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Advancing Disability Equity Together — Conference Session

The Diagnostic Team Starts in the Community: Building Partnerships and Reimagining Care in the Age of AI

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Grounded in Research & Leadership

This session draws on ongoing federally funded research and national leadership in disability-inclusive health professions education.



End Diagnostic Overshadowing (NIH-funded)

Examines how fragmented care, ableism, and communication barriers contribute to diagnostic inequities and delayed diagnosis; developing clinical decision-support approaches.



IDD Health Equity Workforce Program (ACL-funded)

Addresses gaps in disability-related content across interprofessional health education and practice.
iddhealthequity.org



Alliance for Disability in Health Care Education

Board member since 2015; President, 2018–2022 — advancing disability-inclusive health professions education nationally.



NLN Strategic Action Group

Contributed to Advancing Nursing Education: Disability Access, Retention, and Curriculum, guiding more inclusive nursing education.



Objectives

By the end of the session learners will be able to:

1. Describe reframing the diagnostic team as a community-to-healthcare partnership that includes individuals with disabilities, families, caregivers, advocates, and healthcare professionals.
2. Explain how diagnostic inequities arise from fragmented systems of care social determinants of health, ableism, and communication barriers between providers and patients/families/community supports.
3. Identify strategies - including community engagement, universal design, telehealth, and AI-enabled supports- to promote earlier recognition of health concerns and improved entry into diagnostic processes.



PURPOSE

To explore how individuals with disabilities, families, caregivers, advocates, community organizations, and healthcare professionals collectively contribute to the diagnostic process, and to identify strategies for advancing diagnostic equity through community partnerships, accessible communication, and emerging technologies



Case example

- A middle-aged man with an intellectual disability develops increasing lethargy, irritability, and reduced participation in daily activities. Support staff and family report concerns over several months.
- In initial evaluations, changes are attributed to aging and behavioral issues. Eventually he is hospitalized and diagnosed with severe hypothyroidism.



Case example

- Maria is a 35-year-old woman with cerebral palsy who lives in the community and works part-time. Over several weeks, she notices increasing fatigue and shortness of breath when performing activities that are normally easy for her.
- She tells her mother, who also notices that Maria seems less energetic than usual. Staff at her community program observe that she is taking more breaks and participating less in activities.
- Rather than assuming these changes are related to her disability, Maria, her family, and support staff discuss their observations and encourage her to seek medical evaluation.
- Her primary care provider recognizes assessment is warranted.
- Laboratory testing reveals severe anemia.
- Treatment is initiated, symptoms improve, and the underlying cause is identified before serious complications occur.



Delayed Pathway	Successful Pathway
Symptoms observed	Symptoms observed
Concerns raised	Concerns raised
Symptoms attributed to disability	Symptoms taken seriously
Diagnostic delay	Prompt evaluation
Hospitalization	Early treatment



Community Knowledge as Diagnostic Intelligence

Who Detects Early Changes?

- Individuals with disabilities
- Family members
- Caregivers
- Direct support professionals
- Peers and advocates
- Community organization staff

Why It Matters

Early observations often determine:

- Whether concerns are recognized
- Whether evaluation is sought
- Whether symptoms are attributed appropriately
- Whether diagnostic delays occur



The Diagnostic Team is Bigger than the Clinic



Individuals
with
disabilities



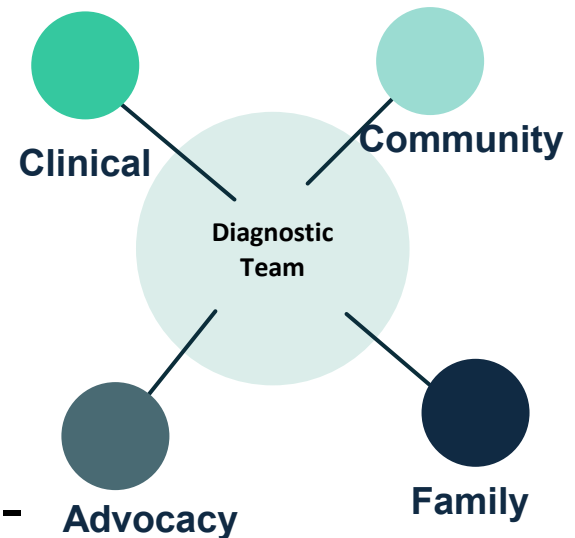
Families &
caregivers



Advocates



Community
organization
staff



Reframing diagnosis as a community-to-healthcare partnership brings people with lived experience into process from the start — not just at point of referral.



Where Diagnostic Inequities Come From

Fragmented Care System



Disconnected referral pathways, siloed providers, slow recognition/ F/U health concerns

Social Determinants of Health



Housing, income, transportation, and access to care shape who reaches a diagnosis — and how quickly

Ableism



Diagnostic overshadowing attributes new symptoms to an existing disability, delaying accurate diagnosis

Communication Barriers



Gaps between providers and patients, families, and community supports break down the information diagnosis depends on



Strategies for earlier recognition and entry

Community Engagement

Build trusted, sustained relationships with disability communities so concerns surface earlier — before crisis points.

Universal Design

Design intake, communication, and clinical environments to be usable by the widest range of people from the start.

Telehealth

Extend specialist reach and reduce access barriers like transportation, scheduling, and geography.

AI-Enabled Supports

Use clinical decision-support tools to flag risk earlier and counter ableism-driven diagnostic overshadowing.



AI as a Tool for Empowerment

Potential Applications

- Helping individuals prepare for healthcare visits
- Generating questions to ask providers
- Translating complex medical language into plain language
- Supporting symptom tracking over time
- Identifying patterns that may warrant further evaluation
- Facilitating communication between individuals, families, and care teams



AI and Diagnostic Equity – What is promising?

- Already used in diagnosis – reading of x-rays, scans, lab results
- Symptom checkers
- Earlier recognition of concerning patterns
- Identification of overlooked diagnostic possibilities
- Support for care coordination
- Expanded access to expertise through telehealth



AI and Diagnostic Equity – What is concerning?

Proceed Thoughtfully

- Healthcare data reflect historical inequities
- AI known to produce recommendations with racial, ethnic, gender biases
- Many critiques regarding lack of data with people with disabilities
- Recommendations/output biased
- Output needs to be reviewed/questioned

Questions We Must Ask

- Whose data trained the model?
- Whose voices are missing?
- Who benefits?
- Who might be harmed?
- How are disability communities involved?

From Concerns to Diagnosis

Reimagining Care in the age of AI

AI-enabled decision support doesn't replace the community-to-healthcare partnership — it strengthens the signal that reaches it.

How community engagement, telehealth, and AI-enabled supports move a concern toward earlier, more equitable diagnosis.

1. Concern raised in community

Family, caregiver, or self-advocate contact — not yet inside the healthcare system.

2. Universal-design intake

Accessible communication captures concerns accurately, regardless of how it's expressed.

3. Telehealth connects specialists

Geography and transportation no longer block access to the right clinician.

4. AI-enabled clinical decision support

Flags patterns clinicians might otherwise attribute to an existing disability, countering diagnostic overshadowing.

Selected References

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Discussion & Questions

Let's build the community-to-healthcare partnership together.

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