

2025 Impact Report



IEC

Institute for
Exceptional Care



*Making Healthcare Better
for People with IDD*

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Message from IEC Leadership

Dear Friend,

2025 was a year like no other. Like many organizations, IEC had to adapt to fast-changing economic and policy conditions. Through it all, **we were inspired by IDD self-advocates, family members, and dedicated healthcare leaders.** Their experiences kept us focused on what matters most and committed to making an even greater impact.

In a year of uncertainty, we leaned into two strategies at once. **We spoke up on policy,** working with partners to protect Medicaid and disability rights and joining coalitions to defend hard-won progress. At the same time, **we kept building and sharing practical tools** for clinicians, healthcare facilities, payers, and patients and families. We believe this transformation work has to continue no matter the political climate. It is the strongest defense we have against any effort to roll back better and safer healthcare for people with IDD.

We helped the Society of Developmental and Behavioral Pediatrics build an advocacy strategy for better payment for the care they provide. We also laid out our vision for how states and the private sector can step up and fill the leadership void on health for people with IDD.

On the tools side, our work reached more people than ever. Positive Discourse and our Environment of Care Resource Guide for Emergency Departments both saw strong uptake among clinicians. **We launched our Always Uniquely Me app pilot,** advanced high-priority quality measures through IIDDEAL, began beta testing our Dental Toolkit, and formed the Access Smiles Coalition to expand access to dental care.

This year also challenged us to hold our community together. Self-advocates and families felt tremendous stress and pressure, and **we showed up for them through town halls and by standing beside individual partners,** including Sherri and Nathaniel, as they worked through real challenges. Their successes are our successes.

We are excited to carry this work into 2026. We will expand our tools and resources for clinicians, continue to lead on IDD health education, and pilot a new fellowship for people with IDD who want to build job skills and strengthen their ability to advocate for better care.

None of this would have been possible without our many steadfast partners, the guidance of self-advocates and family members, and generous support of people like you. Thank you for standing with us as we work toward a better, safer healthcare system for people with IDD.

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 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 and guided by the IDD community.

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 through our Action to Build Confidence and Culture (ABC3) initiatives.

Highlights

Launched the Positive Discourse training on IntellectAbility and the American Academy of Physician Associates (AAPA) websites, with outreach underway for listing on additional professional society platforms.

Elevated national presence: Spoke at national conferences and stakeholder gatherings across the U.S., building ABC3's visibility and reputation as a leading model for systems-level change in IDD healthcare.

Impact

250+ outreach contacts made to raise awareness and engage new partners in the ABC3 movement.

400+ medical professionals have completed our course since launch.

200+ IDD clinical resources reviewed to build training pathways for primary care clinicians and dentists.

Two more organizations joined our ABC3 Steering Group.

“

The resources compiled by the IEC were not only impressive and comprehensive, but they were tangible. I was able to take the resources from IEC to use in my clinical work that day, thus allowing the work of the IEC to have an immediate impact on the lives of the people with disabilities.



Ley Linder

Founder and CEO
Crescent Behavioral Health Services, LLC

Changing How Healthcare is Taught

2025 was a big year for advancing training for dental professionals to improve care for people with IDD through projects in our Access Smiles initiative.

Highlights

Officially launched Access Smiles with strategic partners Delta Dental Michigan, Delta Dental New Jersey and Henry Schein to support scale and long-term sustainability.

Educated dentists on IDD issues at conferences and webinars.

Impact

6+ partner organizations now part of Access Smiles nationally.

11 dental toolkit resources completed and published.

30+ dental offices across the country engaged in beta-testing.

“

The more we talked about things, the more we wanted to add, which is great. **I'm grateful that I was able to be a part of this, and that we're really giving the community something that's gonna be helpful and so important.**



Melanie Hunt-Tsentas, DMD

Dentist and Dental Project Advisory Council Member

“

Access Smiles is built on a simple but powerful idea: give dental practices the practical tools and guidance they need to improve care, then reinforce that progress through better reimbursement and increased patient referrals. **That combination has the potential to drive meaningful, lasting change.**



Kyle Guerin

*Director, Corporate Social Responsibility
Henry Schein Cares*

Changing How Healthcare is Delivered

We're helping clinicians, including doctors, nurses, and dentists, work more safely and effectively with people with IDD.

Highlights

Published the "Environment of Care" guide for emergency departments which shows how to make low-cost changes that reduce stress and improve safety for patients with IDD.

Launched the *Always Uniquely Me* app pilot to help patients share important personal information with clinicians in real time.

Published new geroscience guidance on how researchers and clinicians can better track daily functioning in people with IDD as they age.

Impact

ECHO Autism promoted our Emergency Department Environment of Care resource guide to its network of **over 6,000 members in 100 countries.**

6 guiding principles established to help researchers design more aging studies that include people with IDD.

Proposed 8 specific ways to change how we measure and track aging because people with IDD may age more quickly and differently than other people.

“

I am so excited by what this Geroscience Report makes possible. **The guiding principles will help ensure that this emerging field of aging research doesn't leave people with IDD behind.** And the clinical case scenarios IEC developed makes the clinical and life implications of thinking about aging the right way so concrete and actionable for clinicians and patients.



Erwin Tan, MD

Senior Director of Health
AARP Thought Leadership

Changing How Healthcare is Paid For

We're changing how clinicians, including doctors, nurses, and dentists, are trained to treat people with IDD, helping to serve them fairly and effectively. We influence how government and insurance companies pay for services that people with IDD need.

Highlights

Through IIDDEAL **we identified 12 quality measures** that clinicians, government, and insurers should use to judge whether payment is improving the right things.

We provided thought leadership on how payment policies can better serve people with IDD.

We helped the Society of Developmental and Behavioral Pediatrics build an advocacy policy to improve payment for a specialty in danger of disappearing, even as more children need it.

Impact

70 quality measures were considered by the IIDDEAL group.

12 high-impact measures were identified as top priorities.

30+ national, state, and private sector policy leaders attended our quality measures webinar.

3 articles published on value-based payment and safeguarding IDD health.

Successfully advocated for **one new Medicare payment program** to better support primary care.

“

We can't improve what we can't measure. The lack of high value quality measures for so long has resulted in poor access and outcomes for people with IDD. There is much more work to do, but IEC's inclusive approach serves as a strong start to selecting measures that can address the prioritized needs of people with IDD, while helping clinicians and payers focus their work.



Richard Christopher Antonelli, MD, MS, FAAP

*Medical Director of Integrated Care
Boston Children's Hospital*

Engagement & Advocacy

We're organizing people with IDD and healthcare professionals to reduce systemic barriers that trap families in cycles of poor health and economic insecurity.

Launched Navigate & Advocate to create an interactive map that helps advocates understand current issues in Medicaid and home-and-community based service in their state.

Navigate & Advocate Will

1. **Learn** about Medicaid, Home and Community-Based Services (HCBS), and new federal policy changes.
2. **Compile** Medicaid/HCBS information on each state
3. **Identify** and fill gaps in information.
4. **Create** plain language materials.
5. **Design** online map as an interactive resource hub.

Lizzy is the co-leader of the Self-Advocate Commons subcommittee on IEC's IDD Advocate Corps. She brings two perspectives to IEC's work: professionally, she's spent over a decade as a Medicaid HCBS waiver service coordinator for autistic children with high support needs. Personally, Lizzy brings the lived experience as an autistic, bisexual, transgender woman with ADHD.

“ **It is critical for openly disabled people to be at the forefront of the disability rights movement. We still need allies, but it is important we have a seat at the table. If we are not at the table, we are on the menu.** ”



Lizzy Graham

*IEC's IDD Advocate Corps
Self-Advocate Commons subcommittee*

2025 Champion of Change

Regina Erickson is IEC's 2025 Champion of Change

Regina brings deep compassion, lifelong volunteerism, and powerful lived experience to her advocacy for people with IDD.

Regina's connection to IEC is personal. As a mother of an adult son with IDD, she has spent decades navigating a complex healthcare and support system. Her medical background as a radiation therapist helped prepare her for these challenges, but it has still been a struggle at times.

"The toughest question my son ever asked me was, 'Why do people treat me differently?'" Regina shared. "The journey for him has not always been easy."



Regina embodies the heart of our mission.

Her lived experience, generosity, and unwavering commitment to people with IDD make her an inspiring Champion of Change. We're honored to recognize her contributions.



Mai Pham

President and CEO

Regina spent generous time helping IEC keep our data on partners, projects, and donors up to date. On what brought her to IEC as a volunteer, Regina said, "I am most proud of my contribution to IEC through my daughter, Lauren, and her work at IEC. She has built her career around making healthcare a better system based on her lived experiences as a sibling to someone with IDD."

Our Board in 2025



Rick Gilfillan
Board Chair



Robert Galvin
Board Vice Chair



Staci Alexander
Board Member



Julia Bascom
Board Member



Nell Buhlman
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

Our Staff in 2025

Mai Pham
President and CEO

Madelyn Bahr
Senior Program Specialist

Anna Christ
Development Director

Josh Jacobs
COO and CFO

Rachel Grimm
Program Manager

May-Lynn Andresen
Director of Community Partnerships

Kacy Takamoto
Chief Advancement Officer

Omar Mobasher
Program Manager

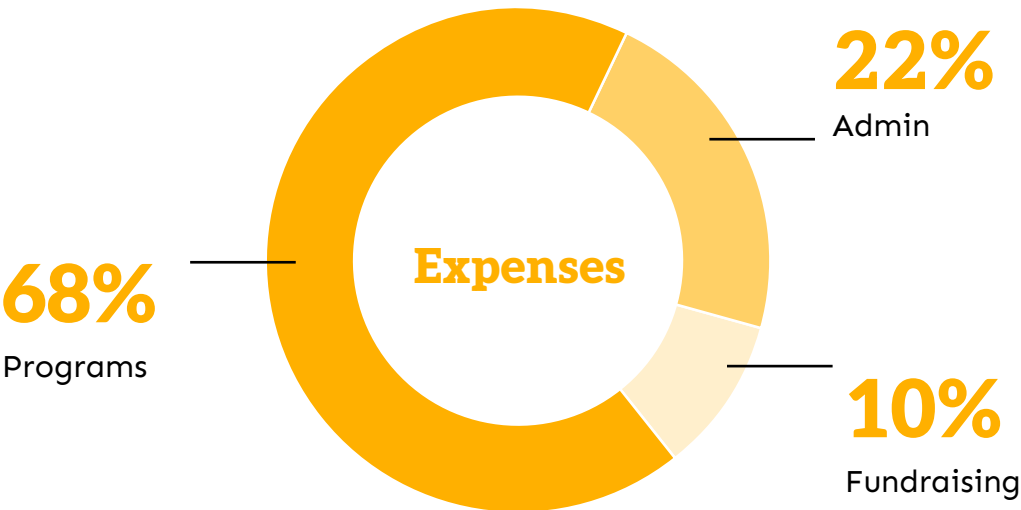
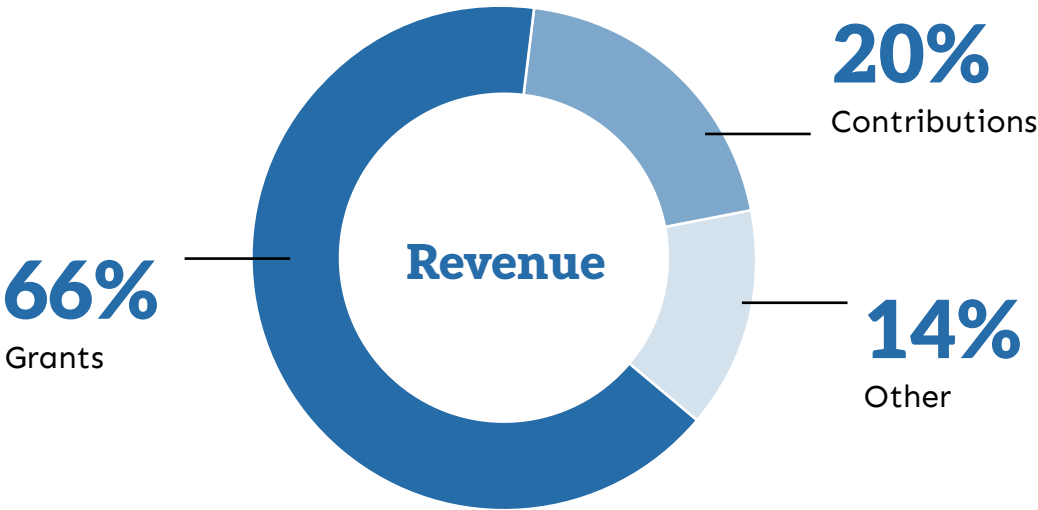
Lauren Erickson
Director of Policy and Programs

Justin Gero
Communications Director

Our Finances

January 1, 2025 - December 31, 2025

YEAR	REVENUE	EXPENSE	CHANGE IN NET ASSETS
2025	\$1,329,056	\$1,707,740	(\$378,684)



Statements of activity for Institute for Exceptional Care (IEC) from January 1, 2025 through December 31, 2025. Unaudited financial statements. Check ie-care.org for IRS 990 forms.

Donor Acknowledgments

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.

Visionary Circle

\$100,000 – \$200,000+

- Robert Wood Johnson Foundation
- CareQuest
- Fay J. Lindner Foundation

Champion Circle

\$50,000 – \$99,999

- Delta Dental Foundation (MI)
- WITH Foundation

Ambassador Circle

\$25,000 – \$49,999

- Delta Dental Foundation (NJ)
- Epic Systems Corporation
- Henry Schein
- Dr. Hoangmai Pham & David Roodman
- Dr. Robert Galvin

Ambassador Circle

\$5,000 – \$24,999

- Dr. Richard Gillfillan
- AAMC
- Dr. Bernard Rosof
- Catalight
- Do & Rickles Family Charitable Foundation
- First State Trust:WPW Foundation
- Healing Works
- Pacific Dental Services
- The Anthony Maymudes Fund
- Ms. Rima Cohen
- The Gentian Philanthropy Fund
- American Psychiatric Association Foundation (APAF)
- Ms. Cathy Farmer
- Optum

Additional Support

IEC would also like to acknowledge our donors—whose contributions under \$5,000 vitalize our daily operations and directly power our projects and initiatives—as well as Covington & Burling LLP, Milliman, and Jennifer Jaremski for their pro-bono services! Our mission moves forward because of your extraordinary commitment.



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