

institute for exceptional care

*Transforming Healthcare for People
with Intellectual and/or
Developmental Disabilities (IDD)*



2021 IMPACT REPORT



WELCOME

Institute for Exceptional Care (IEC) launched in the fall of 2020, powered by a small leadership team and a vision of transforming healthcare for people with intellectual and/or developmental disabilities (IDD).

We are seasoned healthcare leaders who understand the feats our system is capable of when

- It pays for what people need,
- Professionals lift the burden of coordinating services off patients and families, and
- Clinicians are prepared and motivated.

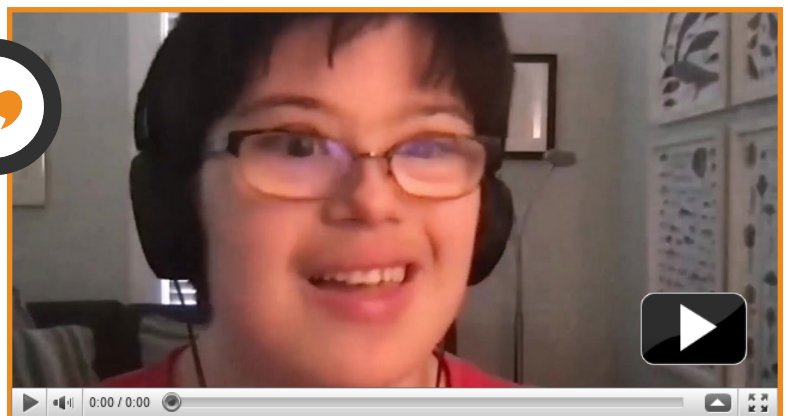
We are also parents of children with disabilities and know all too well that, for 16 million people of all ages with IDD, healthcare is not delivering in these critical ways.

We see the way forward, through transforming these three pillars, to a system that understands, honors, and supports the health and life goals of people with IDD.

This report explores the intense first full year of IEC's work and growth, showing how we've begun foundational work on each pillar for change through program sketches, funding updates, facts and figures, and personal reflections. All quotes highlighted in the report come from individuals with IDD and family care partners, whose lived experience and counsel inform every aspect of IEC's work.

Martha Haythorn, Self-Advocate

"You guys [IEC] ... are really going to educate people. Really going to teach people how to serve, medically, people with disabilities. Because it is not easy work, but the fact that you guys are ... putting research into it, like, wow."



Martha Haythorn for the IIDDEAL project exploring the health and life outcomes that matter most to people with IDD. (June 20, 2022) [Watch Martha's video here.](#)



REFLECTIONS ON IEC'S ORIGINS AND FIRST FULL YEAR



*Mai Pham, MD, MPH
President and CEO*

Our family crashed with my son Alexander's first crisis in high school. We saw our brilliant, gentle, confident son devolve in stress and anxiety as the passionate learner in him collided with the reality that his brain could simply not do what teachers were asking.

We scrambled to put together the kernel of a team – our autism "coach," an evidence-based psychiatrist, and a cognitive behavioral therapist. I coordinated multi-lateral conversations between clinicians and school staff so we could all understand better what supports Alexander needed and how to get them.

Catching breath later that year, I reflected on how we had gotten to this point and saw the long trail of failures in the system. Our pediatrician never offered us specialized referrals or advice. Alexander was diagnosed late by school psychologists. No one pointed us toward peer support or counseled us on what to expect as he grew older.

Even with my background as a physician, researcher, and national policy leader, I still hadn't understood how families with IDD live until we experienced it personally – the burden of managing a fragmented network of providers, the challenge of even finding qualified ones, the sense of "forever seeking" the solutions to our problems.

My lack of professional knowledge, faulty assumptions, and bias make me rather typical of most general healthcare leaders. This implies that we need broad culture change in healthcare. The good news is that we have lots of experience from other areas of healthcare to help us solve these types of system failures.

This inspired me to start IEC to transform healthcare for people with IDD so they can thrive.

Making Change on Multiple Levels

IEC takes a structured approach to system change. We know that true transformation requires building a movement, inside and outside healthcare, that shifts the cultural perspective, creates an inspiring vision, and generates demand and momentum for change. It requires



making change at multiple levels: on the ground with communities, at the industry level, and at the level of policymaking.

Building our vision of healthcare that is empathetic, informed, and supportive means strengthening key pieces of the system that fit together.

- ***Paying for what people need*** means insurance benefits that cover all services people with IDD need, financing for that care, and the payment for those services.
- ***Taking the burden of coordinating services off patients and families*** means clear processes and distinct roles and responsibilities between different providers, like clinicians and home- and community-based services (HCBS) or education.
- ***Preparing all clinicians to serve people with IDD*** means up-skilling general clinicians. We need deep and broad culture change to move from a system of bias and ableism to one of empathy, commitment, and clinical competency.

Building a Bridge

Let's admit that there can be deep mistrust between the disability and healthcare communities, for understandable historical reasons.

As healthcare leaders with decades of policy and operational street cred, as well as family caregivers with lived experience, IEC has the rare opportunity to maintain trust in both communities, to help translate their priorities and concerns, and build safe, constructive spaces for them to solve problems together.

For our movement to succeed, we will need to convince stakeholders – not that the IDD population is special and needs unique supports, but rather that building a healthcare system that serves the IDD population well will result in a system that serves everyone better. By putting the needs of people with IDD front and center, we can make the healthcare system more effective and humane for all of us.

Max, Self-Advocate



"I have Williams syndrome, and not a lot of people know ... how to handle it or how to be patient with people with this condition."

BUILDING SOLUTIONS

Through its program work, IEC is working to build technical and collaborative solutions that can be scaled up and adapted for use across the country. Here are highlights of five projects already under way.



Program Highlight

IIDDEAL (Individuals with IDD Engaged, Aligned, and Leading): Outcomes That Matter



Illustration by Tim Corey,
Colibri Facilitation

Paying for what people need and preparing clinicians to serve them require knowing what we should pay for and try to achieve – what health outcomes are most important to people with IDD and their care partners. This “patient-centeredness” is an essential aspect of ensuring healthcare quality but is dramatically lacking in the care experience of most people with IDD.



The goal of the **IIDDEAL (Individuals with IDD Engaged, Aligned, and Leading: Outcomes That Matter)** program is to drive consensus across people with IDD, care partners, clinicians, and insurers on what health outcomes matter most.

A key part of the work is powerful listening sessions with people with IDD, care partners, clinicians, payers, and regulators. To support the participation of IDD self-advocates, a graphic illustrator listens in and creates a sketch of their insights in real time. For Thomas, whose interview is portrayed here, a good health outcome is, "getting through my day without fear."

Such insights will inform a framework of consensus recommendations to help ensure that future health research will be both meaningful to the IDD community and actionable for providers and payers.

IIDDEAL is a collaboration with Augusta University and is supported by a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award, EASCIDD-00241 PCORI, with additional funding from Arnold Ventures.



Program Highlight

SCANS: Seamless Care Alliance of Nassau & Suffolk

Coleen Mackin, Self-Advocate



"The ER staff overlook me and talk to whoever is with me. I am my own guardian, so they should listen to me. They think that I don't understand, but I do."

All three of IEC's pillars collide in the emergency department (ED). People with IDD too often end up in EDs because payment isn't supporting the services they need in the community and/or because of poor communication and coordination among service providers. Poorly prepared clinicians in both the community and ED settings can lead to unnecessary testing, misdiagnosis, unsafe care, and frightening experiences for people with IDD.



When ED teams don't understand IDD (especially the needs of people with communication challenges), vital information gets missed or lost, and bad situations can escalate quickly.

SCANS is a pilot program that aims to reduce avoidable ED visits, improve the quality of ED care when a visit is needed, and ease people's transitions back to the community.

"EDs are very intense, scary places. Monitors are beeping, lots of people are running around," says Susan Platkin, MD, a retired physician, mother of an adult daughter with IDD, and member of the SCANS Steering Group. "A nurse says, 'I'm going to take your blood pressure,' and a patient with IDD thinks, 'What's a blood pressure? What is she doing to my arm? Why does it hurt? Will it go on forever?'"

A dynamic coalition including health systems, home- and community-based service providers, state and county agencies, insurers, and people with IDD and their care partners have signed on for this three-year project on Long Island, to model, test, and scale up powerful on-the-ground change. (See the full SCANS Steering Group [here](#).)

SCANS is supported by a grant from The Fay J. Lindner Foundation.



During a SCANS site visit to Cohen Children's Medical Center, pediatric ED physicians Matt Harris, MD (left), and Joshua Rocker, MD (right), discuss the [Bee Mindful program](#) which provides education, tools, and procedures to improve the experience of neurodiverse children in healthcare settings, with ED Child Life Specialist Therese Weisbrot (center).



Program Highlight

Action to Build Clinical Confidence and Culture (ABC3)

Despite abundant curricula available to clinicians in training and in practice, most medical and nursing students, trainees, and practitioners are not adequately prepared to serve people with IDD. We need to prepare all clinicians because there will never be enough IDD specialists to serve 16 million people, and as people with IDD live longer, they need oncologists, neurologists, and every clinician they encounter to be ready to meet their needs.

The goal of **Action to Build Clinical Confidence and Culture (ABC3)** is to build a movement that motivates clinicians to seek training and become effective, committed advocates for their patients with IDD.

Eight in ten medical school graduates receive no IDD-specific preparation. Nursing schools report similarly low rates of preparation. Persons with IDD are abundantly aware of this lack of preparation and clinical confidence.

ABC3 is a coalition of major national organizations representing accreditors, leading physician organizations, medical educators, and self-advocates who want to create a healthcare system that is prepared and welcoming to individuals with IDD.

“The ACGME is actively supporting the collaborative so we can universally deliver tailored training, and reinforce through residency, critically needed competencies to serve all persons with IDD,” says Eric Holmboe, MD, Chief, Research, Milestones Development and Evaluation at the Accreditation Council for Graduate Medical Education (ACGME), and an ABC3 Steering Group member.

Martha Haythorn, Self-Advocate



“When I get sick, it’s hard for me to identify what is hurting. It takes time understanding where these things are bothering me.”



While we see gradual improvements in acceptance of patients with IDD, and the motivation to be better prepared, ABC3 can accelerate uptake through levers such as presentations at national forums, promoting prominent role models, enhanced licensure and certifications requirements, and demonstrating improvements in clinical confidence from incremental changes to curriculum.

Steering Group Members

- Accreditation Council for Continuing Medical Education
- Accreditation Council for Graduate Medical Education
- American Academy of Developmental Medicine and Dentistry
- American Academy of Pediatrics
- American Association of Intellectual and Developmental Disabilities
- American College of Physicians
- Association of American Medical Colleges
- BJ Stasio, Self-Advocate
- The Center for Dignity in Healthcare for People with Disabilities
- Developmental Disabilities Nurses Association
- ECHO Autism
- IntellectAbility
- Kayte Barton, Self-Advocate
- Nisonger Center
- Special Olympics International

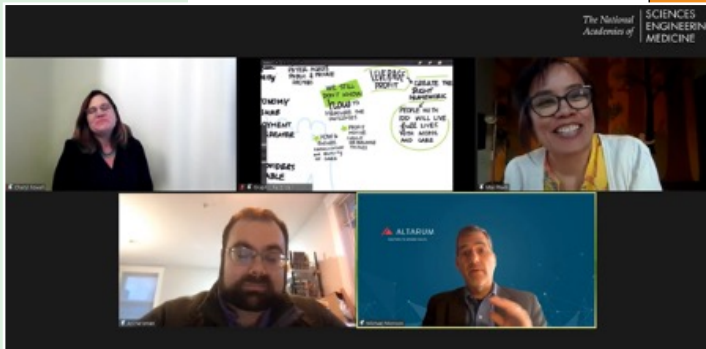
ABC3 is supported by funding from The WITH Foundation and Special Olympics International.





Program Highlight

Exploring an Optimal Integrated Care System for People with IDD



THREE CASE STUDIES

Innovative Financing and Payment Models for Care of People with I/DD

By Brede Eschliman, MPH
Director, Medicare
Aurrera Health Group

institute for exceptional care

Aurrera
HealthGroup >>>

Shaping a bold agenda for transforming care for people with IDD, IEC’s Mai Pham and Board member James Perrin co-chaired the planning committee for this National Academies of Sciences, Engineering, and Medicine (NASEM) workshop, which spanned three days and drew more than 900 participants.

From a welcome by White House Domestic Policy Council Director of Disability Policy Kimberly Knackstedt to reflections by former CMS Innovation Center director Rick Gilfillan, the event explored strategies for scaling up innovative models of care, strengthening financing and payment, and creating a better prepared workforce.

Workshop planning was supported by The WITH Foundation, three IEC-commissioned white papers were supported by an anonymous donor, and a graphic illustrator was supported by the Lucile Packard Foundation for Children’s Health.





Program Highlight

Making IDD Visible



You can't address someone's needs if you can't see them. But many pediatric providers, and most adult providers, do not screen their patients for IDD and do not note it in their medical records or insurance claims.

Many people with IDD are therefore not "visible" in healthcare data, so their unique needs go drastically unmet, under-counted, and under-resourced.

Making IDD Visible is critical for improving all three pillars of payment, coordination, and preparing clinicians to improve care. This multi-year project will deploy machine learning—Artificial Intelligence—to analyze large sets of clinical and socioeconomic data to identify people with IDD.

Accurate prevalence information will help build a business case for smarter investments, better targeted services, and more appropriate payment. This incentivizes better screening, charting, and care.

IEC's standing among payers and health systems has allowed us to engage partners as diverse as Intel's Network & Edge Group, the Director of the Montefiore Einstein Center for Health Data Innovations, Duke University, Cleveland Clinic, and the Developmental Disabilities Practice Based Research Network.

We are actively seeking project funding for Making IDD Visible.

Zanetha Matisse, Self-Advocate



"It is so validating to be seen, heard, and respected."



CHANGING THE CULTURE

IEC is building demand for culture change in healthcare by leveraging thought leadership from IEC senior leaders, working with consumer and trade media, and forging relationships that bridge the healthcare and disability communities.



Thought Leadership

Publications

- *Modern Healthcare* guest piece [Let's build a 'neurodiverse-friendly' healthcare system](#): Mai Pham co-authored with Julia Bascom and Richard Antonelli
- *Helen: The Journal of Human Exceptionality*: Mai Pham contributed to *Behind the Numbers of People with IDD* and *Why Institute for Exceptional Care's Mission Is Both Professional and Personal*
- *Journal of the American Medical Association*: Submitted *Signs of Progress: Data Suggest Racial Gap for ASD Diagnosis is Closing: Research Letter*. Co-authors Mai Pham and the Epic Clinical Team
- *Autism (journal)*: *Distilling Innovative US Autism Care Programs that Address Widely Perceived Unmet Patient and Family Needs*. Co-authors Mai Pham, Venus Wong, Kristen Godfrey, and Arnold Milstein
- HRSA's Blueprint for Change (published in *Pediatrics*): Submitted comment letter on financing care for children with special healthcare needs
- New York State's proposed 1115 Waiver Amendments: Submitted comment letter
- Interagency Autism Coordinating Committee 2021 proposed strategic plan: Submitted comments

> *continued on next page*



- *Autism (journal): Listening to the Autistic Voice: Mental Health Priorities to Guide Research and Practice in Autism from a Stakeholder Driven Project.* Co-authors May-Lynn Andresen and IEC partner Teal Benevides, et al.
- *Interventions to Address Health Outcomes among Autistic Adults: A Systematic Review.* Co-authors Teal Benevides, Steven Shore, May-Lynn Andresen (IEC), et al.

Presentations



Mai Pham moderates a panel at the Global Health Care Virtual Health Equity Summit (June 9, 2021)

- Academy Health Policy Roundtable: Mai Pham chaired *Preparing the Workforce to Serve People with Intellectual and/or Developmental Disabilities*
- 2021 Health Equity Summit: Mai Pham moderated three sessions on disability
- AADMD Annual Conference: Mai Pham delivered plenary address
- Special Olympics Inclusive Health Summit: Mai Pham delivered keynote address

Convening and Advisory

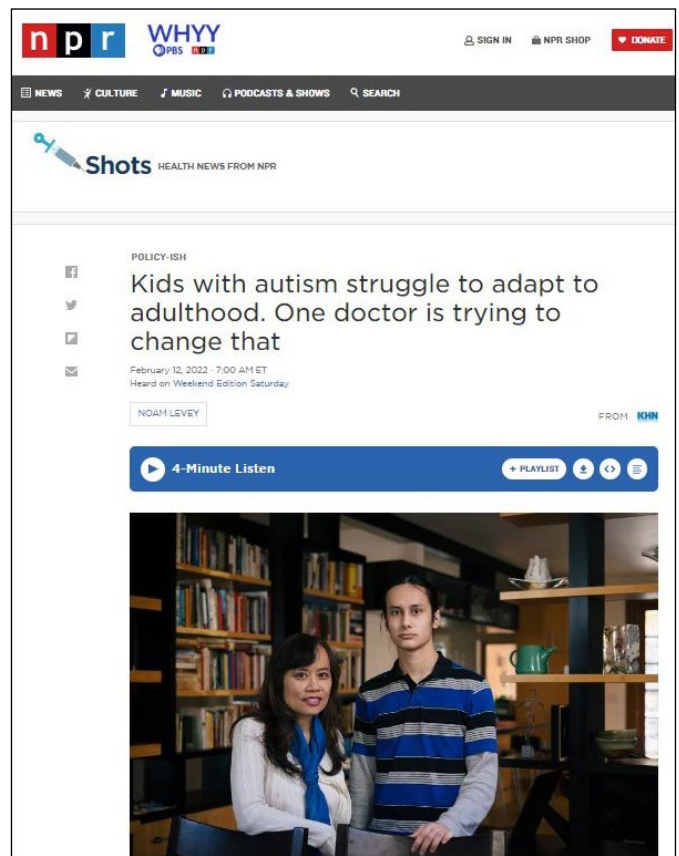
- National Academies of Sciences, Engineering, and Medicine (NASEM): Mai Pham co-chaired workshop planning committee for *Exploring an Optimal Integrated Care System for People with Intellectual and Developmental Disabilities*
- National Academy of Medicine Leadership Consortium and NASEM Board on Health Care Services: Mai Pham co-chaired workshop *Financing That Rewards Better Health and Well-Being*
- Special Olympics International Inclusive Health Advisory Council
- National Council on Disability: provided solicited input for report on improving healthcare for people with disabilities
- Coalition to Transform Advanced Care (C-TAC): Board Member



Media Coverage

IEC's reach is extended by coverage in mainstream and specialized media outlets, including:

- National Public Radio: This extensive profile appeared both on NPR ([Kids with autism struggle to adapt to adulthood. One doctor is trying to change that](#)) and in Kaiser Health News ([This Doctor Thought She Could Navigate US Health Care. Then Her Autistic Son Needed Help](#))
- *Exceptional Parents* magazine: Mai Pham published a first-person account [When My Son Was in Crisis: Why My Medical, Government, and Insurance Background Didn't Help](#)
- AAMC News: *News About America's Medical Schools and Teaching Hospitals*: The ABC3 program was highlighted in [Caring for Adults with Intellectual and Developmental Disabilities](#)
- Relentless Health Value radio interview: EP325: [The Show in Which Dr. Mai Pham Disagrees With Three of My Value-Based Care Premises](#)





Building Community

Active listening, collaboration, and promoting self-determination are core IEC values that inform our work and help create an inclusive community in which IDD self-advocates and their families and care partners participate fully and authentically.

Examples of IEC community integration activities include:

- Participation of three IDD self-advocates on IEC's board
- Consultation with the IEC [Advisory Council](#) and the IEC [Values Framework Group](#)
- Consultation with the SCANS program [Steering Group](#)
- Preparation of Plain Language versions of key IEC documents (such as our [Process Guardrails document](#)) by compensated self-advocates
- Participation of a graphic illustrator in interviews and events to support IDD self-advocacy
- Including guest pieces by self-advocates in the majority of e-newsletter editions
- Joining events with community organizations, including Vong Tay Cha Me Viet (Vietnamese-language IDD parent group in Boston), CA Human Services (for families with developmental disabilities in Northern Virginia), and the Riverview School (on Cape Cod)

OUR STORY

We share the story of Mai Pham's autistic son, Alexander, and their family's struggle to find the right care for him, in this exceptional video created by two of his childhood friends the year they all graduated from high school. Watch the video [here](#).



FUNDING AND SUPPORT

IEC has been honored to receive funding support and affirmation from numerous foundations and institutional funders in the past year. Our thanks to:



The Fay J. Lindner Foundation



CEO Mai Pham addresses an IEC fundraiser and reunion event for colleagues from the CMS Innovation Center, at DCanter Wine Bar (November 5, 2021 in Washington, DC)



IEC is extremely grateful for the financial contributions of individual and family donors:

- Robert Berenson
- Jay Desai
- The Do & Rickles Family Foundation
- Robert Galvin and Gail D'Onofrio
- Rick Gilfillan and Carmen Caneda
- The Karp Family Foundation
- The Debbie and Lloyd Myers Family Foundation
- The Dan and Jane Och Charitable Trust
- The Pham Roodman Family Foundation
- Gary and Rowena Roodman
- Bernard Rosof and Adrienne Rosof
- Samantha Sheridan and Brian Seasholes
- Anonymous

IEC Board of Directors

IEC is fortunate to have a diverse and accomplished Board of Directors guiding our progress. Find full bios on the members of the IEC Board at our [website](#).

- Bernard M. Rosof
IEC Board Chair
Professor of Medicine, Zucker School of Medicine
at Hofstra/Northwell
Board of Directors, Huntington Hospital, Northwell Health System
- Staci Alexander
Director, Thought Leadership, AARP
- Julia Bascom
Executive Director, Autistic Self Advocacy Network
- Donald M. Berwick
IEC Board Member Emeritus
Founder, Institute for Healthcare Improvement;
Former Administrator, Centers for Medicare & Medicaid Services
- Cuong Do
IEC Board Vice Chair
CEO, BioVie; Founder and Chairman, M6P Therapeutics
- Chester Finn
Individual and Family Advocate, New York State Office for Persons
with Developmental Disabilities (OPWDD)
- Merrill Friedman
Senior Director, Disability Policy Engagement, Anthem, Inc.
- Robert Galvin
Chief Medical Officer and Operating Partner, Blackstone
- Rick Gilfillan
Independent Consultant
Former Director of CMS Center for Medicare and Medicaid
Innovation
- Morénike Giwa-Onaiwu
Educator; Autism & HIV Advocate
- Margaret O’Kane
President, National Committee for Quality Assurance

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- James M. Perrin
Professor, Massachusetts General Hospital
Founder, Autism Treatment Network
- Vish Sankaran
Chief Innovation Officer, Walgreens Boots Alliance



An Afternoon with IEC: This event held in the home of IEC Board member Bob Galvin brought together program partners, supporters, and new members of the IEC community (May 15, 2022 in New York City).

BUILDING IEC

Communications and Outreach

- IEC's monthly e-newsletter, [Exceptional Progress](#), launched in July 2021, offers updates, a message from Mai Pham, and [guest posts](#) by IDD self-advocates. 1,450 subscribers.
- IEC's website accommodates an expanding program portfolio, collateral materials (such as IEC [publications](#) and [recordings](#) of NASEM workshop sessions), and a secure online donation link.
- IEC's social media outreach uses a LinkedIn [page](#) (800 followers), a Facebook [page](#) (76 followers), and a Twitter [account](#) (141 followers).

Organizational Growth

The IEC staff, originally just three people, has recently grown to five as we welcomed a Chief Operating Officer and a Program Specialist. Find full bios on all of us at our [website](#).



**Hoangmai (Mai)
Pham,
MD, MPH**

President, CEO,
Board Member



**May-Lynn
Andresen,
DNP, RN**

Director of
Partnerships



**Samantha
Sheridan,
MA**

Director of
Advancement



**John
Stowe**

Chief
Operating
Officer



**Miriam
Edelman,
MPA, MSSW**

Program
Specialist

Additional Support

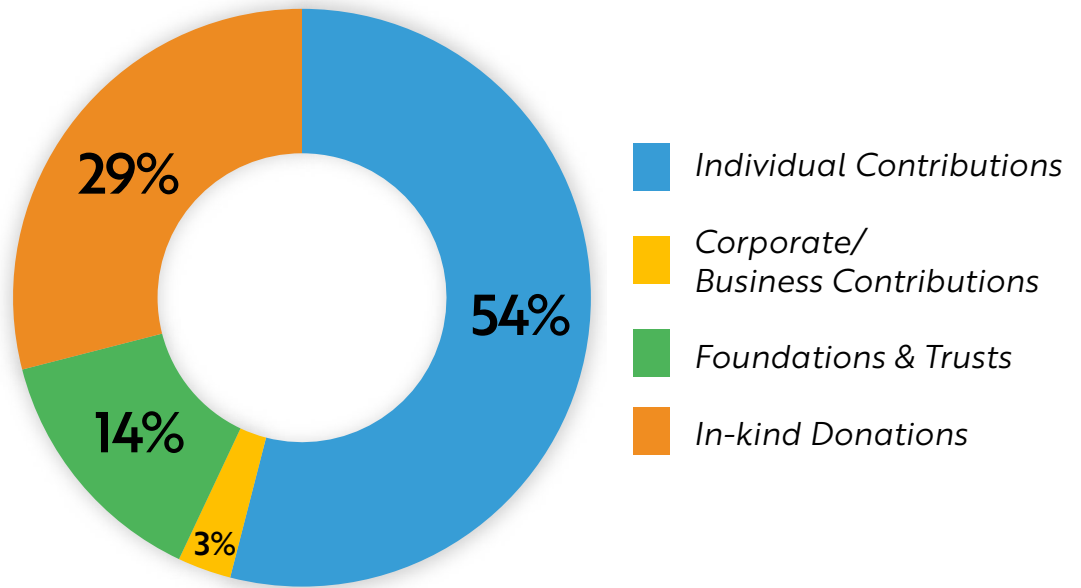
IEC would also like to express our thanks to The Arc (US) for their administrative and fiscal management support for our operations, to Covington & Burling LLP for providing pro bono legal services, and to SCP (Strategic Communications & Planning) for communications consulting support.



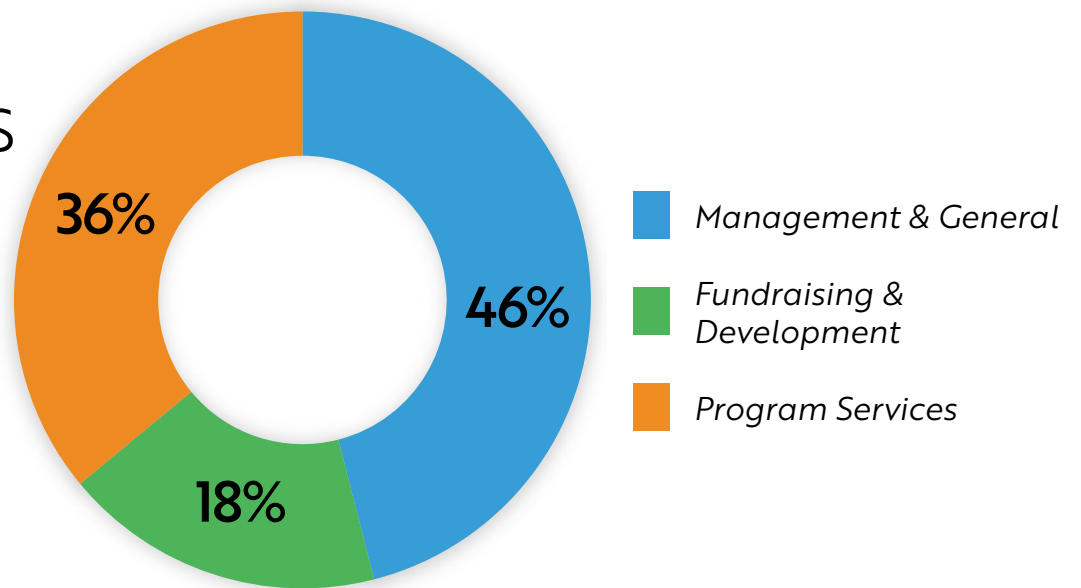
FINANCIAL OVERVIEW

This financial information represents fiscal year 2021.
To learn more, please visit our website, www.ie-care.org.

IEC INCOME



IEC EXPENSES





*Transforming healthcare so people
with intellectual and/or developmental
disabilities (IDD) can thrive*




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Exceptional Care**

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