Our healthcare system does some things really well, like turning scientific research into powerful lifesaving cures and interventions. But for most of us, the system can be complicated and frustrating.

Those challenges are magnified for 16 million people with intellectual and/or developmental disabilities (I/DD) – including conditions such as autism, Down Syndrome, and cerebral palsy – who often receive care that is ineffective and even unsafe.

People with I/DD struggle in our system and have poor health and quality-of-life outcomes. Disparities are even worse for the 30 percent of people with I/DD who are Black, Brown, or low-income.

**Why?**

Insurance companies, government, and medical organizations don’t “see” all people with I/DD equally in their data, so they can’t meet everyone’s needs.

Many people with I/DD experience gaps in care, late diagnoses, poor communication with clinicians, and inadequate services and supports.

Many clinicians have outdated ideas and knowledge about people with I/DD and don’t feel prepared to care for them.

The result: high costs for payers, frustration for providers, and preventable hardship for patients and families.

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**IEC: POWERING PROGRESS THROUGH INNOVATION**

Institute for Exceptional Care (IEC) was founded in 2020 to address these issues and help people with I/DD and their families get the care and support they need in order to thrive.

**WE CAN DO THIS BY STRENGTHENING THE THREE C’S: COVERAGE, CONNECTIONS, AND CARE.**

**Smarter COVERAGE**

Smarter COVERAGE will generate better data and investment, track outcomes including racial disparities, and reward quality.

**Stronger CONNECTIONS**

Stronger CONNECTIONS to home- and community-based services will improve coordination and support and address social determinants of health, because healthcare cannot solve every problem.

**Better CARE**

Better CARE will allow families to stop “forever seeking” good care, improve care equity, and offer training and support so clinicians feel confident caring for I/DD patients.

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**MEET IEC’S CEO**

IEC’s President and CEO is Hoangmai (Mai) Pham, MD, MPH.

Mai is an internist and health policy leader who previously served as Vice President at Anthem (the nation’s second largest insurer) and Chief Innovation Officer for Medicare and Medicaid. As the mother of an autistic young man, Alexander, she experiences first-hand the struggles many families endure trying to get services they need.
IEC PROJECTS

**ABC3: Action to Build Clinical Confidence and Culture:** A multi-stakeholder action collaborative to scale strategies for engaging, preparing, and supporting general clinicians to provide better I/DD care.

**SCANS: Seamless Care Alliance of Nassau & Suffolk:** A direct care pilot program, based on Long Island, to reduce ED visits and improve outcomes and transitions back to the community by strengthening care coordination.

**IIDDEAL (Individuals with I/DD Engaged, Aligned, and Leading) Outcomes that Matter:** Engaging people with I/DD, caregivers, clinicians, and insurers/government to develop consensus on health and life outcome priorities and generate a research framework.

**Exploring an Optimal Integrated Care System for People with I/DD:** A National Academies of Sciences, Engineering, and Medicine workshop.

**Making I/DD Visible:** A groundbreaking initiative to deploy machine learning/artificial intelligence to identify people with I/DD in clinical and claim data, address disparities, and build a business case for better care.

OUR TEAM AND ADVISORS

IEC’s team combines personal commitment, uncommon expertise in healthcare innovation, deep understanding of how large health systems work, and the standing to influence decisionmakers. IEC is grateful to our distinguished Board, Advisory Council, and Values Framework Group, which is helping ensure that our work is inclusive and respects core values like self-determination and community integration.

**IEC BOARD OF DIRECTORS**

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JOIN THE MOVEMENT Together we can create a system that is equitable, supports our whole health, and focuses on the outcomes that matter most. These innovations will help ensure better care, for people with I/DD and for all of us. To learn more about IEC, please visit www.ie-care.org. To support the mission of IEC, please visit www.ie-care.org/donate.