistics between 0.1-0.25[13] (See Table 1).

Risk adjustment can be used to determine a dollar amount or to establish tiers of payment (e.g., high, medium, low). In this work, we use the term "risk adjustment" when referring to both forms of implementation and use "risk stratification" when referring to the use of tiers in program implementation.

B. Risk Adjustment and Value-Based Payments

Value-based payment—programs for improving care quality while reducing spending—is the cornerstone for payment reform in the United States, so it is natural to consider how payments for services delivered to an IDD population may fit a value-based payment framework.

One of the chief ways people with IDD can fit into a value-based payment framework is by being present and appropriately accounted for as part of risk-based capitation — one way in which spending reduction incentives are delivered. Capitation provides a fixed payment irrespective of whether patients use services, so capitation rewards care that might otherwise be difficult to quantify (e.g., integrated care efforts across a wide variety of involved clinicians). Attention to how risk adjustment affects risk-based capitation may also help address one of the chief concerns facing people with IDD, which is that they lack access to healthcare because the capitated payment levels associated with their care are lower than what is needed to induce healthcare providers to take them on as patients.

Another way that payment for services for people with IDD can fit into a value-based payment framework is being part of payment experiments involving blends of capitation with other types of payment. Capitation also has potential downsides—it could induce providers to avoid delivering care even when it is needed (also known as stinting), and it does not necessarily drive improvements in care quality.

Payment combinations can counterbalance the potential downsides of purely capitated payments. These include capitation in combination with fee-for-service payments (aka, blended capitation), strong quality reporting requirements (e.g., Medicaid Managed Care programs), or in combination with pay-for-performance incentives (aka, alternative quality or accountable care organization contracts)—that link payments to the health and healthcare of people with IDD.

Given the current trend in connecting insurance enrollees with community-based services, particularly within the Medicaid program, it may be important to investigate the degree to which HCBS receipt relates to Medicaid care quality, spending, and value.[14]

Design of risk adjustment should follow the payment approach and its use should be aligned with policy goals. For example, a payer would want to risk adjust payment levels for a month of healthcare and HCBS services that will vary from person to person but may not want to risk adjust how much is paid for a provider based on the percentage of their eligible patients who received a recommended flu vaccine (because everyone eligible should receive the vaccine).

C. New Frontiers for Healthcare Risk Adjustment Algorithms

Diagnosis information has been a mainstay in risk adjustment algorithms for healthcare payment.

Risk adjustment methods for healthcare payment have undergone continuing testing and development by open-source and proprietary efforts.[15] In the 1980s, risk adjustment methods included demographics such as age and sex, without ability to gather information about diagnoses or how patients used healthcare in the past.[16] In the 2000s, risk adjustment methods began to examine how this information could improve the explanatory power of algorithms.[17] The addition of diagnostic information and service use into risk adjustment was considered a major improvement upon simple demographic information. (See Table 1.)

More recently, interest has grown in examining whether and how to include social variables in risk adjustment algorithms.[18] The potential usefulness of data on functional ability and use of social supports in healthcare risk adjustment has also been raised but requires further exploration.

The potential for unintended consequences is always present.

Factors used in risk adjustment algorithms for payment ideally reflect individuals' true health conditions and needs for services,[19] but there are numerous ways for service providers to take advantage of any approach. Emphasis on capitated payment models generally fosters an environment of "upcoding," when service providers choose codes to make their patients appear more complex and costly. Inclusion of past use of services in risk adjustment models may explain variation in spending across different groups of patients, but rewards providers for delivering more healthcare services without necessarily improving health.[20] Over-reliance on past spending patterns may also result in payment rates biased against people who have less access to services to begin with. For example, a low-income person with less ability to take time off from work for doctors' visits may have more healthcare needs than a high-income person who is better able to make multiple doctors' visits, but a risk adjustment algorithm may score the high-income person as needing more services in the future because they used more services in the past.[21]

Table 1. Factors Tested in Risk Adjustment Models Over Time

Decade	Personal Characteristics (Age, Gender)	Diagnoses	Functional Ability	Social Supports
1980s	✓			
2000s	✓	✓		
2020s	✓	✓	?	?

When geocoded socioeconomic background was added to a pediatric risk adjustment algorithm, social factors were found to explain a similar level of variation, as did gender.[22] People from higher socioeconomic backgrounds spend more than those from lower ones; thus, implementing an algorithm with social variables can direct more funds to providers caring for people from high socioeconomic backgrounds—the opposite of its intended effect.[23] This same paradox has been observed for Medicare insured patients and for health outcomes.[24]

The bottom line is that risk adjustment methods must not only be considered carefully for whether they are meaningful representations of patient health status that are resistant to artificial inflation and result in their intended effect—the effort to evolve risk adjustment also requires testing in multiple patient populations and payment contexts.

D. Risk Adjustment Algorithms for HCBS Payments

Functional assessments are central to current risk adjustment algorithms for HCBS payment.

While risk adjustment algorithms for healthcare payment typically use diagnoses but lack indicators of functional ability, HCBS spending algorithms tend to rely heavily on functional assessment but lack information about patient diagnoses. Spending might initially be expressed in total annual HCBS expenditures but may also be tiered into spending ranges or budget levels based on a person's support need.

While state Medicaid programs vary greatly in how they use functional assessment data to determine a per-person budget or rate, some examples of methods for determining an assessment-based budget include:

- Using weights associated with items/scales on the functional assessment in addition to other budget factors (e.g., where a person lives) in a regression-type equation that calculates a budget amount per person per unit of time;

- Responses to individual assessment items that are tied to an amount of support time (e.g., "full physical support" for dressing equals 12 hours per week) that are then summed to determine the total number of hours of support allotted for payment;

- A "case mix" that classifies individuals based on their assessment responses into groups that share similar resource use patterns; or

- A support level framework that uses assessment data along with other data (e.g., age) to assign a level of support need to the individual that then corresponds to a budget commensurate with that need.

The most common approach to setting HCBS budgets is developing a framework of support levels with a different budget associated with each level.[25] This approach has the advantage of being simple, straightforward to modify and improve incrementally, transparent, and flexible across different populations and programs. Nonetheless, states vary a great deal in their approaches, and total budgets reflect major constraints on total funds available.[26]

Risk adjustment for HCBS budgets could improve with the addition of other data, such as clinical diagnoses or socioeconomic factors. Alternatively, creating a cohesive risk stratification model across both healthcare and HCBS sectors would allow for shared information and understanding of the population and individuals seeking care in either sector. Traditional types of data combined with novel information could greatly enhance such a risk stratification model. We discuss these options further in later sections of this paper.

III. HOW TO MAKE PEOPLE WITH IDD MORE VISIBLE IN HEALTHCARE AND HCBS DATA

A. Healthcare

When healthcare providers submit claims, they must include diagnoses, using an international classification scheme called the International Classification of Diseases (ICD)-Clinical Modification (CM). Since 2015, the US has used the tenth version of the ICD (ICD-10-CM). Although providers may submit claims directly, more commonly non-clinical staff handle the submissions. For a person's IDD status to appear in claims information, several conditions would need to be satisfied:

1) People with IDD will need to use healthcare.

People with IDD face many barriers in accessing care in the current system—due to the health literacy required to recognize when medical problems exist, the complexity of understanding where to go when and the logistics of getting there, understanding insurance rules, and understanding how to navigate a healthcare facility, especially given the sensory and communication challenges in many settings. Thus, existing healthcare structures can prevent full representation of people with IDD in claims data.

2) The codes that reflect IDD conditions must be available for use in the classification scheme called the International Classification of Diseases-Clinical Modification (ICD-CM).

3) Physicians and other clinicians must be aware that they are caring for a person with IDD.

As with many cognitive impairments, physicians and clinicians may not be actively aware that they are working with a person with IDD. This may particularly be true for intellectual and/or developmental conditions that are diagnosed during childhood and are lifelong but are not obvious to a clinician seeing the patient for the first time as an adult long after their IDD diagnosis.

4) Physicians and other clinicians must be aware that they can code for the care that they deliver to a person with IDD.

Codes reflecting IDD exist (i.e., mild, moderate, severe, and profound intellectual disability), but there are numerous other codes that reflect IDD that do not have "intellectual" or "developmental" in the diagnostic code (e.g., Down Syndrome).

5) Physicians or their staff who help with billing must bill for care delivered to people with IDD.

Although physicians sometimes submit claims, usually clerks with variable understanding of billing and coding rules handle the submissions. Billers must navigate a high volume of available codes (now over 77,000 in ICD-CM Version 10). Simply put, it may just be difficult to find the relevant codes and use them appropriately.[27]

6) Payments should reflect the degree to which IDD introduces complexity into patient care or outcomes.

The primary purpose of billing codes is to ensure payment, and healthcare providers alter their coding habits to maximize financial gain. They are less likely to take the time and effort to include any codes that do not link to meaningful payment. A famous example of this phenomenon is how coding for wrong-sided surgery dropped

suddenly when Medicare decided to stop paying for such surgeries.[28] The visibility of people with IDD in claims may vary depending on a clinician's payment contract. For example, a fee-for-service contract will motivate providers to code for acute self-limited illnesses because they are more frequent, and a provider receives payment for each instance. In contrast, a capitation contract will motivate coding for chronic conditions because that may raise the level of the per-person lump sum payment.

The care setting also matters. Payment levels for hospital services are usually set based on the immediate reason for admission, such as a stroke, rather than on chronic issues such as untreated high blood pressure that are the true underlying cause. In addition to IDD codes on claims usually not being linked to payment, many providers lack training to recognize IDD conditions, and as a chronic condition, IDD may be the underlying cause but not the immediate reason for a new health complaint.

7) Claims-based algorithms for identifying at-risk populations must include IDD-relevant diagnoses.

Many claims-based algorithms have been developed to tier populations into levels of health and spending risk. To our knowledge, only one claims-based algorithm has been developed with a focus on people with IDD—the Children with Disabilities Algorithm (CWDA).[29] CWDA was validated against parent and physician reports and tested in both commercial and Medicaid claims.[30] CWDA delivers childhood-onset disabilities prevalences commensurate with rates observed in nationally representative surveys—(surveys: 5.56-9.10%[31;] commercially 4.3-4.9% and Medicaid-insured 5.3-9.0%).[32]

However, other routinely used algorithms do not capture information about childhood-onset disabilities like IDD. One-fifth of a population of children with disabilities was considered not to have a chronic condition per the AHRQ Chronic Condition Indicator (CCI).[33] Similarly, one-eighth of the children being followed by the state of California's California Children Services via the Chronic Disease Payment System (CDPS) were not flagged as children with disabilities.[34]

Identifying people with IDD in claims data needs more work, but it can be done. While there is no national claims-based estimate of the prevalence of IDD in the US, national commercial health plan data suggests that 66% of the children with disabilities identified by CWDA have IDD, which is consistent with survey-based estimates. (The American Community Survey and National Health Interview Survey suggest the prevalence of IDD ranges between 4.2-6.8% for children aged 5-17 and that 75% of children with disabilities have IDD).

While a number of surveys have been used to determine rates of disability generally or IDD specifically, few were designed for that purpose.

B. Home- and Community-Based Services (HCBS)

People with IDD often need more than just healthcare services, and whether they get those other supports may affect how much and what kind of healthcare they need. Home- and-community-based services such as help with basic life activities (e.g., food shopping, personal hygiene, or employment support) can be critical for people with IDD to thrive.

People with IDD account for a significant portion of those served by HCBS; however, the number of people with IDD receiving HCBS is much lower than the total number of people of IDD in the general population who may benefit. Conservatively estimating that people with IDD comprise 3% of the population, that means approximately 10 million people have IDD, compared to the 0.8-1.0 million receiving HCBS. In 2018, there were 879,062 people with IDD receiving HCBS through Medicaid Waivers and another 208,889 on waitlists for such benefits.[35] However, based on good estimates of clinical severity, HCBS experience in a number of states suggests that up to 5 million people with IDD might need the highest level of HCBS services (i.e., 2:1 support, 24 hours a day, 7 days a week), and about another 5 million might need the second highest tier of HCBS services (e.g., 1:1 support daily). These estimates do not include others with less support needs.

C. Identification Summary

Although claims data and HCBS receipt can include people with IDD, their representation within these two contexts is likely incomplete. Population-based estimates of the prevalence of people with IDD span a wide range, but the numbers identified via claims data tend to fall on the low end of that spectrum.

The same is true for the number of people receiving HCBS. These findings suggest that decision-makers in both sectors are not reliably identifying people with IDD. Insurers and healthcare providers prioritize populations they can see and that they believe need significant services and attention. Budget limitations drive (and limit) HCBS services. In section IV, we suggest three distinct strategies for improving the visibility of people with IDD in data used for risk adjustment.

IV. WHAT SHOULD THE FUTURE OF RISK ADJUSTMENT LOOK LIKE FOR PEOPLE WITH IDD?

The strengths and limitations of current risk adjustment approaches point to areas where new methods could greatly improve the accuracy and meaningfulness of risk adjustment as a tool for predicting the types and levels of supports that a person with IDD may need, and hence the effort and amount of spending that providers and insurers should devote to them. We describe these recommendations below and summarize them in Table 3.

This report also lays out ways to better capture IDD information in the data sources upon which risk adjustment for payment traditionally depends. While some solutions require rectifying the myriad of ways that people with IDD may be under-identified in healthcare and HCBS data systems, the remainder has to do with finding new techniques for incorporating information about functional ability or social supports.

One could continue to use expert-informed algorithms that allow functional ability to be probabilistically derived from diagnostic codes (e.g., CWDA),[36] while another method involves bringing functional assessment and social support information from HCBS and other sources to healthcare data (e.g., Medicaid Long Term Services and Supports, Program of Advanced Care for the Elderly, Medicare Medicaid Dually Eligible Special Needs Plans), while the third involves taking healthcare data and importing it into HCBS algorithms.

A. Guiding Principles

We propose here key policy principles that take into account practical considerations:

- Risk adjustment should adhere to the social model of disability, as in the WHO and UN classifications, and thus combine personal, clinical, and social factors, using combinations of data that reflect all those inputs to what services and supports a person will need.

- IDD is a lifelong condition but has different manifestations and needs across a person's lifespan. Therefore, an optimal risk adjustment approach should be flexible and dynamic enough to adapt its predictions to different life and developmental stages.

- Risk adjustment methods that are more expensive and time-consuming will be less practical than those that can be automated and/or rely on data that is less expensive to collect. Surveys and individual needs assessments can produce very meaningful data but are expensive and time-consuming.

- Related to issues of cost and time, methods that can be easily produced by different organizations such as insurers, hospitals, and government will be more useful than methods that rely on difficult to access data or proprietary methods.

B. Evaluating New Risk Adjustment Methods

Once a new risk adjustment model is developed, it needs ongoing evaluation to assess how well it performs along key parameters:

- How feasible and practical is it to use in real life circumstances?

- How easily does it allow for the addition of new types of data or other changes to the methodology?

- To what extent does it help improve programs and policies for people with IDD? For example, does it make it easier to implement a program by building more trust among the IDD community and providers?

- Does its use lead to better health and life outcomes for people with IDD?

- What is the effect of its use on health disparities for specific subpopulations?

- Does it enhance the predictive power beyond current approaches?

- Does it improve or worsen health inequities across different demographic groups?

C. Data Sources

Initial strategies to improve healthcare risk adjustment should expand the sources of data beyond age, sex, and diagnoses to include:

- A person's socioeconomic circumstances. It is now possible to obtain data on such key factors as housing, employment, debt, household composition, education, and how people spend their time and money. Such information should always be kept confidential, but if masked to prevent identification of the individual, socioeconomic factors predict health outcomes better than clinical factors do. Combining the different types of data about individuals (rather than just about their neighborhoods) could improve the explanatory power of risk adjustment algorithms.[37]

- Data on social supports. Similar to socioeconomic data, information on the types and degree of supports to which a person has access can improve the accuracy of risk adjustment, although care must be taken not to "downgrade" a person's risk because of inability to access needed supports in the past.

- To help ensure adequate attention to disparities, risk adjustment methods should use data on as comprehensive a population of people with IDD as possible. For example, relying mostly on data of people in residential facilities or who are on Medicaid will skew risk adjustment results for other people with IDD. Similarly, using data sources that are not representative of Black/Brown or rural populations will skew risk adjustment results for those subgroups of people with IDD.

D. The Dual Importance of Healthcare and HCBS

People with IDD have complex needs that typically span healthcare and HCBS. Those different needs and services also interact. A person who receives appropriate vocational support may better find and hold a job, and therefore be less likely to have depression that requires medical care. Or a person who is over-medicated with anti-psychotic medications may require more in-home support from an HCBS attendant. Creating a cohesive risk stratification model across the healthcare and HCBS sectors would allow for shared information and understanding of the population and individuals seeking care in either sector. Traditional types of data (clinical, functional status, support needs, demographic information) combined with novel information could greatly enhance such a risk stratification model.

With regard to standardizing HCBS risk stratification, we recommend analyses based on a simple 5-level structure for individuals with IDD using their support needs. Table 2 displays the levels and short description for such a 5-level model. This example is adapted from a 5-level model developed using data from the Supports Intensity Scale-Adult version, similar to several other assessments of support need.[28,29] Such an approach also allows for a person's risk level to change over time. It is not equivalent to labeling a person has having "mild" or "severe" disabilities.

Along with "independent" efforts to strengthen healthcare risk adjustment and HCBS risk stratification, we also recommend investigation into integrating data across both systems to develop a more robust risk strategy for people with IDD.

Table 2. Example of a 5-level Model from the Supports Intensity Scale-Adult Version

LEVEL	SHORT DESCRIPTION
0	Individuals in Level 0 require the same amount of support as their non-disabled peers. While sometimes they may need assistance due to specific circumstances (e.g., illness or injury), no formalized ongoing regular supports for day-to-day activities are needed.
1	Individuals in Level 1 have low support needs. They can manage many parts of their lives independently or with little help, and rarely, if ever, require 24 hours per day of support. Someone in this level may need support with tasks like clothing care, preparing meals, and housekeeping. They may require physical support for a few specific tasks, but their support most often looks like monitoring or prompting. They may need help at times to participate in leisure activities, get and keep a job, or visit family and friends. Individuals in this level often require support such as facilitating doctor's appointments, preparing or administering medications, or supporting adherence to diets to promote health. Any more serious medical needs are typically well managed within the course of general daily supports.

Table 2 Continued

LEVEL	SHORT DESCRIPTION
2	Individuals in Level 2 have moderate support needs. Individuals in this level often require support during much of their day but extensive dedicated support is not required. Individuals in this level require varying amount of support depending on the specific task or situation. Considered across all areas of support, on average, individuals in this level require supports that are beyond prompting but not complete physical support. However, some individuals in this level do require partial physical support in the majority of areas. An individual in Level 2 could need no support for eating meals or getting dressed; monitoring or prompting for personal hygiene; partial physical assistance for housekeeping and communicating with others; and full physical assistance for meal preparation and transportation. The combination of supports needed by individuals in this level will vary person to person. Individuals in this level often require support such as facilitating doctor's appointments, preparing or administering medications, or supporting adherence to diets to promote health. Most serious medical needs are well managed; however, some individuals have medical support needs that require dedicated attention (e.g., daily diabetes management).
3	Individuals in Level 3 have high to very high support needs. Adults in this level often require support during much of their day and require some physical supports in most areas. However, supports may be limited to prompting or supervision in some areas. Adults in this level have at least some support needs which require 1-to-1 support on a regular, but not constant, basis. An individual in this level could need daily physical help to prepare food, get dressed, bathe, complete household chores, and maintain physical safety while requiring only prompting and supervision to eat foods that have been prepared or to communicate their wants and needs with others. An individual in this level may also likely need partial-to-full physical help to get and keep a job, access the community, and take part in preferred community activities. Individuals in this level may also have medical support needs, though these medical needs most often do not require dedicated attention outside of daily supports. They may need physical support for facilitating doctor's appointments, preparing or administering medications, or supporting adherence to diets to promote health.
4	Individuals in this level typically need support 24 hours a day from one or more individuals, likely due to extraordinary medical or behavioral needs. Individuals in this level would be at risk for hospitalization or injury to themselves or others without constant supervision and/or support.

E. New Data and Analytic Methods

Expert-based algorithms for identifying people with IDD are underway and promising, but they need further development. The CWDA has an Impairments Crosswalk that estimates the types of impairment affecting children with disabilities—intellectual/developmental, sensory, physical, or mental. Applying CWDA to health plan claims data that span adolescents and young adults is also being used to identify childhood-onset disability in adults [unpublished work, in process]. Beyond claims data, better information from various surveys can help in planning and organizing services for people with IDD, by increasing the visibility of people with IDD in multiple data sources.

Current healthcare risk adjustment approaches typically use "regression models," which include specific factors (variables like age, sex, diagnoses) decided in advance as likely to predict service needs. These models use a snapshot of those factors to make a prediction. Once set, changing or adding new factors to the model is difficult and/or expensive. Claims-based strategies can also examine diagnostic patterns and hierarchies to transform multiple diagnostic codes to a much smaller and cohesive set that relate directly to IDD, much as the CWDA does for children.

An alternative approach would use more automated methods like artificial intelligence that can detect complex data patterns more easily and accurately than human analysts alone and that can more easily adapt to absorb new types of data. Newer approaches can integrate data across multiple sectors (e.g., healthcare and clinical data, socioeconomic information, and supports and needs). Here, too, the data must be as balanced and fair as possible in including different subgroups of people (such as Black/Brown, non-English speaking, poor, rural populations) to minimize any bias in the resulting algorithm.

Improving HCBS coverage will benefit from more generous budgets (including from sources other than Medicaid) as well as standardization of a tested risk stratification approach that gets services to people according to their needs. As noted above, current strategies keep many eligible people with IDD and other conditions without needed services. Ultimately, it will help to consider how to integrate healthcare and HCBS risk adjustment strategies to help assure the breadth of services that can support best functioning and outcomes for people with IDD.

Table 3. Components of Risk Adjustment Algorithms for Payment (Summary)

	CURRENT	RECOMMENDED FOR TESTING
DATA	• Age • Sex • Clinical diagnoses (healthcare) • Prior service use • Functional ability (HCBS) • Clinical severity • Claims-based diagnostic patterns/ hierarchies (healthcare)	• Functional ability (healthcare) • Socioeconomic background • Social support
METHODS	• Diagnostic and/or claims-based regression models • Regression models considering functional ability and past utilization • Models that group by functional ability then consider past utilization and policy goals	New approach that uses rich socioeconomic data combined with clinical, functional, and social data with automated methods of continual refinement
OTHER FEATURES	• Lacks data across functional ability, clinical severity, and/or socioeconomic data • Modest predictive power	• Takes into consideration societal perspective • Is dynamic and reflective of different developmental and life stages • Draws on data for comprehensive populations of IDD • Is not overly burdensome in terms of cost and effort for data collection • Has significant predictive power for both spend and health/clinical outcomes • Combines data from multiple service sectors • Contributes to programmatic goals • Contributes to better quality of services • Is fair and equitable • Feasible to implement • Is replicable by different stakeholders

V. ABOUT THE AUTHORS

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Dr. Chien is a physician researcher based at Harvard Medical School and Boston Children's Hospital and focused on the relationship between incentives and disparities. After providing most of the available empirical information on the effectiveness of value-based purchasing and care quality for children, she created the Children with Disabilities Algorithm, and received an R01 from NICHD to examine health care transitions for adolescents and young adults with IDD. Dr. Chien's national committee service has included the Patient Centered Outcome Research Institute (Disparities), the National Quality Forum (Risk Adjustment), the Centers for Medicaid and Medicare Innovation (Next Generation Accountable Care Organizations) and the National Academies of Medicine (Value Incentives and System Innovation Collaborative). However, at the beginning and end of each day, she is the proud aunt, godmother, and sister-in-law to family members with IDD.

Colleen Kidney, PhD

Dr. Kidney is a policy associate at Human Services Research Institute whose work is driven by a passion for self-determination and equity of individuals with intellectual and/or developmental disabilities. She has led or collaborated on the development of individual budget methodologies for Medicaid Home and Community Based Services Waiver programs in multiple states. Dr. Kidney is particularly dedicated to working with public agency staff to analyze and present data to improve understanding of systems and inform evidence-based policies that impact individuals with intellectual and/or developmental disabilities. Dr. Kidney is also highly skilled in community-based participatory research and in program evaluation, data analysis, and data visualization. In addition to supporting clients in methodology and data analysis, Colleen also has extensive experience working with disability populations and stakeholders.

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SECTION VII. ENDNOTES

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