TRANSFORMING HEALTHCARE FOR PEOPLE WITH INTELLECTUAL & DEVELOPMENTAL DISABILITIES (IDD)

Transforming Care for People With IDD Helps Us All

institute for **excəptional** care

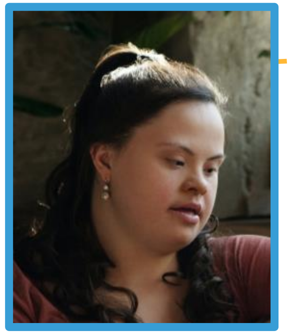
Transforming Healthcare for People With IDD

Our healthcare system does some things really well,
but it can also be complicated and frustrating.

For 16 million people with intellectual and developmental disabilities (IDD),
it can be ineffective and even unsafe.

Current State

Example: Current State



Lisa, age 19, suffers stomachache

Scheduled with PCP who limits visit time because of low payments

PCP prescribes Rx & refers to mental health provider due to agitation. Does not code Lisa’s IDD diagnosis in her chart.

Lisa feels unwelcomed, frustrated and isolated

Family seeks specialist for IDD without help from insurer (doesn’t know Lisa has IDD) or local disability agencies. Stomachache worsens

Parents take off work to drive Lisa to IDD specialist 50 miles away, who refers to medical specialist

Medical specialist can’t understand Lisa, isn’t aware of communication aids, orders full work-up

A month later, Lisa is still sick and more frustrated. Medication is not helping. PCP receives no feedback on poor outcome.

Example: Future State

Rob experiences stomachache

Rob sees neurodiverse-friendly PCP within 1-3 days

Rob's condition worsens, PCP refers to medical specialist, alerts insurance company to arrange transportation.

Specialist has productive visits due to advance communication and tailored sedation for endoscopy. Rob is diagnosed with a severe ulcer.

Specialist, PCP, and insurance company coordinate to set a treatment plan and follow-up.

Insurance company arranges respite care from a community agency for Rob's caregiver.

Challenges – Clinicians hold outdated views. Few are trained

Misperception that this is a small, “niche” group handled by specialists

Doctors (82%) rate quality of life as lower for people with disabilities

59% are not confident they can give quality care

Medical students receive an average of 11 minutes of exposure to IDD

IDD Care Is Not a "Niche"

- Population is large (3-5%) & growing, mostly adults
- Lifespans have risen from 20 to 70 years
- Cost of care is high: $350 billion annually (US)
- Most rely on general healthcare;
  limited access to IDD specialists
- Most are privately insured through employers/parents; NOT on Medicaid or SSI
- Stress for family caregivers (health, work productivity, financial)

Poor health and life outcomes

- Higher rates of obesity, diabetes, and poor overall health
- High rates of avoidable unemployment
- Suicide risk 3x higher with ID, 6-10x higher with autism
- Other than age, ID is the strongest predictor of COVID death
- Black/Brown, poor people with IDD have even worse outcomes

IEC launched in 2020

Our goal:

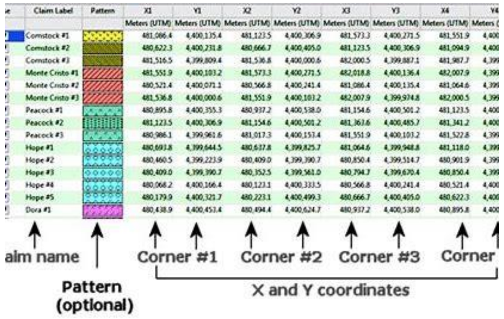
People with I/DD have better health and better lives

Pay for better care

Train more capable and caring clinicians

Take care coordination burden off patients and families

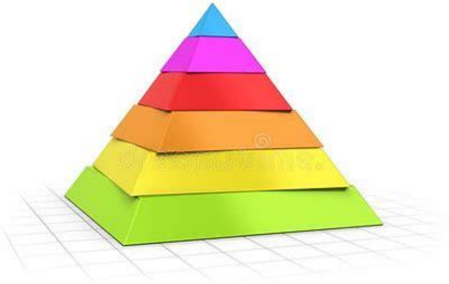
Paying for better care requires key tools



Claim Label	Pattern	X1	Y1	X2	Y2	X3	Y3	X4	Y4
		Meters (UTM)	Meters (UTM)	Meters (UTM)	Meters (UTM)	Meters (UTM)	Meters (UTM)	Meters (UTM)	Meters (
Comstock #1	▨	481,086.4	4,400,135.4	481,123.5	4,400,306.9	481,573.3	4,400,271.5	481,551.9	4,400
Comstock #2	▨	480,622.3	4,400,231.8	480,666.7	4,400,405.0	481,123.5	4,400,306.9	481,094.9	4,400
Comstock #3	▨	481,516.5	4,399,809.4	481,536.8	4,400,000.6	482,000.5	4,399,887.1	481,987.7	4,399
Monte Cristo #1	▨	481,551.9	4,400,103.2	481,573.3	4,400,271.5	482,018.8	4,400,136.4	482,007.9	4,399
Monte Cristo #2	▨	480,521.4	4,400,071.1	480,566.8	4,400,241.4	481,086.4	4,400,135.4	481,064.6	4,399
Monte Cristo #3	▨	481,536.8	4,400,000.6	481,551.9	4,400,103.2	482,007.9	4,399,974.8	482,000.5	4,399
Peacock #1	▨	480,895.8	4,400,355.3	480,937.2	4,400,538.0	481,154.6	4,400,501.2	481,123.5	4,400
Peacock #2	▨	481,123.5	4,400,306.9	481,154.6	4,400,501.2	481,363.6	4,400,485.7	481,341.2	4,400
Peacock #3	▨	480,986.1	4,399,961.6	481,017.3	4,400,153.4	481,551.9	4,400,103.2	481,522.8	4,399
Hope #1	▨	480,693.8	4,399,644.5	480,637.8	4,399,825.7	481,064.6	4,399,948.8	481,118.0	4,399
Hope #2	▨	480,460.5	4,399,223.9	480,409.0	4,399,390.7	480,850.4	4,399,514.7	480,901.9	4,399
Hope #3	▨	480,409.0	4,399,390.7	480,352.5	4,399,561.0	480,794.7	4,399,670.4	480,850.4	4,399
Hope #4	▨	480,068.2	4,400,166.4	480,123.1	4,400,333.5	480,566.8	4,400,241.4	480,521.4	4,400
Hope #5	▨	480,179.9	4,400,321.7	480,223.1	4,400,499.3	480,666.7	4,400,405.0	480,622.3	4,400
Dora #1	▨	480,438.9	4,400,453.4	480,494.4	4,400,624.7	480,937.2	4,400,538.0	480,895.8	4,400

- Data that is complete & accurate

- Knowing what outcomes to pay for



- Ability to predict what services a person needs

The Data Challenge

IDD is invisible

People with IDD are not labeled consistently in healthcare data.

- Lack of clinical awareness
- Lack of resources for testing and diagnosis
- Missed co-occurring IDD conditions
- Lack of self-disclosure
- Lost medical history during care transitions
- Lack of payment incentives

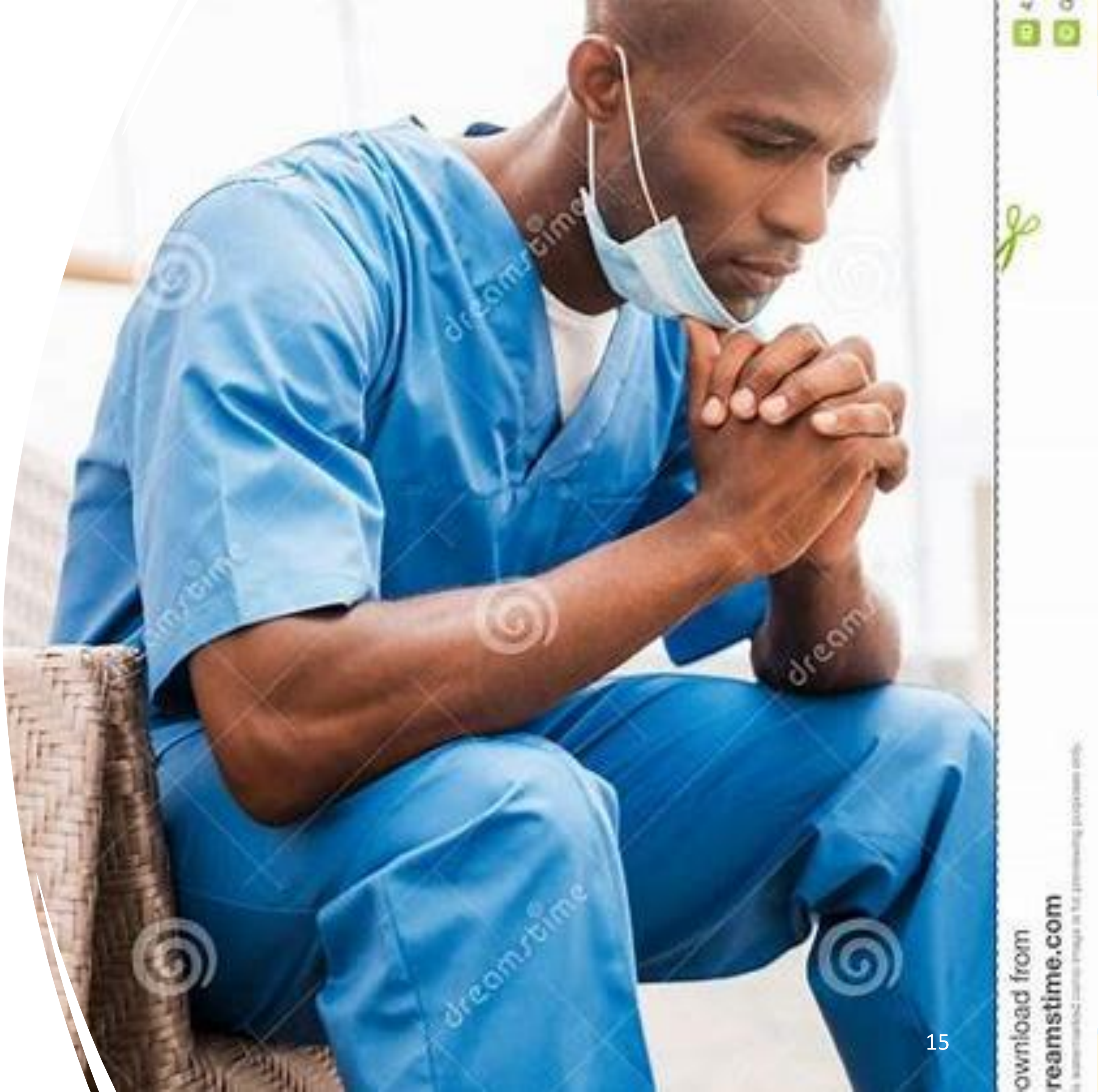
How much are we undercounting IDD?

- Ostensible prevalence in claims from a national insurer and EMR data from EPIC are a fraction of expected based on CDC monitoring and surveys (1-3 vs. 30-50 per 1,000)
- Subgroups at higher risk of under-counting
  - Adults
  - Females
  - Black/Brown/poor/rural
  - Those with less visible features

You can't address someone's needs if you can't see them

- Payers don't prioritize people with IDD
- Clinicians continue to believe they are a niche population
- Hard to reliably measure quality, spending, or disparities
- Hard to create business cases for better investment or payment
- Missed opportunities to understand the connection between IDD and avoidable ED visits, mental health crises, hospitalizations, & other poor outcomes
- Hard to target interventions to improve outcomes

Imagine a surgeon amputating limb after limb without knowing that diabetes exists….



The Solution

Paths to Making IDD Visible

- Rely on better diagnosis and documentation
  - Worked for HIV, depression, and other stigmatized conditions
  - Presumes basic clinical awareness
  - Meaningful improvement can take many years
- Invest in national data collection
  - Supports public health, tracking, and population analysis
  - Not useful for day-to-day business & clinical decision-making
- Create a proxy for actual documentation ✓

Making IDD Visible (e-IDD)

- Goals: Create a machine learning tool to comprehensively identify children and adults with IDD in typical healthcare data.
- Partnering with:
  - Montefiore, Duke, Jefferson Health, Cleveland Clinic, LISH, Nationwide Children’s Hospital
  - Unite Us, Intel
  - DD-PBRN, Colibri, READi, The Arc, Autism Society, Special Olympics
- Proposed $3M grant to PCORI.

Technical Challenges & Opportunities

- Selecting a “gold standard” definition of IDD
- Accessing a large pool of known IDD cases
- Resource intensive chart reviews
- Building case scenarios to coach the algorithm
- Making the most of EMR and billing data
- Leveraging rich socio-economic data
- Federated learning

Potential Unintended Consequences

- Propagation of current disparities in diagnosis & documentation
- Exposing patients to bias and harm
- Lack of clinical confirmation leads to inappropriate services

Ethical Challenges and Opportunities

- Ensuring that data fairly represents "at-risk" groups
- Ensuring that stakeholders understand the power & pitfalls of machine learning & use of proxy labels
- Ensuring that self-advocates and care partners perspectives and priorities inform algorithm development & application
- Conducting external validation & piloting before broad use

Access to e-IDD

- Desire for broad use in the industry
- Access mostly limited by costs of matching &linking socio-economic data
- Earliest applications likely for research
- Differential fees for research, clinical, business applications? Government and non-profit users vs. for-profit users?

Thank You!

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