2022

IMPACT REPORT

Making healthcare better for people with intellectual and/or developmental disabilities (IDD) so they can live life to the fullest

institute for exceptional care

WHAT IS IDD?

Intellectual and/or developmental disabilities (IDD) include conditions like Down Syndrome, autism, ADHD, and cerebral palsy. There are at least 16 million people with IDD in the US.

- **Developmental disabilities** start when someone is born or in childhood and last for a person's whole life. Developmental disabilities can affect many parts of a person, such as how they learn, grow, talk, and think, or get along with others.
- **Intellectual disabilities** are a type of developmental disability. They make it harder to learn.

It can be hard for people with IDD to do some things in their everyday lives. When the world around them doesn't try to help, it can be even harder.

People with IDD have unique strengths. It's important to notice and use these strengths. Figuring out what someone is good at and what they need help with is a good start. Then, you can work on helping people find roles that fit their strengths.

Throughout this report, you'll find perspective from many of the disability self-advocates who work with IEC on all our projects.

SOME OF IEC'S SELF-ADVOCATE PROJECT PARTNERS

Ivanova Smith & daughter Alexandra

Kayla Rodriguez

Thelma Green

Thomas Mangrum

Coleen Mackin (center) and friends

Kayte Barton

REFLECTIONS AND LOOKING AHEAD: *FROM OUR CEO*

What a year it has been, fueled by our vision of a world where people with disabilities enjoy the best possible health so they can live life to the fullest. 2022 was the second full year of IEC's pursuit of our mission to drive large-scale changes in healthcare to improve wellbeing for people with IDD.

We are so grateful for the hundreds of partners and donors who have joined us on this journey, and proud of the trust and solutions we've built together.

Self-advocates with IDD and family members taught us that the genius of lived experience will guide us to more meaningful ways of defining good health and healthcare, better tools to help people advocate in healthcare settings, and more effective ways to train clinicians.

Healthcare partners showed us their thirst for authentic connection with community members and how to unlock their emotional and intellectual curiosity about serving people with disabilities.

Our donors understood the value of IEC's approach – that healthcare problem-solving guided by those with the greatest needs becomes the foundation for equity and generates universal benefits for many other people (the healthcare equivalent of curb cuts.)

The doubling of our staff and budget reflects the credibility we have developed with stakeholders and donors.

Looking ahead, we're anticipating several exciting launches. Our digital snapshot (learn more here). A consensus health outcomes framework (learn more here). A consensus national strategy for training general clinicians (learn more here). And a network of community members and healthcare professionals collaborating to advocate for change from within healthcare (learn more here).

All the foundational work of 2022 will bear fruit as these initiatives knit together and engage change makers across the country who share our passion and goals.

Thank you for your commitment and for being part of our community.

Onward, in gratitude,
Mai Pham, MD, MPH
President and CEO

BJ STASIO

Peer Specialist Western Region 1/Self-Advocacy Coordinator,
New York State Office for People with Developmental Disabilities

Pictured with his wife Amber and their dog Chico

Nobody with a disability is the same. We all have our unique qualities which make us productive human beings, whatever our capabilities are.

A UNIQUE ORGANIZATION:
FROM OUR BOARD CHAIR

IEC is unique in its fervent desire to take on what many have said is impossible: changing the health trajectory for persons with IDD in every stage of life.

I practiced medicine for 30 years and believe strongly that in order to deliver quality healthcare, it is necessary to understand my patient. Particularly for persons with disabilities, this means listening intently and earning their trust.

This is a lesson that healthcare professionals have to learn. IEC is working to bring awareness to those in positions to affect that change, in healthcare, education, business, and the wider community.

Critical to accomplishing this mission is a very dedicated IEC team and Board, and, importantly, the disability self-advocates who serve on the Board and our advisory groups. These individuals are consistently at the table, and their impact is palpable.

It is a privilege to learn from these colleagues. I invite you to join us.

Bernard Rosof, MD, MACP
Inaugural Board Chair

ABOUT IEC'S BOARD OF DIRECTORS

25%
people with IDD

31%
medical doctors

62%
have a family member with IDD

MORÉNIKE GIWA ONAIWU

IEC Board member

Morénike Giwa Onaiwu, PhD, is an IEC Board member, activist-scholar, author, and community leader. A proactive, resourceful professional and disabled person of color in a multicultural, neurodiverse, serodifferent family, Morénike possesses undergraduate and graduate degrees in International Relations, Education, and Interdisciplinary Humanities.

CO-DESIGNING SOLUTIONS:

BETTER TOGETHER

IEC brings an unequivocal commitment to centering the experiences and leadership of people with disabilities in designing solutions.

This builds meaningful connections between the disability and healthcare communities and has unlocked amazing levels of energy and inspiration.

ABOUT IEC'S PARTNERS

87 *people with IDD*

77 *participating family members*

12 *medical centers*

140 *clinicians*

5 *health plans*

18 *government agencies*

9 *clinical societies*

28 *disability organizations*

PROGRAM HIGHLIGHT: SCANS

REDUCING FEAR DURING HEALTH EMERGENCIES

For people with disabilities, the Emergency Department (ED) is a scary place.

Loud noises and glaring lights can be overwhelming. Some people shut down, get upset, or have trouble explaining their needs.

This puts them at real risk of harm – having their symptoms under-estimated, getting the wrong treatment, or even being chemically or physically restrained.

IEC's response: the **SCANS (Seamless Care Alliance of Nassau & Suffolk)** initiative - a pilot program on Long Island working to make the ED and hospital experience better and safer.

There's an App for That

Now in development: a unique cellphone app to make critical information available in emergencies. It lists allergies and contacts, but also a "digital snapshot" of the person's communication preferences ("I can speak but can become non-speaking with stress"); sources of comfort (fidget items, specific music or videos, or headsets to muffle noise); and cognitive support tips ("check for understanding after asking a question.")

The app was designed collaboratively by a coalition of persons with disabilities, family members, leaders of health systems, disability support and care coordination organizations, payers, and government agencies.

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

ZANETHA MATISSE

Self-Advocate

Being in clinical environments that support wellbeing and health specifically for those with IDD would be fantastic...

I'll ask for them to turn the lights off or lower the lights. I can hear all that stuff in my body. That can kind of drive me nuts.

PROGRAM HIGHLIGHT: IIDDEAL

WHAT MATTERS MOST TO ME

What does good health look like? And who decides what health outcomes we aim - and pay - for? Often it's government agencies and/or insurance companies.

People with IDD have different priorities, and their responses to the question "What health outcomes matter most?" have been eye-opening, extending far beyond traditional medical parameters.

The **IIDDEAL (Individuals with IDD Engaged, Aligned, and Leading)** initiative uses a uniquely inclusive process to identify priorities that are true to the lived experiences and desires of people with IDD.

Our approach starts with centering self-advocates and their perspective, then driving consensus with other stakeholders (health insurance executives and other payers; clinicians, including clinicians who self-identify as having IDD; and family care partners) about how to support those priorities.

"Participating in the IDDEAL Stakeholder Workgroup has been eye-opening," said Michael G. Skoch, MD, Chief Medical Officer with Sunflower Health Plan of Centene, the country's largest Medicaid insurer. "The engagement of a broad spectrum of people from all walks of life has contributed to robust discussion, insightful suggestions, and the potential for new and creative ways to look at data and outcomes."

IIDDEAL has been supported by grants from PCORI and Arnold Ventures.

EXAMPLES OF HEALTH OUTCOMES THAT MATTER MOST TO PEOPLE WITH IDD

- Healthcare providers taking the time to listen
- Mental health support (mindfulness, meditation, and counselors who understand IDD)
- Being presumed capable
- Sexual and reproductive health
- Help understanding and communicating pain
- Support for family care partners
- Better dental care

> **As both a physician and parent with personal experience, I appreciate IEC's impact on strengthening the health care system, promoting person-centered care, and improving the quality of life for people with IDD.**

Carolyn Langer, MD, JD, MPH

Vice President and Chief Medical Officer, National Accounts, Elevance Health

JENNIFER KUCERA

Member, Ohio Developmental Disabilities Council

My primary care doctor has never once asked me if I am sexually active. It's a human need, but doctors make assumptions, and they shouldn't.

I've only ever had one pelvic exam. I had a breast exam several years ago and haven't been back because the room and the equipment were so poorly set up for a wheelchair user.

This is basic lifesaving women's healthcare that women with disabilities cannot reliably get.

PROGRAM HIGHLIGHT: ABC3

PREPARING GENERAL CLINICIANS TO PROVIDE GOOD CARE

Contrary to widespread belief, most people with IDD cannot get their healthcare at the few specialized centers that exist. Instead, they see providers of all kinds in their own communities.

So it's essential that all clinicians know how to serve people with IDD.

Yet the vast majority have little to no training, and even today, medical students receive an average of 11 minutes of exposure to IDD.

Perhaps for that reason, research shows that eight out of ten physicians harbor negative views of people with disabilities.

ABC3 (Action to Build Clinical Confidence & Culture) seeks to ensure – and require – that all clinicians are willing and able to treat patients with IDD.

IEC has built a coalition of organizations with the authority to increase the IDD-related content in educational curricula, testing standards, certifications, licensure, regulation, accreditation, continuing education, and more.

Building skills is critical. Requiring them will help us build a healthcare culture and ecosystem where dismissal and disparities become a thing of the past.

ABC3 is supported by funding from The WITH Foundation.

WHO'S IN: *THE ABC3 COALITION*

- Accreditation Council for Graduate Medical Education (ACGME)
- American Academy of Developmental Medicine and Dentistry (AADMD)
- American Academy of Pediatrics (AAP)
- American Academy of Physician Associates (AAPA)
- American Association of Intellectual and Developmental Disabilities (AAIDD)
- American College of Physicians (ACP)
- American Dental Education Association (ADEA)
- Association of American Medical Colleges (AAMC)
- Autistic Doctors International (ADI)
- BJ Stasio, Self-Advocate
- Dena Gassner, Autism Researcher
- Developmental Disabilities Nurses Association
- ECHO Autism
- IntellectAbility
- Kayte Barton, Self-Advocate
- Nisonger Center
- Special Olympics International Inclusive Health
- The Center for Dignity in Healthcare for People with Disabilities

> **"** ***My work with IEC has clearly demonstrated the vast unmet healthcare needs of the IDD community. Clinicians and the healthcare system must open their hearts and minds to this community. We can and must do more to help IDD patients.***
>
> *Helen Burstin, MD, CEO, Council of Medical Specialty Societies*

PROGRAM HIGHLIGHT: IDD ADVOCATE CORPS

CHANGE FROM THE INSIDE OUT

Healthcare insiders are ideally positioned to change healthcare. People with disabilities are experts in what will work for them. The IDD Advocate Corps brings them together for grassroots advocacy that works from the inside out.

The **IDD Advocate Corps** is composed of disability self-advocates, family care partners, and healthcare professionals using their professional standing, relationships, and lived experience to advocate for change within their own organizations and communities, and across sectors.

"Being part of the IDD Advocate Corps is a unique and rewarding experience," says Howard Haft, MD, former Executive Director of the Maryland Primary Care Program at the Maryland Department of Health.

Robbie Singhal, DrPH, director of the Science and Technology Platform at Ariadne Labs, agrees: " I'm learning the power of incorporating people's lived experience into our work to bring about much needed changes in our healthcare system."

NICOLE LeBLANC

Self-advocate and IDD Advocate Corps member

The IDD Advocate Corps is a movement that's desperately needed. The medical system is unprepared to deal with disability, especially people with autism and other developmental disabilities.

PROGRAM HIGHLIGHT: MAKING IDD VISIBLE

A BETTER COUNT FOR BETTER CARE

One reason people with IDD don't get good care is that there often isn't full or accurate information about their conditions in their medical charts. The same gaps tend to exist in their insurance claim data.

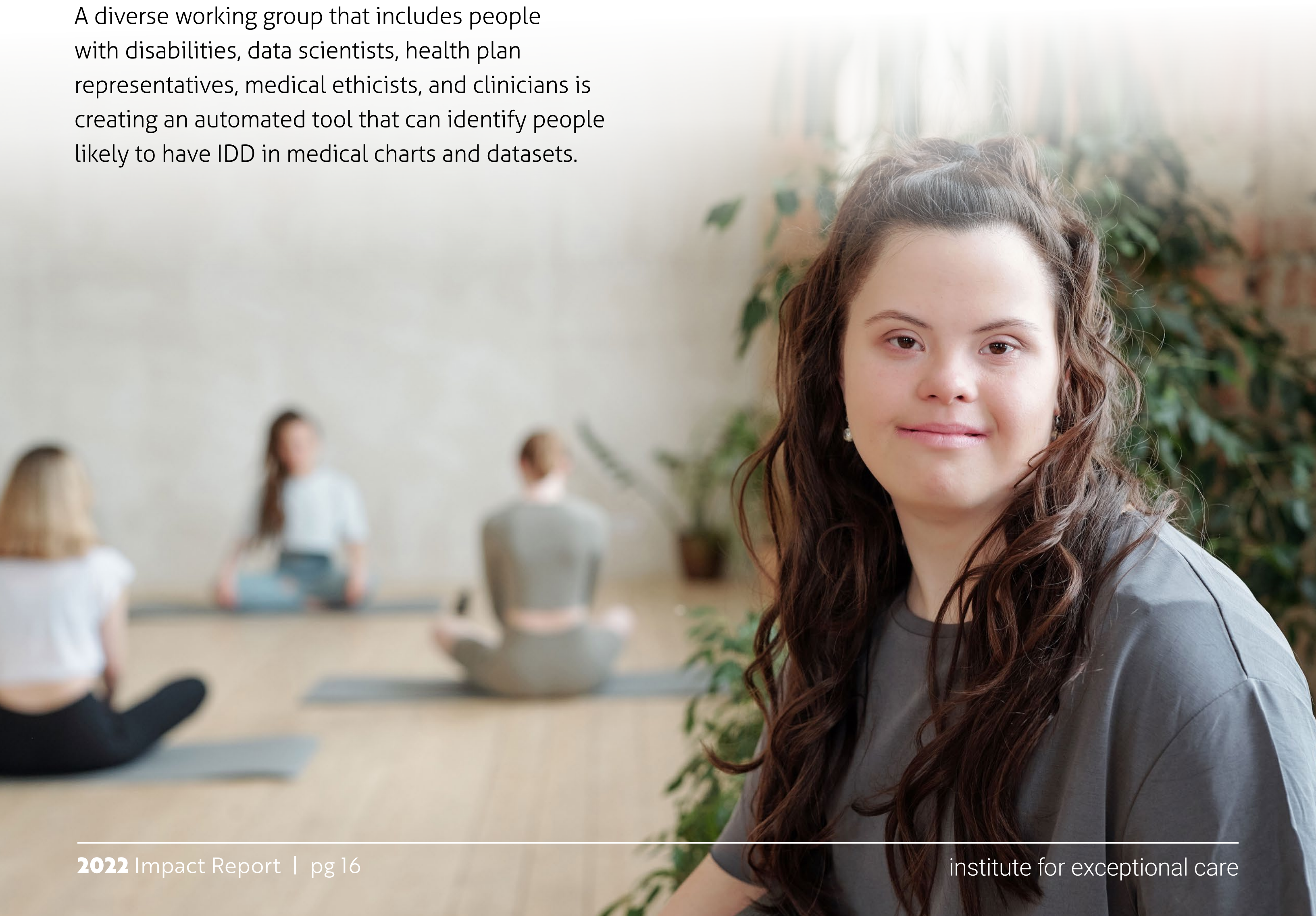
When such fundamental information is invisible, it hurts clinicians' ability to understand and treat their patients fully and correctly. It limits insurance companies' and other payers' ability to predict, budget for, and respond to the full range of needs in people that they are responsible for.

Making IDD Visible seeks to make it easier.

A diverse working group that includes people with disabilities, data scientists, health plan representatives, medical ethicists, and clinicians is creating an automated tool that can identify people likely to have IDD in medical charts and datasets.

While identifying these patients will not fix everything, it is an essential first step, since:

- Insurers and payers will be able to formulate a better business case for reimbursing services.
- Clinicians will have a fuller understanding of the person they are caring for, and may be able to get paid for spending extra time with them.
- People with disabilities will have a better chance of better-informed care.



WHO'S IN: *MAKING IDD VISIBLE*

Project partners include IDD self-advocates and family members, Duke University, Jefferson Health, Montefiore Medical Center, Nationwide Children's Medical Center, Cleveland Clinic, the Developmental Disabilities Practice Based Research Network, and EPIC Systems.

ALEXANDER ROODMAN

Alexander (above) with his older brother, Benjamin (below), in 2017. Alexander, who is autistic, is bringing his mathematical talent to an IEC working group addressing ethical issues associated with using artificial intelligence to identify people with IDD.

MEDIA AND PRESENTATIONS

About IDD

Helen: The Magazine of Human Exceptionality: Behind the Numbers of People with IDD: Why Institute for Exceptional Care's Mission is Both Professional and Personal

"Risk Adjustment for Payment of Healthcare and Home- and Community-Based Service Sectors: The Case for People with IDD" – IEC-commissioned paper based on a NASEM workshop

Different Brains podcast: Exceptional Care for the Neurodivergent

Patient Partner Innovation Community podcast: Creating an Inclusive Environment through Partnership, Teaching, and Shared Learning

Linux Foundation Public Health webinar: Surfacing Intellectual and Developmental Disabilities in Healthcare Data: Opportunities and Risks for a Vulnerable Population

Panel: Administration for Community Living's IDD Counts Summit

Presentation: Commonwealth Autism's 20th Annual Autism Conference

Presentation: One Voice Conference hosted by the American Academy of Developmental Medicine & Dentistry

Journal of the American Medical Association Open Research Letter: "Racial and Ethnic Differences in Rates and Age of Diagnosis of Autism Spectrum Disorder"

About Health Policy

STAT First Opinion: "Empower primary care with adequate payments and technology"

Health Affairs: "An Option for Medicare ACOs to Further Transform Care"

Medicare Meet-Up podcast (Aurrera Health Group): Re-Examining Value

Mathematica webinar: Primary Care's Critical Role in Advancing Health Equity

Bipartisan Policy Center webinar: Primary Care Payment Reform: the Future of Value-Based Payment in Medicare

Keynote address: Institute for Advancing Health Value: Health Equity Strategic Planning for Advanced APMs

Panelist: University of Pennsylvania's Leonard Davis Institute of Health Economics: Payment and Policy Solutions for America's Mental Health Care Crisis

Panelist: National Primary Care Transformation Summit

IEC'S PEOPLE

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Vish Sankaran
Chief Innovation Officer, Walgreens Boots Alliance

THANK YOU TO ALL OUR SUPPORTERS

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The Karp Family Foundation

The Pham Roodman Family Foundation

Bernard Rosof and Adrienne Rosof

Vish Sankaran and Brinda Nair

Samantha Sheridan and Brian Seasholes

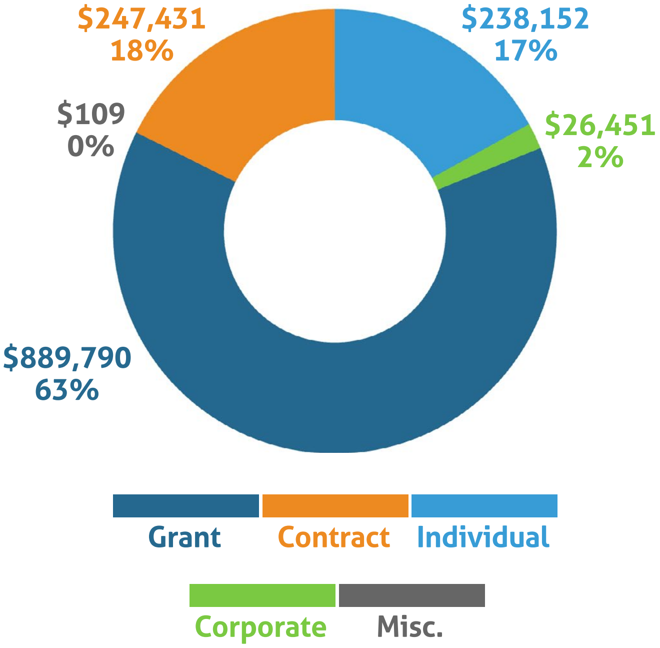
Additional Support

IEC would also like to thank Covington & Burling LLP for providing pro bono legal services.

FINANCIAL OVERVIEW

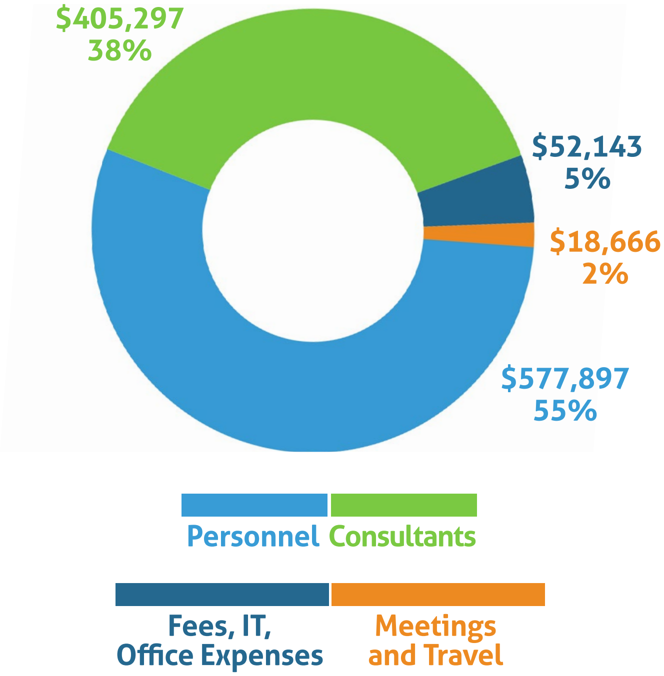
IEC REVENUE

(TOTAL $1,401,932)



IEC EXPENSES

(TOTAL $1,054,003)



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Editorial services by Elliott Sparkman Walker
and design by Carly Warner of SCP
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