IEC

Making IDD Visible

August 2026

Why Do We Need to Make IDD Visible?

IDD Remains Invisible to Healthcare Stakeholders

Number of PWIDD in medical claims and electronic health records (EHR) is a fraction of expected based on survey & CDC data

- Based on analyses of Epic's Cosmos data, PCORNet EHR data, and Milliman's commercial claims
- 1-3 per 1,000 instead of 30-50 per 1,000

Worse undercounting for certain subgroups

- Adults, females, Black/Brown, poor, rural
- Those with less visible disabilities/features

Likely causes of IDD invisibility in data

- Limited clinical training to detect IDD
- Limited resources for testing and diagnosis
- Missed co-occurring IDD conditions
- Lack of self-disclosure due to stigma
- Lost medical history during life & care transitions

IEC

e-IDD: An AI Tool To Comprehensively Identify Children & Adults With IDD

Better data is a critical first step in improving the lives of people with IDD

e-IDD can be used in daily decision-making

- For PWIDD across lifespan
- Usable by clinicians, payers, government, researchers
- Accounts for sex/racial/ethnic/geographic/lifespan diversity
- Developed on a large population

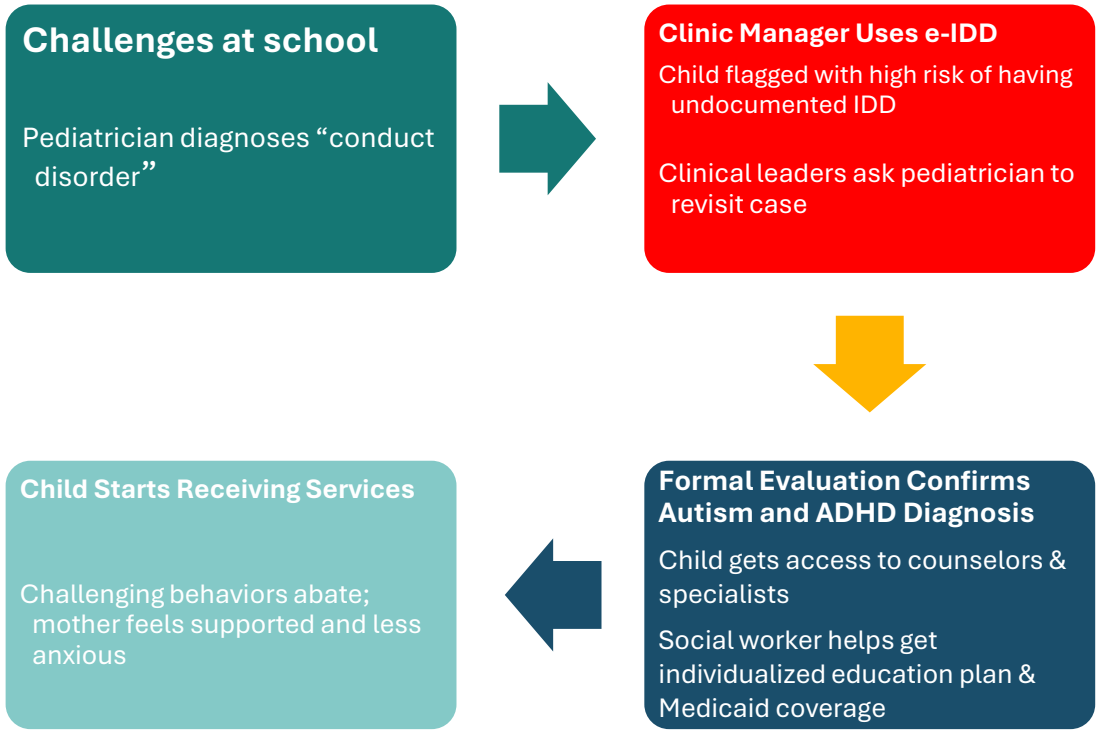
More data can improve detection

- Clinical and billing data from electronic health records
- Public socioeconomic data

IEC

e-IDD Supports Better Outcomes For Children & Parents

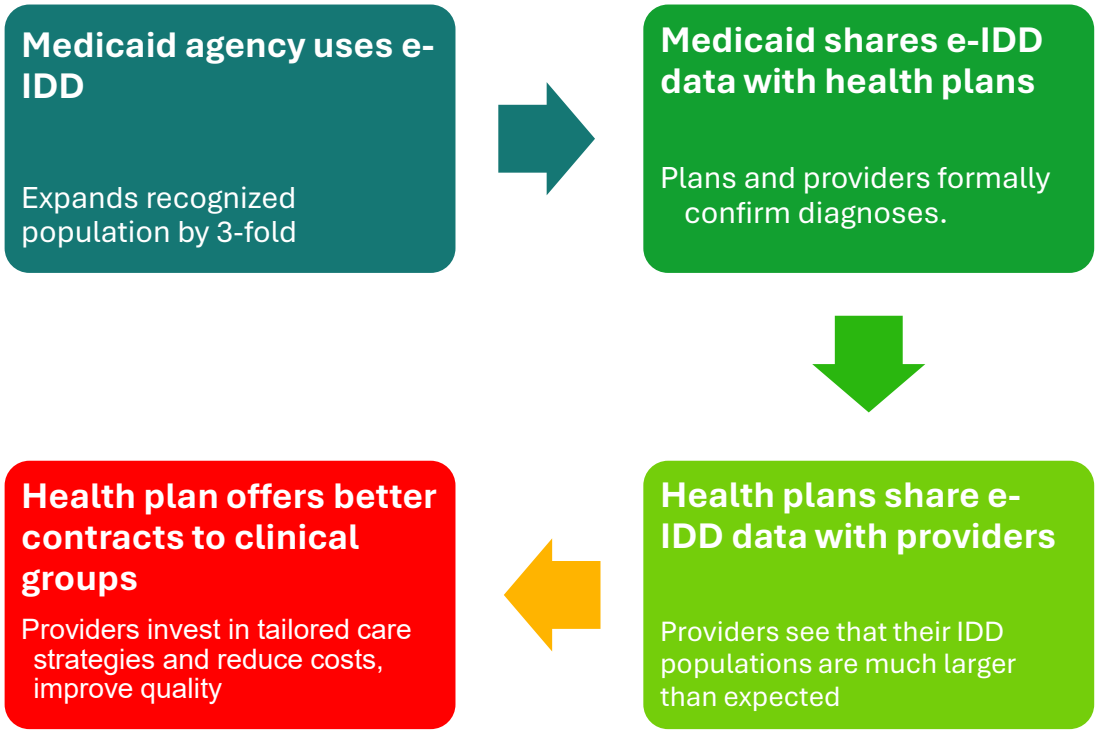
Black mother of twins cannot get pediatrician to take her concerns about developmental delays in one child seriously.



IEC

e-IDD Helps Public Payers Improve Cost/Quality Outcomes

Medicaid agency uses e-IDD to design value-based payment programs



IEC

How Do We Make IDD Visible?

First Focus on Autism & Intellectual Disability (ID)

- Account for over 75% of people with IDD
- Harder to diagnose (especially with co-occurring conditions)
  - Can’t be confirmed with a lab test
  - Greatest opportunity to improve detection
- Diagnosis is uneven (biased)
  - Opportunity to improve fairness

IEC

Use Clinical Expertise & Lived Experience To Develop "Computable Phenotypes"

- Clinicians experienced in working with autistic children and/or adults and those with ID
- Autistic adults and adults with ID
- Family members of autistic children and those with ID
- What is a **computable phenotype**?

  Descriptions of how an autistic person or someone with ID might present clinically and/or socially, expressed in a way that allows use of data to identify cases.

  For example – a six-year-old child who is non-speaking and anxious and but has met all their physical developmental milestones.

IEC

Apply Artificial Intelligence

- Use AI approaches (some terms include **logistic regression models, decision-trees, random forest, neural networks, and deep neural networks**).
- Also use "**large language models**," like ChatGPT.
- Use many kinds of data in EHRs, such as visit notes and problem lists.
- Use information on a person's social context in the EHR.
- Use publicly available social data such as urban/rural location.
- Use **agentic AI** to support better documentation and communication with patients and caregivers about the results.

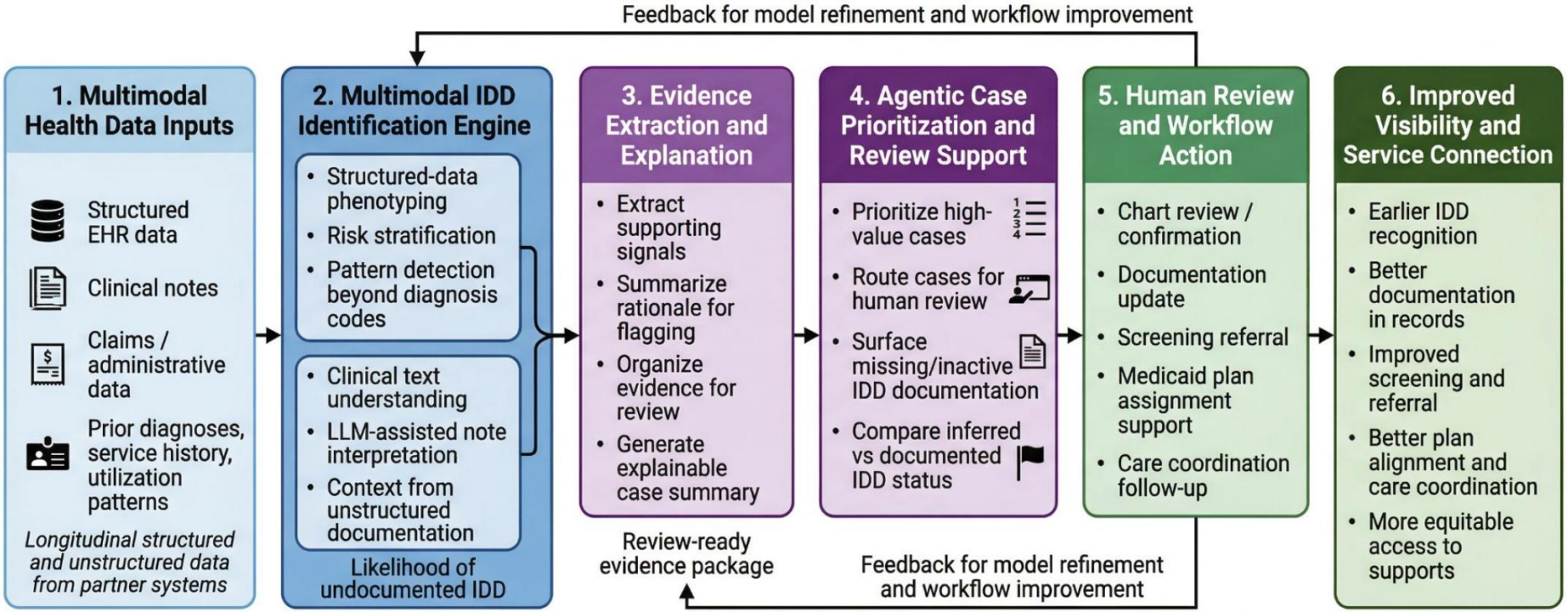
IEC

Favor High Finding People Who *Might* Have ASD/ID

- The problem we're trying to solve is invisibiliy of IDD
- e-IDD is intended to serve as a **screening tool**
- Favor design features that **over-detect** potential autism and/or ID
- e-IDD will show how high a person's **risk** is for having undocumented autism and/or ID
- Users (clinicians, health plans, government, researchers) will decide the level of certainty they want to apply for their specific use
    - Clinicians may be willing to consider lower risk of IDD (e.g., 70%) because they can approach individual patients to confirm diagnosis
    - Researchers may focus on higher risk of IDD (e.g., 95%) depending on the question they're trying to answer, and because they cannot confirm individual cases

IEC

Technical Workflow



How Will We Make Sure e-IDD Tools are Safe and Fair?

All Team Members Receive Training In Relevant Content Areas

- **IDD Lived Experience 101:** Common life and healthcare experiences for children and adults with autism and/or ID, and for family members.
- **IDD Clinical 101:** Clinical issues common in people with autism and/or ID.
- **AI 101:** Key concepts and decision-points.
- **Algorithmic Bias 101:** Common sources of unfairness (bias) and ways to address them.
- **Ethics 101:** Ethical framework for decision-making throughout the project.

IEC

We Have an Ethics Workgroup To Maximize Benefits and Minimize Risks to People with IDD

- Possible benefits
  - Better access to services and supports
  - People with IDD learning more about themselves
  - Redefine what IDD means from the person's perspective
  - Better clinical decisions
  - Improve health outcomes
- Possible Risks
  - Stigma, negative self-image
  - Feeding the narrative of autism or IDD as an "epidemic"
  - Results used to deny benefits, put employment at risk, institutionalize, or do other harm
  - How e-IDD works or is used not made transparent to people
  - Invaded privacy

IEC

Take Steps to Build Ethical Tools (1)

- Develop consensus on what “fairness” means to us
- Identify sources of unfairness in diagnosis & documentation of autism and ID
  - Patient factors – age, sex at birth, race/ethnicity, primary language, socioeconomic status
  - Social factors – urban/rural, state policies on eligibility for public benefits
  - Clinical factors – other clinical conditions, type of clinician or clinical setting
- Identify points where we can improve fairness when using AI tools
  - When talking with patients and caregivers – including communication, emotional support, etc.
  - When referring patients for formal diagnosis
  - When trying to improve documentation in health records
  - When communicating with other parties (e.g., health plans, Medicaid)
  - When referring patients for other services like transportation support

Take Steps to Build Ethical Tools (2)

- How we treat the data can reduce current unfairness and make tools more fair
  - How we select data & patients – e.g., over-represent groups at risk for not being documented
  - Computable phenotypes – e.g., include phenotypes typical of groups at risk for not being documented
  - Creating AI tools – e.g., overweight cases of patients from groups at risk for not being documented
  - Safeguards– e.g., checking the AI tools' "sources" of data to make sure what it produces is real and not made-up

- Build a robust governance process for e-IDD tools
  - Review through Duke's AI Evaluation processes
  - Set criteria for organizations that want to use it
  - Set rules on how it can be used
  - Set requirements for appropriate user training, informed consent
  - Build guidelines for discussing results with patients
  - Create a process for reviewing requests to use e-IDD tools
  - Do regular review of results and lessons learned from using the tools

IEC

What Have We Learned So Far?

EHRs have a lot of useful “hidden” information

- **Text that relates to IDD:**
  - Diagnoses and ***misdiagnoses***
  - Descriptions of behavior and relationships
  - Clinicians’ interpretation and actions
  - Information from caregivers

- **Documents that relate to IDD:**
  - From other healthcare providers: neuropsychological testing, speech therapy reports, etc.
  - From outside healthcare: IEPs, SSI applications, etc.

- **Actions by the clinician:**
  - Referrals to specialists (OT, PT, speech therapy, neurology, etc.)
  - Orders for testing
  - Orders for medical equipment

IEC