Institute For Exceptional Care (IEC)

Summary

What is our goal?

We want people with intellectual and developmental disabilities to have the best care from doctors, nurses, and therapists.

Best care means that your doctors, nurses, and therapists care about what is important to you and what you need. It also means that they work with people important to you, such as your family members, friends, support workers, and other people you choose.
When you get the best care, it means you get good health care from people who understand and care about you.

**Who started Institute for Exceptional Care (IEC)?**

Dr. Hoangmai (Mai) Pham, MD, MPH is the founding President of the Institute for Exceptional Care. She and the Institute for Exceptional Care team are healthcare experts. They are also family members of individuals with intellectual and developmental disabilities (IDD).
What is the problem?

- Many doctors do not know much about people with intellectual and developmental disabilities. They especially don’t know much about adults with IDD.
- Many people with IDD do not receive care that is right and helpful for them. Doctors, nurses, and therapists need to give better care to people with intellectual and developmental disorders.
- Many people with IDD have challenges with their physical and mental health. It can also be hard to find a job, and find a place in the community to socialize and relax.
- All of these challenges are greater for Black, Brown, and poor people.
What will we do?

1. We will find examples of the best care for people with intellectual and developmental disorders. We will also find ways to pay for the best care.
2. We will study how good hospitals and clinics provide care for people with IDD.
3. We will measure how good the health care that doctors, clinics, therapists and hospitals give is.
4. We will work with public and private insurers and employers to pay for good care.
5. We will help many hospitals and clinics give the best care.
6. We will help doctors, nurses, and other people understand people with IDD and we will teach them how to work with people with IDD.

What is IEC good at?

- We care about, listen to, and understand the needs of people with IDD.
- We respect and partner with people with IDD and their families.
- We know how to advocate for more payments for services for people IDD.
- We know how to improve big healthcare systems.
• We are leaders in healthcare and have good relationships with other leaders.
• We are good problem solvers.

**Who will IEC partner with?**

We partner with people with IDD. We partner with doctors, nurses, and therapists. We partner with organizations that care about people with IDD. We value your opinions about who we partner with. Here are some examples of our other potential partners:

Potential partners in understanding the quality of health care for people with IDD:

• Employee Benefit Research Institute
• Patients Like Me
• Health Care Cost Institute
• United Health Group, Anthem, and other public and private insurance companies
• Council on Quality and Leadership
• Mathematica Policy Research, Urban Institute, Manatt
• Kaiser Permanente Research Foundation
• Autism Treatment Network
• Association of University Centers on Disabilities
• Academic institutions and experts in disability research

Potential partners in understanding ways to pay for the best health care:

• Health insurance companies,
• Large employers & employer coalitions
• National Business Group on Health
• Health Transformation Alliance
• Pacific Business Group on Health
• Healthcare Transformation Task Force
• Medicaid agencies
• Medicare
• American Network of Community Options and Resources
• National Alliance for Advancement of Adolescent Health
• Providers paid by the above

Potential partners in training doctors, nurses, and therapists:

• American Academy of Cerebral Palsy and Developmental Medicine
• Academy of Cognitive and Behavioral Therapies
• American Academy of Developmental Medicine & Dentistry
• American Academy of Nursing
• American Medical Association and individual specialty academies
• Center for Dignity in Healthcare
• Council of Specialty Medical Societies and individual medical societies
• National Organization of Nurses with Disabilities
• American Board of Medical Specialties and individual specialty boards
• Organization of Direct Support Professionals
• Robert Wood Johnson Foundation
• Aspen Institute
• Commonwealth Fund