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 (IDD) – including conditions such as autism, Down Syndrome, and cerebral palsy – who often receive care that is ineffective and even unsafe.

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

**WHY?**

- Insurance companies, government, and medical organizations don’t “see” all people with IDD equally in their data, so they can’t meet everyone’s needs.
- Many people with IDD 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- Many clinicians have outdated ideas and knowledge about people with IDD and don’t feel prepared to care for them.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.

**IEC: POWERING PROGRESS THROUGH INNOVATION**

Institute for Exceptional Care (IEC) was founded in 2020 to address these issues and help people with IDD 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 community-based services 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 IDD patients.

**MEET IEC’S CEO**

IEC’s President & 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 AND PRIORITIES

IEC is developing innovative projects that include:

A *National Academy of Medicine workshop*, to explore building an integrated IDD care system, including care coordination models, financing/payment, and clinician preparedness.

*ABC3: Action to Build Clinical Culture and Confidence*, by engaging organizations such as medical societies and accrediting bodies that can take training resources and requirements to scale nationally.

*Making IDD Visible*, to develop automated tools for identification of people with IDD that can help address disparities in care and support business cases for insurers and healthcare purchasers to better invest in IDD care.

The *Health Outcomes Framework*, to develop methods for measuring the quality of care, including health and life priorities, data, feasibility and relevance tests, and provider scorecards.

OUR TEAM AND PARTNERS

With a team that combines personal commitment, uncommon expertise in healthcare innovation, deep understanding of how large health systems work, and the standing to influence decisionmakers, IEC is poised to lead a multi-front effort to transform care for people with IDD.

IEC ADVISORS

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

Bernard Rosof (Chair), Professor, Hofstra Northwell School of Medicine

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Morénike Giwa Onaiwu, Autism & HIV Educator and advocate

James Perrin, Professor, Massachusetts General Hospital

Vish Sankaran, Chief Innovation Officer, Walgreens Boots Alliance

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 IDD and for all of us. To learn more about IEC, please visit [www.ie-care.org](http://www.ie-care.org). To support the mission of IEC, please visit [www.ie-care.org/donate](http://www.ie-care.org/donate).