

Institute for Exceptional Care

# National Roadmap for Disability-Inclusive Healthcare

## ABC3: Action to Build Clinical Confidence and Culture



# Agenda

- Overview of IEC
- Background of ABC3
- Roadmap
  - Development
  - Sectors
  - Goals & Action Steps
- ABC3 in Action
  - Current Projects & Partnerships
  - Looking Ahead



Mai Pham, IEC President and CEO with BJ Stasio, disability self-advocate, ABC3 Steering Group member, and IEC Advisory Council member.

**IEC: Institute for Exceptional Care**

# About IEC

- National nonprofit committed to making healthcare better and safer for people with IDD
- Bringing the disability and healthcare communities together to create solutions
- Applying deep expertise in healthcare delivery, financing, and policy
- Leveraging lived experience with IDD, supporting loved ones with IDD
- Building solutions with an eye toward benefits for everyone



Sue Hingle, clinician, care partner, and IEC project partner with Chester Finn, disability self-advocate and IEC Board member.

# Changing how Healthcare is...

## Taught

*(Preparing the Workforce)*  
Culture Change  
Training at scale

## Delivered

*(Care Design & Delivery)*  
Emergency Care  
Dental Care

## Paid For

*(Coverage & Payment)*  
Making IDD visible  
Quality Measurement

## Crosscutting Activities

*Advocacy*  
*Policy Development*  
*Authentic Engagement*

# Challenges We're Facing: Stigma and Misunderstanding

- Only 20% of clinicians feel confident about giving high quality care to people with disabilities
- False assumptions about quality of life
- Outdated assumptions about life expectancy
- Perceived as “Other”, something less than human
- Misunderstood behaviors
- Medical students report getting an average of 11 minutes of exposure to IDD



Coleen Mackin, disability self-advocate and SCANS Steering Group member.

# Challenges We're Facing: Poor Health & Life Outcomes

- Higher rates of obesity, diabetes, and poor overall health
- 57% higher maternal mortality
- Other than age, ID is the strongest predictor of COVID death
- Black/Brown, poor people with IDD have even worse outcomes
- Higher rates of depression, anxiety, other mental illness



Ivanova Smith, disability self-advocate and IEC Advisory Council member, with their daughter.

# ABC3: Action to Build Clinical Confidence and Culture



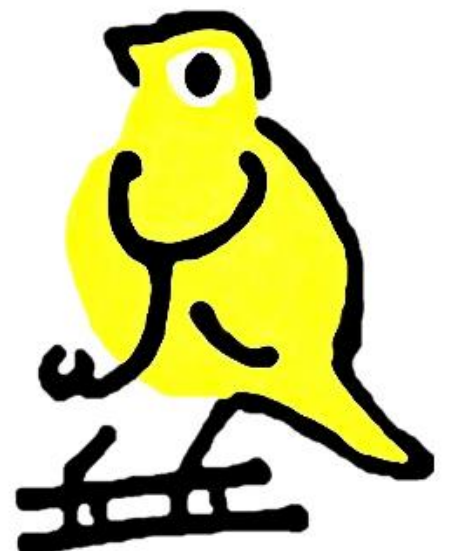
# What is ABC3?

- ABC3: Action to Build Clinical Confidence and Culture
- Coalition created by IEC in 2021
- Membership includes:
  - Self-advocates
  - Caregivers/partners
  - Leaders from clinical, disability, and education organizations
- Working on national strategies that will prepare general clinicians to give good care for people with IDD
- Developed the ABC3 *National Roadmap for Disability Inclusive Healthcare*



BJ Stasio, ABC3 Steering Group member, with his primary physician and IEC project partner, Shannon Poupalos.

# What organizations are members of ABC3?









# ABC3 Roadmap

# What is the ABC3 Roadmap?

- A plan that clinicians and sectors involved with healthcare can follow to help make healthcare better for people with IDD
- The plan includes:
  - Goals that sectors should set to help clinicians
  - Steps sectors and clinicians can take
  - Ways that sectors can work together to make change happen faster



# Why is the Roadmap needed?

- People with IDD deserve the best healthcare possible
- Clinicians often don't know a lot about caring for people with IDD because:
  -  Most schools don't teach them about how to care for people with IDD
  -  They haven't met many people with IDD or had them as patients
- Offices, clinics, and hospitals are often missing things that help people with IDD get better care, such as:
  -  Exam tables that can be used by people with physical disabilities
  -  Scales that work with wheelchairs
  -  Larger spaces that help people with IDD get around
  -  Ways to correctly charge insurance so they can pay for extra costs

# What are the goals of the ABC3 Roadmap?

- Give clinicians the skills and confidence to care for people with IDD
- Help clinician offices to be welcoming and accessible for people with IDD
- Offer clinicians a place to learn about caring for people with IDD
- Make sure schools and other places that teach new clinicians have classes about caring for people with IDD
- Make sure the rules and guidelines for how clinicians do their jobs include how to best care for people with IDD



# How was the ABC3 Roadmap created?

We chose which clinicians to target first

We created the Clinician Journey

We did focus groups

We voted on what steps are most important



# Step 1: Choosing what clinicians to target first

- Medical doctors (physicians)
- Nurse practitioners
- Physician associates
- Clinicians who work in:
  - Primary care
  - Dentistry
  - Sexual and reproductive health
  - Emergency care
  - Mental and behavioral health

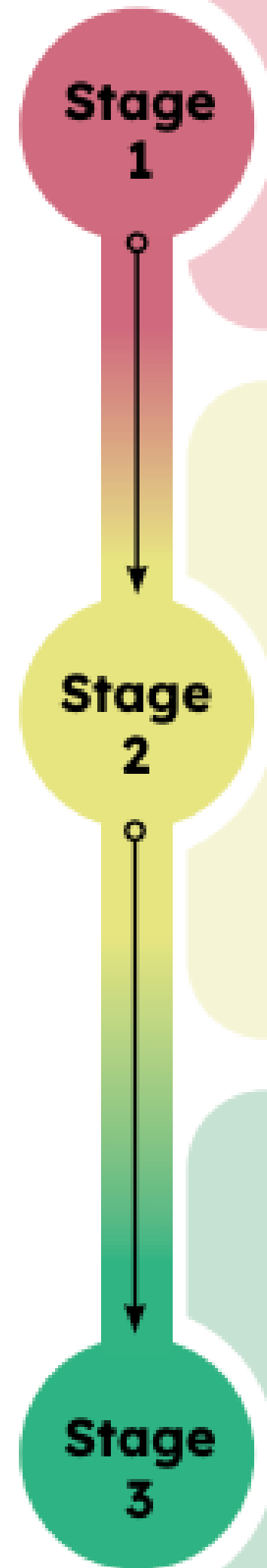


All clinicians should get better because all people with IDD deserve to access good care in their communities!



# Step 2: Clinician Journey

- Initial version created by ABC3 Steering Group
- Focus group participants added more influential factors



- When a clinician does not know much about IDD. They may:**
- 📍 Feel uncomfortable or fearful about caring for people with IDD
  - 📍 Not be ready to help people with IDD

- When a clinician is starting to feel more confident. They:**
- 📍 Understand why getting better at caring for people with IDD is important
  - 📍 Have learned more skills for working with people with IDD
  - 📍 Have started to make their office more welcoming for people with IDD

- When a clinician has learned a lot about IDD. They:**
- 📍 Feel very confident that they can give great care for people with IDD
  - 📍 Their offices, clinics, or hospitals have put time and money towards making care better for people with IDD
  - 📍 They are ready to help other clinicians get better at caring for people with IDD

# Step 3: Focus groups

- Focus groups with **87 clinicians**
- Targeted 5 groups of clinicians:
  - Clinicians who specialize in IDD care (43)
  - Clinicians who did not learn about IDD care (15)
  - Clinicians who have IDD (7)
  - Clinicians of color (14)
  - Clinicians who teach new clinicians and/or manage clinical organizations (8)

## Key themes from focus groups:

- ➔ Positive exposure to IDD
- ➔ Training opportunities
- ➔ Communication skills
- ➔ Longer appointments
- ➔ Shared lived experiences



# Topic 1: What has been your exposure to people with IDD?

- Most clinicians first interacted with people with IDD while providing clinical care
- Clinicians who specialize in IDD care often had personal connections to or experiences with people with IDD

“The only experience that I got, officially, was my psychiatry rotation. In medical school, you know, that is about the only place that I dealt with any kind of teaching or interactive environment.”

“ I always had a desire to support people who did not necessarily have a voice and needed advocacy, and I began working with individuals with IDD when I was 16. It just happened that way. I never thought I would follow that path, but I always just went back to it again and again. ”

# Topic 2: Do you feel you had enough guidance to learn how to serve people with IDD successfully?

- Most clinicians received no training during pre-licensure coursework
- Current medical students and recent graduates have experienced revamped curricula
- Clinicians who specialize in IDD sought additional training opportunities

“I have had absolutely no training or exposure to IDD other than I remember a couple of days on one of my clinical rotations serving at a mental health facility for mostly children with severe mental disabilities.”

“My reason for seeking out training was that I was tired of my fellow nurses on the floor treating individuals with IDD as third-class citizens. They were not getting the proper care that they needed.”

“For us, it is mandatory. For all incoming, it is part of the curriculum; it is part of the revamped curriculum where diversity, justice, and equity are really centered.”

# Topic 3: What have been barriers to improving your confidence in serving people with IDD?

- Lack of communication structures
- Lack of resources for people with IDD to access and receive appropriate care
- Medical system structure and a lack of workplace support

“There is something to be said for getting a history from a person watching their facial reaction, watching how they respond to your questions. And all of that is lost when you have to use a translator or have somebody try to communicate what you are asking them and their responses.”

“These patients need longer appointment times. But I do not have the luxury to schedule longer appointments for them like all my appointments are still 15 minutes long. And that is just wildly inadequate.”

“Just because of the way somebody with IDD may appear, somebody may not even ask their name or how they are feeling. They will just direct their questions to the person that is next to them and totally ignore the patient.”

“Our healthcare systems are not set up, how we train, how we train everyone in the hospital to manage IDD patients; if that is not set up in a way that really allows us to be able to do it in the best way possible, whether it is time, space, or the expectation of being able to see volume.”

# Topic 4: What would be the most successful format to teach clinicians about people with IDD?

- Additional exposure to people with IDD and training opportunities
- Workplace support and policies to improve clinical skills
- Shared characteristics and lived experiences

“The one thing that I wish is that everyone had exposure because I feel like if you have exposure...you realize these people are just like you, maybe they have some different needs, but that exposure was what definitely led to my revelation.”

“ Training should include demographics first, incidences of disabilities in the community, and the amount of care those individuals need. It would substantiate education for all patients. A broader approach to communication...to communicate effectively with all populations.”

“The only reason I knew what to do is because of my own experience. And that is part of why I was sent to the room and the other students were not because they knew I would be able to give the patient and his mom equal treatment, that I would not talk down to them.”

“When you have a provider that looks like you, that speaks your language, your trust is there, like there is a greater connection. I think I have a greater ability to listen to the provider and maybe more adherent to the treatment being offered or to the ideas being shared and to follow up on a plan. And so, I think when you have that, it is a lot more positive experience.”

# Topic 5: Who can influence clinicians to seek more preparation in serving people with IDD?

- Educational associations
- Accrediting and licensing bodies
- Professional societies
- Advocates and peers role models

“I think the professional societies offering training, offering conferences, things that you are willing to go to, that you are interested in going through...I think that would be the best route.”

“There needs to be advocacy at the legislative level that coordination of care is really important. If you want clinicians to turn to it, the work has to be valued for the time that gets put in.”

“Through the accrediting bodies because that will give you the reciprocity so that everytime you go to a different state, you do not have to either redo or it is slightly different requirements or anything like that.”

“ What needs to be done or created is a conference all about different specialties like podiatry and pediatrics, internal medicine, an immersion of how to treat this population, how to be a better dentist for this population, how to take care of this and build from that on.”

# Step 4: Voted on goals and action steps

- IEC combined learnings from focus groups
- Analyzed key themes and influential factors
- Noted **4 key sectors** to target:
  - ABC3 Coalition
  - Professional Societies
  - Educational Associations
  - Accrediting & Regulatory Bodies
- Voted to reach consensus on action steps and goals

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**ABC3 SECTOR OVERVIEW**

SECTOR	GOALS
ABC3 Coalition & IEC	<b>GOAL #1:</b> Use data & stories to illustrate the need for action <b>GOAL #2:</b> Advocate for educational associations and professional societies to include IDD in curricula and continuing medical education (CME) <b>GOAL #3:</b> Advocate for inclusion of IDD content in licensure, recertification, and accreditation
Professional Societies	<b>GOAL #1:</b> Change clinical culture to see people with IDD as individuals rather than a medical diagnosis <b>GOAL #2:</b> Create quality measures specific to IDD care <b>GOAL #3:</b> Incentivize continuing clinical education (CCE) for IDD learning <b>GOAL #4:</b> Promote clinical environments that are supportive for people with IDD
Educational Associations	<b>GOAL #1:</b> Sponsor culture change campaigns <b>GOAL #2:</b> Develop curricula of clinical skills for supporting diverse cultural backgrounds in graduate and prelicensure programs <b>GOAL #3:</b> Include IDD content in training programs for trainers & learners
Accrediting Bodies: For Clinicians	<b>GOAL #1:</b> Mandate IDD learning through licensing renewals <b>GOAL #2:</b> Mandate IDD learning through board (re)certification
Accrediting Bodies: For Healthcare Facilities	<b>GOAL #1:</b> Sponsor culture change campaigns among facility leaders <b>GOAL #2:</b> Incorporate IDD-related tools and processes into requirements for facility accreditation



# What sectors are included in the Roadmap?

- **Education associations**



- Set rules for schools where people learn how to be clinicians

- **Professional societies**



- Organize and represent certain types of clinicians

- **Regulatory bodies**



- Set rules for how clinicians must do their jobs

- **Accrediting bodies**



- Make sure clinicians and the places they work follow the rules

- **ABC3 Coalition**



- People and organizations who care about making healthcare better for people with IDD


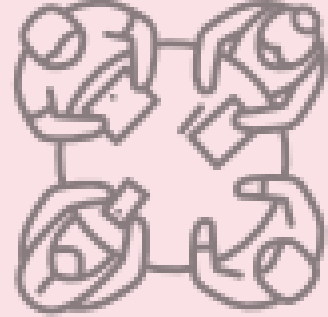
# Why these sectors?

- Power to change things across the United States
- Trusted leaders in the areas they work
- Control how in-training clinicians learn
- Determine how working clinicians do their job
- Set rules and guidelines for all clinicians



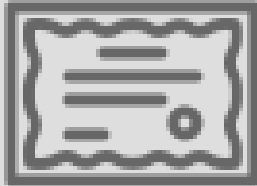


# Sector Goals

# Sector Goals for ABC3 and Professional Societies

Sector	Goals
<b>ABC3 Coalition &amp; IEC</b> 	<p><b>Goal 1</b> Use facts and stories about people with IDD to show the need for action</p> <p><b>Goal 2</b> Ask organizations that teach or represent clinicians to include IDD as part of their coursework and continuing medical education (CME)</p> <p><b>Goal 3</b> Ask organizations that create coursework and tests that clinicians use to get licensed, recertified, and accredited (accrediting organizations) to include IDD content</p>
<b>Professional Societies</b> 	<p><b>Goal 1</b> Show clinicians that it's more important to get to know a person than to focus on their IDD</p> <p><b>Goal 2</b> Create quality measures, which are tools to measure the quality and safety of healthcare for people with IDD, including methods, patient viewpoints, and health results</p> <p><b>Goal 3</b> Motivate clinicians to get continuing clinical education (CCE) credits for learning about IDD</p> <p><b>Goal 4</b> Promote healthcare settings that support people with IDD</p>

# Sector Goals for Educational Associations and Accrediting Bodies

Sector	Goals
<b>Educational Associations</b> 	<p><b>Goal 1</b> Sponsor culture change campaigns</p> <p><b>Goal 2</b> Create courses (curricula) that teach and train clinicians how to support patients of diverse cultural backgrounds</p> <p><b>Goal 3</b> Include information about IDD in training programs for both teachers and the students they teach</p>
<b>Accrediting Bodies: For Clinicians</b> 	<p><b>Goal 1</b> Make IDD learning required for clinicians who are renewing their licensing</p> <p><b>Goal 2</b> Make IDD learning required for clinicians who are getting board (re)certification (the tests they must pass to be able to see patients)</p>
<b>Accrediting Bodies: For Healthcare Facilities</b> 	<p><b>Goal 1</b> Sponsor culture change campaigns among leaders of facilities</p> <p><b>Goal 2</b> Include IDD-related tools and processes into requirements for facility accreditation</p>

# Other Key Guiding Principles

- Centralize lived experience to ensure alignment with core disability values
- Promote existing resources
- Engage sectors simultaneously to produce coordinated, unified messaging to clinicians
- Offer multiple, incentivized, and guided options for learning
- Engage leadership to grow buy-in and momentum



# ABC3 in Action

# Looking Ahead: Tailored and Universal Solutions

- Prepared and empathetic clinicians provide better communication, accommodations, and goal-oriented care for all
- Universal design supports equity and dignity
  - Acknowledges and normalizes that people have different needs
  - Removes unnecessary barriers
  - Leaves fewer people behind
  - Leaves room for choice and preferences
  - Encourages pro-active understanding of how differences manifest
  - Frees time, energy, resources to address individual needs





# Universal Solutions Make Healthcare Better For Everyone



# Projects & Partnerships

## Work In Progress:

- CEU module: Communication Disabilities 101 for Healthcare Professionals – February 2025
- Collaterals for dental teams to use in workflow to support communication disabilities and IDD
- Incorporating IDD education into Family Medicine residency program
- Environmental Scan of existing training materials



# Projects & Partnerships

## Exploratory & Future Work:

- Starting ABC3 General Membership in 2025
- Review existing training materials and create training pathways for different types of clinicians
- ACGME Disability Summit Planning Committee
- Culture Change Campaigns for professional societies and educational associations



# Thank you!

Email us: [info@ie-care.org](mailto:info@ie-care.org)

ABC3 website: [www.ie-care.org/abc3](http://www.ie-care.org/abc3)

Roadmap website: [www.inclusivecareroadmap.org/](http://www.inclusivecareroadmap.org/)

