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# Message from IEC Leadership

Dear Friend,

At IEC, we are driven by a bold vision: a healthcare system where people with intellectual and/or developmental disabilities (IDD) feel safe, respected, included, and confident in the care they receive.

This vision stems from a hard truth. For too many individuals with IDD and their families, healthcare is still a source of harm and fear rather than healing. It's a system that still too often lacks the training, tools, and culture to serve people with IDD equitably. Changing this reality is not easy, but thanks to you, we made real progress in 2024.

Our work is guided by a clear strategy: to transform how healthcare is taught, delivered, and paid for. This approach keeps us focused on creating lasting, systemic change that improves care from every angle.

With your support, we **launched our ABC3 Roadmap**, a community-driven vision to improve how healthcare is taught. With the support of more than 180 individuals and organizations, we took this message on the road, speaking at conferences across the country and rallying healthcare leaders around what better care can and should look like. And we convened public and private experts at our second **IIDDEAL Policy Summit**, and **published our shared health goals in JAMA**, raising national awareness of the health outcomes that matter most to people with IDD.

You helped us create tools for real change. We **created a 90-minute training** to help clinicians better serve patients who have communication disabilities. We **built the *Always Uniquely Me* app**, which helps individuals with IDD and their families advocate for themselves in emergency rooms. We also **designed common-sense tools to help dental practices** better support patients with IDD.

Most importantly, our community grew. With your help, our **IDD Advocate Corps** tripled in size from 30 to 90 members, bringing together self-advocates, care partners, and healthcare professionals to lead this work.

This is what it means to create culture change. Each conversation, course, app, or policy recommendation is a step forward in building trust between the healthcare system and the IDD community.

As we look ahead to 2025, we are more determined than ever to press for change. And thanks to your support, we are moving forward with hope, strength, and momentum. People with IDD deserve the best health and the best lives possible. Our team remains committed to making that a reality.

With gratitude,



A handwritten signature in black ink.

Mai Pham, MD, MPH

President and CEO



A handwritten signature in black ink.

Rick Gilfillan, MD, MBA

Board Chair



## Our Mission

Bring together healthcare insider knowledge and lived experience to make healthcare better and safer for people with IDD.

## Our Vision

A world where people with disabilities enjoy the best possible health so they can live life to the fullest.

## Our Story

IEC was founded by healthcare professionals with lived experience supporting loved ones with IDD.

# Why Our Work Matters



1 in 20 Americans have IDD, but **60% of physicians** feel unprepared to provide quality care to people with disabilities

“

**I literally cannot find a doctor's office that has accessible examination tables for people like myself who have limited mobility.** I just want to get a Pap smear. But every time it feels like a months long process. I just want to make sure that I'm okay internally. **It shouldn't be this hard.**



Yolanda Vargas

*IDD Advocate  
Corps member*

“

**It wasn't easy to explain the complexity or technicality of my diagnosis or problems I was having** due to lack of plain language easy-to-understand documents, materials, resources, tools, paperwork, or data.



Matthew Lawrence  
LeFluer

*IDD Advocate  
Corps member*

“

I'm very limited to whatever doctor can cover the type of insurance I have, and **a lot of doctors I have don't truly understand what neurodiversity is,** they didn't understand how to help me navigate my autism and ADHD.



Dennis Tran

*IDD Advocate  
Corps member*



Even small organizations can have a ***big impact***. Here are just some of the ways IEC made a difference.



# 192

supporters of our ABC3  
Roadmap to Disability-  
Inclusive Care



# 1,500

adults with IDD targeted  
for the *Always Uniquely Me*  
app pilot project



266

stakeholders engaged in  
our IIDDEAL program to  
identify quality measures



70

new members of our  
IDD Advocate Corps



# Changing How Healthcare is Taught

We're changing how clinicians, including doctors, nurses, and dentists, are trained to treat people with IDD, helping to serve them fairly and effectively.

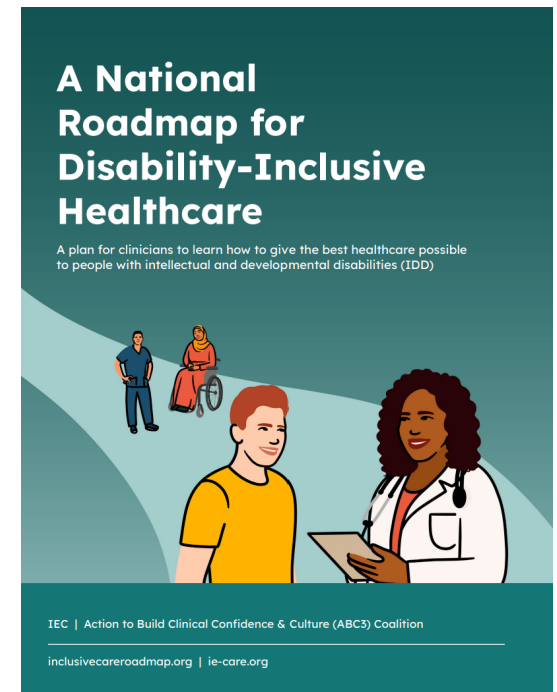
## Published the National Roadmap for Disability-Inclusive Healthcare

The Roadmap is a plan for clinicians to learn how to give the best healthcare possible to people with IDD. IEC's Action to Build Clinical Confidence and Culture (ABC3) Coalition created the Roadmap.

**117 individuals and 75 organizations supported** the Roadmap, including clinical, disability, academic, and healthcare institutions.

**Made 250+ outreach contacts** to raise awareness and engage new partners in the The Roadmap.

**Presented at 10 national forums** helped spotlight ABC3's work and influence efforts to change how clinicians are trained and supported in IDD care.



“

Like everything in life, it's a journey. Healthcare is no different. **The Roadmap provides a helpful guide to equitable healthcare for those with IDD.** Change happens with listening and continued dialogue.



BJ Stasio

ABC3 Steering  
Group member

“

**IEC is not only transforming how care is delivered, but how it is understood -** centering the voices of people with lived experience. IEC's work brings hope, equity, and humanity to a space that has often fallen short.



Susan Hingle

ABC3 Steering  
Group member



## Fostering More Inclusive Dental Care

IEC worked closely with our Dental Advisory Council and partners to identify challenges that people with IDD face when visiting the dentist. Our team then began developing tools that dentists and patients with IDD can use to improve the dental care experience.

**Mapped the full dental workflow** for people with IDD, identifying key points where accessibility, communication, and care could be improved.

**Created 4 tools** which are designed to improve accessibility, communication, and patient preparation for dental visits.

**Built strong partnerships** with organizations such as Delta Dental, the American Dental Education Association (ADEA), American Academy of Developmental Medicine & Dentistry (AADMD), Henry Schein, and People Advocating for Optimal Health to support scale, clinical testing, and sustainability of project efforts.



In my opinion, they [dentists] don't seem like they have the ability to work with special needs people. As a person with disabilities, I don't feel like we're heard by dentists or the staff. **This project will make a big difference in the world, not just for me but for all special needs people.**



Shawn Richards

Dental Advisory  
Group member

## Discourse

Powered by IEC + Ability Central

### **Communication Disabilities 101 for Healthcare Professionals**

introduces providers to common communication disabilities and offers practical strategies to support patients with diverse communication needs. The course emphasizes empathy, inclusion, and the importance of accessible care for all.

## Educating the Healthcare Workforce

**Produced a 90-minute, CME/CE-eligible course** introducing clinicians to communication disabilities and practical strategies for more inclusive encounters.

**Secured accreditation and distribution of *Discourse*** through American Medical Association, American Academy of Physician Associates (AAPA), and IntellectAbility.

**Accessible design** including captions and transcripts, plain language glossaries, and screen-reader-friendly PDFs.

# Changing How Healthcare is Delivered

We're changing how people with IDD get healthcare, including avoiding unnecessary Emergency Room (ER) visits, improving care, and easing transitions back into the community.

## Reducing Stress in the ER

ERs are the number one most identified pain point in healthcare for people with IDD. We are working to make ERs better, safer, and less stressful. In the process, reducing misdiagnoses and improving quality of life for everyone.

**3 hospitals engaged** at Northwell Health in New York whose Emergency Departments treat 275,000 patients each year.

**One New York hospital designed and implemented a dedicated sensory free room** in part based on our recommendations.



### BEFORE

Emergency rooms are loud and overwhelming, leading many people with IDD to leave without care or face misdiagnosis and unnecessary restraint.



### AFTER

Staff are trained to recognize and support people with IDD, workflows reduce sensory stress, and spaces promote calmer, more accurate, and efficient care.



**Emergency rooms are terrifying for everyone.** Making them safe spaces for people with IDD by dimming lighting, simplifying protocols, and providing means to distract them, as well as giving medical staff the information they need to communicate effectively with patients and their families, **will reduce stress for all involved, and ultimately, improve medical care.**

Susan Platkin

*SCANS Steering Group member*



## Empowering People with IDD During Emergencies

*Always Uniquely Me* is a mobile app that was designed to support the needs of people with IDD during medical visits – especially in high-stress environments like emergency rooms.

**Completed design** of the *Always Uniquely Me* app.

**Prepared to launch pilot project** with 1,500-2,000 children and adults with IDD in New York City.

**Completed site visits** of community clinics and group homes to prepare for recruitment of the pilot project.



### What's on the App?

**Snapshot of Me** – A short video that shows who the person is when they are at their best.

**Tips for Taking Care of Me** – Calming strategies, sensory activities, and triggers to avoid.

**My Medical Information** – Key medical history and emergency details tailored to ER teams.

**Videos & More** – The app offers rich multimedia options include videos, audio clips, text, and pictures.

**User-controlled** – Information is entered and managed by the person with IDD or their caregiver.

**Quick to Review** – Designed so ER staff can understand the person in 2 minutes or less.

“

**I shared the app with my doctors, and they LOVE it!** They said they can't wait for others to use it too.



Coleen Mackin

SCANS Steering  
Group member

# Changing How Healthcare is Paid For

We're innovating by addressing which healthcare outcomes get measured and how, ensuring person-centered care for people with IDD.

## Shaping a National Outcomes Agenda

We're changing what success looks like in healthcare for people with IDD through our IIDDEAL (Individuals with IDD Engaged, Aligned, and Leading) initiative.

**Engaged 266 stakeholders** including self-advocates, caregivers, payers, providers, and policymakers.

**Held 2 national summits** with participation from federal and state leaders, health plans, clinical leaders, and disability groups.

**Published national goals in *JAMA*** for IDD health outcomes.

## Making IDD Visible: Improving Data for Accountability

We're working to ensure that people with IDD are counted and cared for in healthcare data.

**Provided guidance to HHS** on defining IDD in national data standards to improve equity in policy and research.

**Built a strong research team** with Duke, Jefferson Health, and Nationwide Children's Hospital.

## Advocating for What Healthcare Should Cost

We're pushing for smarter payment models that support primary and specialty care for people with IDD.

**Successfully influenced Centers for Medicare & Medicaid Services (CMS)'s new Accountable Care Organization (ACO) Flex Model**, which allows clinicians to tailor visits for patients with complex needs.

**Provided technical support for bipartisan legislation** (Pay PCPs Act) sponsored by Senators Cassidy and Whitehouse, to support stronger primary care.

**Helped the Society for Developmental and Behavioral Pediatrics** create its advocacy strategy focused on improving payment and supports for the endangered specialty.



# IDD Advocate Corps

## Building a Network of Advocates

We're fostering a collaborative community of healthcare professionals and people with lived experience of IDD motivated to improve healthcare by advocating within the system.

**Grew by 70 members** bringing total membership to nearly 90 individuals.

**Added 20 new leaders**, including 10 self-advocates, who received leadership coaching.

**Formed 6 new committees** to lead the Corps on governance, communications, research, policy, peer-support, and changing health systems.



This organization is top notch. **This organization teaches people with disabilities leadership skills. When I come here, I can laugh, I can be myself.** It's a great learning experience. And I can't thank everyone enough for their input and their leadership!



Nathaniel Lentz

IDD Advocate Corps member



I'm a member of IDD Advocate Corps because I really believe in the mission and what I can contribute to it. I like the camaraderie of like-minded people, meeting other self-advocates, and **being part of something bigger than myself.**



Gyasi Burks-Abbott

IDD Advocate Corps member

**Launched an online portal** for members that enhances communication and provides task management, a shared calendar, and access to resources.

**Began collecting stories** to show the real-life challenges that people with IDD and their caregivers face trying to get quality healthcare.

**Trained all members** on *Working Together in Partnership*, which uses our approach to authentic community engagement to equip everyone with better tools for communication and collaboration.

# 2024 Champion of Change

## Elyse Pegler is IEC's 2024 Champion of Change

Elyse brings both professional expertise and personal dedication to advancing person-centered care for people with IDD. Her journey started with her deep connection to IEC's mission, inspired by her own family experience navigating the healthcare system with two neurodiverse children.

Elyse has seen firsthand the demeaning treatment that people with IDD often experience. When her 15-year-old daughter was hospitalized, two nurses handled her roughly during an IV insertion, dismissed her concerns when the procedure was done improperly, and later, it was confirmed her daughter was right.



“

Elyse truly embodies IEC's mission of uniting lived experience with healthcare expertise. As both a parent and a health insurance executive, her leadership on the Advocate Corps is invaluable, and her dedication makes her an integral part of our team.

**Elyse is an inspiration and I'm proud to recognize her hard work with this award.**



**Mai Pham**

*President and CEO*

Elyse sees her work at IEC as a bridge between self-advocates and healthcare professionals. Her vision for the Advocate Corps is to unite advocates and practitioners in their shared mission of equitable healthcare. She is eager to see the Advocate Corps take its next steps in 2025, turning the solid foundation they've built into a powerful movement.



# Our Team



**Mai Pham**  
*President and CEO*



**Josh Jacobs**  
*COO and CFO*



**Lauren Erickson**  
*Director of Policy and Programs*



**Madelyn Bahr**  
*Senior Program Specialist*



**Rachel Grimm**  
*Program Manager*



**Omar Mobasher**  
*Program Manager*



**Justin Gero**  
*Communications Manager*



**Anna Christ**  
*Development Director*



**May-Lynn Andresen**  
*Director of Community Partnerships*

# Our Board



**Rick Gilfillan**  
*Board Chair*



**Robert Galvin**  
*Board Vice Chair*



**Staci Alexander**  
*Board Member*



**Julia Bascom**  
*Board Member*



**Donald Berwick**  
*Founding Board Member*



**Rima Cohen**  
*Board Member*



**Cuong Do**  
*Board Member*



**Cathy Farmer**  
*Board Member*



**Chester Finn**  
*Board Member*



**Dena Gassner**  
*Board Member*



**Matthew Holder**  
*Board Member*



**Margaret A. Nygren**  
*Board Member*



**Morénike Giwa Onaiwu**  
*Board Member*



**Bernard M. Rosof**  
*Emeritus Chair*

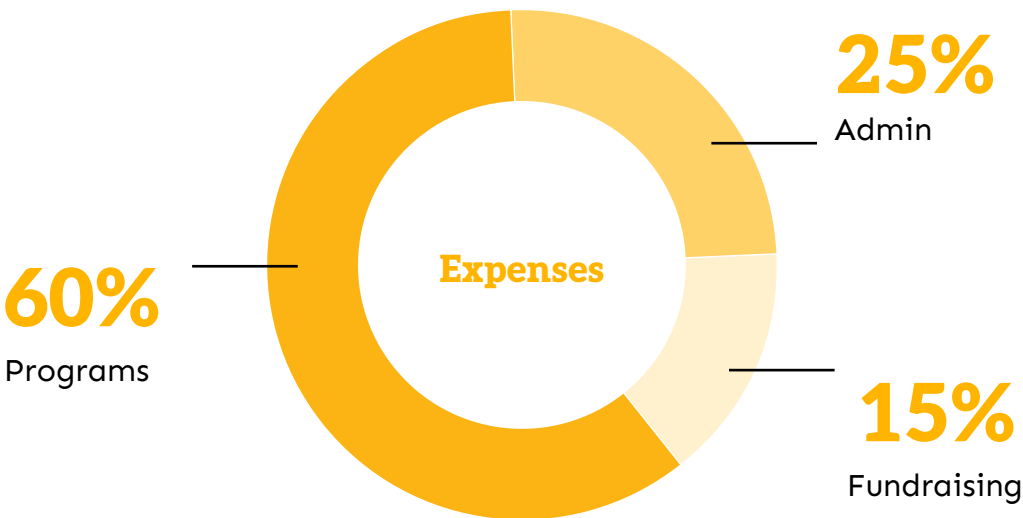
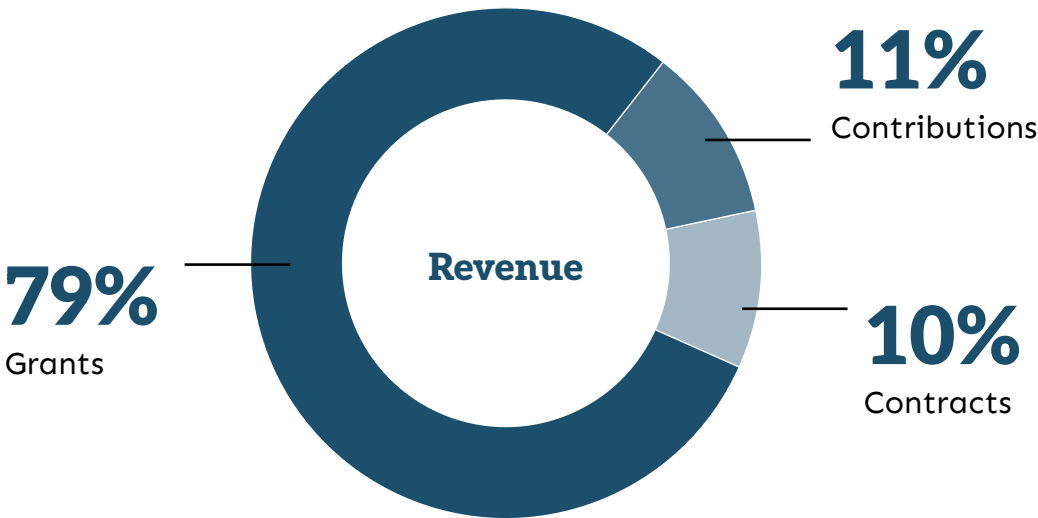


**Nell Buhlman**  
*Board Member*

# Our Finances

January 1, 2024 - December 31, 2024

YEAR	REVENUE	EXPENSE	CHANGE IN NET ASSETS
2024	\$2,183,875	\$1,852,193	\$331,682



Statements of activity for Institute for Exceptional Care (IEC) from January 1, 2024 through December 31, 2024. Unaudited financial statements. Check [ie-care.org](http://ie-care.org) for IRS 990 forms.

# Our Supporters

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IEC's work is made possible through the generous support of forward-thinking partners. We're grateful to the institutions and funders who share our vision for an equitable and high-quality healthcare system.

- Robert Wood Johnson Foundation
- WITH Foundation
- Joan Solotar Charitable Fund
- Bob Galvin and Gail D'Onofrio
- Golob Family Fund
- Saul Schottenstein Foundation B
- Berenson Charitable Fund
- The Gentian Philanthropy Fund
- Elevance Health
- Howard Gold
- IntellectAbility
- Rima Cohen and Sean Cavanaugh
- Behavioral Health Tech
- WPW Foundation
- Gray Foundation
- Margolis Family Foundation
- The Do & Rickles Family Charitable Foundation
- Fay J. Lindner Foundation
- AARP
- Bernard and Adrienne Rosof
- Healing Works Foundation
- Anthony-Maymudes Family Foundation
- Emily and Greg Waldorf Family Fund
- Rick Gilfillan
- Mai Pham and David Roodman
- Diane Archer
- Leavitt Partners, LLC
- Society for Developmental and Behavioral Pediatrics
- Delta Dental Foundation - Michigan
- Delta Dental Foundation - New Jersey
- UnitedHealth Group
- Ability Central Philanthropy

## Additional Support

IEC would also like to thank Covington & Burling LLP, Stott Group, Arielle Mir, and Milliman for their pro bono services.





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