

# A National Roadmap for Disability-Inclusive Healthcare

A plan for clinicians to learn how to give the best healthcare possible to people with intellectual and developmental disabilities (IDD).



**Endorse the Roadmap**

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# What are the goals of the National Roadmap?

## The goals of the National Roadmap are to:

- 📍 Give clinicians (such as doctors, nurses, and dentists) 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 that 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



The Roadmap was made by the **ABC3 coalition**—a group that includes **self-advocates** (people with IDD who speak out and stand up for their rights to get the best healthcare, don't let others speak for them, and take part in decisions that affect them).

# Why is the Roadmap needed?

Because people with IDD deserve the best healthcare possible.

## Clinicians often don't know a lot about caring for people with IDD. This is because:

- 📍 Many schools for new clinicians don't teach them how to care for people with IDD
- 📍 Clinicians haven't met many people with IDD or had them as patients:
  - ➔ They may feel uncomfortable or even fearful around people with IDD
  - ➔ They may believe having an IDD makes life worse for people no matter what
  - ➔ They don't know how to communicate well with people with IDD

For all these reasons, many clinicians don't feel confident in caring for people with IDD.

**We made the Roadmap to help with all these issues.**

## The offices, clinics, or hospitals where clinicians work 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 companies, so they can pay for any extra costs. For example, an appointment for a person with IDD can take extra time, which costs more.





## Even clinicians who want to do better don't know where to go.

Some groups have created classes for clinicians who care for people with IDD. These classes can really help. However, they can only teach a few clinicians at a time. These classes also aren't always available.

## What is in the Roadmap?

The Roadmap is a **plan** that different clinicians and groups involved with healthcare can follow. This plan will help make healthcare better for people with IDD.

### The plan includes:

- 📍 Goals these groups should set
- 📍 Steps they can take to reach those goals
- 📍 Ways these groups can work together to make change happen faster



# What kinds of groups are included in the Roadmap?



## Regulatory bodies

Groups that set rules for how clinicians must do their jobs. For example, the Joint Commission makes sure places where people get healthcare meet quality standards.



## Accrediting bodies

Groups that make sure clinicians and the places where they work follow the rules. For example, the Accreditation Council of Graduate Medical Education accredits places where new doctors get extra training in a specialty.



## Education associations

Groups that set rules for the schools where people learn how to be clinicians, such as medical schools. For example, the American Dental Education Association sets rules for schools where people learn to be dentists.



## Professional societies

Groups that organize and represent certain types of clinicians. For example, the American Medical Association represents doctors.



## The ABC3 Coalition

A group of people and organizations who care about making healthcare better for people with IDD.



**Endorse the Roadmap**

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# Why these groups?

**The clinicians and groups in the Roadmap can help change things for the better because they:**

- 📍 Are trusted leaders in the areas where they work
- 📍 Work across the country, not just in 1 city or state
- 📍 Can change how in-training clinicians learn
- 📍 Can change how working clinicians do their jobs
- 📍 Can reach many people with the rules or guidelines they set. This can make changes that will help now and in the future.



# How can clinicians get better at caring for people with IDD?

It takes new skills to give better healthcare to people with IDD. Clinicians must learn and practice these skills to get better.

**We think there are 3 stages clinicians go through as they get better at caring for people with IDD:**



## Stage 1

**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

## Stage 2

**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

## Stage 3

**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

# Which clinicians should get better at caring for people with IDD?

- 📍 Medical doctors (physicians)
- 📍 Nurse practitioners
- 📍 Physician associates
- 📍 Our first goal is to improve care by clinicians who work in certain areas, including:

Sexual and reproductive health

Emergency care

Primary care

Dentistry

Mental and behavioral health

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

## Why start with these clinicians?

**They can make a big difference in making healthcare better for people with IDD.**

**This is because:**

- 📍 They tend to have more patients who have IDD
- 📍 They can make sure patients take the right medicines (people with IDD are often prescribed too many medicines)
- 📍 They can suggest other clinicians a person can see for different kinds of healthcare (referrals)
- 📍 They can suggest places people can get things they may need such as hoist lifts, crutches, or oxygen equipment





# How did we create the Roadmap?

## We formed the ABC3 Coalition

- 📍 Starting in 2021, the Institute for Exceptional Care (IEC) created the ABC3 Coalition.

ABC3 stands for Action to Build Clinical Confidence and Culture. It is made of 37 members (people and groups) who want to make healthcare better for people with IDD.

### What kinds of people and groups are in the ABC3 Coalition?

1. Self-advocates and family members
2. Groups that represent doctors, nurses, dentists, physician associates, and other clinicians
3. Groups that represent medical and nursing schools
4. Nonprofits
5. Researchers
6. Accreditors



### The members of ABC3 talked about:

- 📍 The best steps clinicians can take to get better at caring for people with IDD
- 📍 Who should take these steps
- 📍 How they can take these steps
- 📍 Ways to measure how well clinicians care for people with IDD



## We did focus groups

**In 2022 and 2023 we did focus groups with 87 clinicians.**

**There were 5 groups:**

- 📍 Clinicians who did not learn about IDD in school, but now specialize in IDD care
- 📍 Clinicians who did not learn about IDD in school, and did not learn about it in other ways
- 📍 Clinicians who have IDD
- 📍 Clinicians of color
- 📍 Clinicians who are in charge of teaching new clinicians



We asked what would help the most to make healthcare better for people with IDD. We listened to everything they told us and then used their and others' ideas to create the Roadmap

# How can I help?

You can endorse the Roadmap. This means you show your support for the Roadmap and its goal of making healthcare better for people with IDD.

[Click here to add your name to the list of people and groups who support the Roadmap!](#)



## Why should my group endorse the Roadmap?

An endorsement from your group will help:

- Raise awareness about the challenges people with IDD face
- Put rules and policies in place that make care better for people with IDD
- Create a healthcare workforce that is ready to care for people with IDD

**The more endorsements we get, the greater the chance the ideas in it are put into action!**

## Who can endorse the Roadmap?

### Individual people, such as:

- 📍 People with IDD
- 📍 Those who care for people with IDD
- 📍 Anyone who cares about this issue


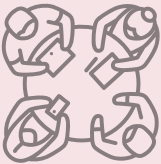
### Groups, such as:

- 📍 Health and healthcare organizations
- 📍 Disability advocacy groups
- 📍 Any group who care about this issue






# ABC3 Sector overview

What can different areas (sectors) of healthcare and healthcare education do to improve care for people with intellectual and developmental disabilities (IDD)?

Sector	Goals
<b>ABC3 Coalition &amp; IEC</b> 	<p>Goal 1 Use facts and stories about people with IDD to show the need for action</p> <p>Goal 2 Ask organizations that teach or represent clinicians to include IDD as part of their coursework and continuing medical education (CME)</p> <p>Goal 3 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>Goal 1 Show clinicians that it's more important to get to know a person than to focus on their IDD</p> <p>Goal 2 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>Goal 3 Motivate clinicians to get continuing clinical education (CCE) credits for learning about IDD</p> <p>Goal 4 Promote healthcare settings that support people with IDD</p>



## ABC3 Sector overview (continued)

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

# Sector goals and action steps

## ABC3 Coalition and Institute for Exceptional Care (IEC)



The ABC3 Coalition is a group of self-advocates, family caregivers/partners, and organizations that work to improve healthcare for people with IDD. The Institute for Exceptional Care (IEC) organizes programs such as the ABC3 Coalition and advocates for better IDD healthcare.

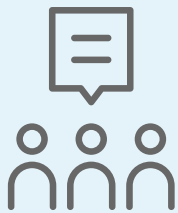
What are their goals around care for people with IDD?	What steps can they take to reach their goals?
<div>Goal 1</div> <div>Use facts and stories about people with IDD to show the need for action</div> <div></div>	<ul style="list-style-type: none"><li>• Gather health stories from people with IDD</li><li>• Create videos that tell stories about people with IDD and their healthcare</li><li>• Collect facts about IDD from books and papers in medical journals</li><li>• Build a group of learning tools that help clinicians such as doctors, nurses, and physician associates improve their thinking and skills around serving people with IDD (culture change campaign)</li><li>• Join with organizations from the other sectors in the Roadmap to work on culture change campaigns</li><li>• Help lawmakers learn about the need for culture change and training</li></ul>

# ABC3 Coalition and Institute for Exceptional Care (IEC)

(continued)

## Goal 2

Ask organizations that teach or represent clinicians to include IDD as part of their coursework and continuing medical education (CME)



- Find and gather leaders in those organizations to ask what they need to reach this goal
- Help these organizations create learning goals and tools that include:
  - Training packages with step-by-step plans for using coursework, videos, case scenarios, and ways to work with people with IDD
  - A tool to help doctor's offices, clinics, hospitals, and other healthcare offices decide if they are ready to serve people with IDD (audit tool)
  - Role play activities (case scenarios), created with help from people with IDD, for clinicians to see what healthcare is like for people with IDD
  - In-person and online trainings for clinicians
  - Programs that train clinicians to teach other clinicians about serving people with IDD ("train the trainer" programs)
  - Help organizations partner with people with IDD to create "train the trainer" programs (programs that train clinicians to teach other clinicians about serving people with IDD)

## Goal 3

Ask organizations that create coursework and tests that clinicians use to get licensed, recertified, and accredited to include IDD content



- Figure out which accrediting organizations are most important to partner with
- Ask accrediting organizations what they need to reach this goal
- Help accrediting organizations find people with IDD and healthcare experts who can work together to design coursework and tests about serving people with IDD

## Professional societies



These are organizations that represent different groups of clinicians.

### What are their goals around care for people with IDD?

#### Goal 1

Show clinicians that it's more important to get to know a person than to focus on their IDD



### What steps can they take to reach their goals?

- Partner with ABC3 to create lists of skills that clinicians should have to better serve people with IDD (competencies). Then, ask professional societies and accrediting organizations to use these competencies in coursework and testing.
- Partner with ABC3 to run culture change campaigns
  - Share ABC3's culture change campaign tool kit with society members
- Encourage professional society members to use the ABC3 training package and audit tool in their own organizations
- Develop learning materials for clinicians who specialize in certain types of healthcare, such as care of the brain or heart





## Professional societies (continued)

### Goal 2

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



- Partner with ABC3 to develop quality measures that support the IIDDEAL Health Outcomes Framework (a plan for learning what people with IDD, clinicians, and others think are the most important things about health and life)
- Get support for (endorsement) IDD quality measures by Medicare and Medicaid
- Promote use of IDD quality measures with clinicians, insurers, and government agencies

### Goal 3

Motivate clinicians to get continuing clinical education (CCE) credits for learning about IDD



- Partner with ABC3 to create IDD-related CCE
- Offer free CCE credit for clinicians to attend IDD-related sessions at society conferences
- Find ways for existing CCE test questions to include information about IDD
- Spread the word about IDD CCE trainings

### Goal 4

Promote healthcare settings that support people with IDD





- Encourage organizations such as The Joint Commission to require healthcare (clinical practice) and community services sites be IDD-friendly
- Create checklists to help healthcare sites build IDD-friendly environments
- Teach clinicians about:
  - Meeting American Disabilities Act (ADA) requirements
  - Legal risk for mistreating people with IDD

## Educational associations



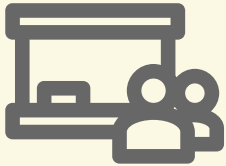
These are organizations that train new clinicians.

What are their goals around care for people with IDD?	What steps can they take to reach their goals?
<p><b>Goal 1</b></p> <p>Sponsor culture change campaigns</p> 	<ul style="list-style-type: none"><li>• Partner with ABC3 and people with IDD to build learning tools that help clinicians improve their thinking and skills around serving people with IDD (culture change campaigns)</li><li>• Ask leaders from colleges and graduate training programs that teach and train new clinicians to help with culture change campaigns</li></ul>
<p><b>Goal 2</b></p> <p>Create courses (curricula) that teach and train clinicians how to support patients of diverse cultural backgrounds</p> 	<ul style="list-style-type: none"><li>• Partner with ABC3 to decide what students must learn from curricula (standards)</li><li>• Agree on a list of things clinicians need to know and do (competencies) and the ways those things will help people with IDD</li><li>• Include IDD material into existing courses to train teachers and the students they teach</li><li>• Encourage association members to use the ABC3 training curricula</li><li>• Track who uses the curricula and get their ideas on how to make it better</li><li>• Help teach standardized patients and real patients about the list of healthcare skills needed to care for people with IDD. (Standardized patients are people who play the role of real patients to help clinicians in training learn.)</li><li>• Work with IDD educators and their networks</li><li>• Host meetings with key education leaders and community members to share what the ABC3 Coalition has learned</li></ul>

## Educational associations (continued)

### Goal 3

Include information about IDD in training programs for both teachers and the students they teach



- Use ABC3 training curricula
- Include people with IDD in trainings so they can share their experiences
- Focus on trainings for primary care doctors, nurses, and physician associates before reaching out to other specialties
- Work with accrediting organizations to agree on the most important IDD learning and skill competencies for students training to be doctors, nurses, and physician associates
- Include IDD information in coursework



# Accrediting bodies: For clinicians



These are organizations that test and review professionals to make sure they know enough to treat patients, then give them a license.

What are their goals around care for people with IDD?	What steps can they take to reach their goals?
<div>Goal 1</div> <p>Make learning about IDD required for clinicians who are renewing their licensing</p>	<ul style="list-style-type: none"><li>• Set the level of IDD-related continuing clinical education (CCE) needed for clinicians who are renewing their professional licenses</li><li>• Encourage creating and using more IDD information in CCE courses</li></ul>
<div>Goal 2</div> <p>Make learning about IDD required for clinicians who are getting board (re) certification (the tests they must pass to be able to see patients)</p>	<ul style="list-style-type: none"><li>• Partner with ABC3 to plan how certification exams and requirements can include IDD competencies</li><li>• Agree on a set of skills-based competencies (things clinicians learn how to do) with accreditors of graduate training programs for each area of healthcare</li><li>• Use the ABC3 training package</li></ul>

# Accrediting bodies: For healthcare facilities



These are organizations that test and review healthcare facilities such as doctor’s offices and hospitals to make sure they are safe and know enough to treat patients, then accredit (certify) them.

What are their goals around care for people with IDD?	What steps can they take to reach these goals?
<div>Goal 1</div> <div>Sponsor culture change campaigns among leaders of facilities</div>	<ul style="list-style-type: none"><li>• Partner with ABC3 and people with IDD on culture change campaigns</li></ul>
<div>Goal 2</div> <div>Include IDD-related tools and processes into requirements for facility accreditation</div>	<ul style="list-style-type: none"><li>• Partner with people with IDD and ABC3 to figure out how facilities should prepare to support people with IDD</li><li>• Build off existing tools to certify facilities as IDD-inclusive</li><li>• Include items for supporting people with IDD in the requirements for healthcare facilities</li></ul>





# The ABC3 clinician journey:

How can clinicians become better at caring for people with Intellectual and Developmental Disabilities (IDD)?



## As the journey begins

### A clinician:

- May not know how to care for people with IDD
- May not know where to go for help

### Important steps (supporting factors) for clinicians as their journeys begin

#### Learn from people with IDD

- Spend time with people with IDD
- Learn about barriers they face

#### Learn from other professionals

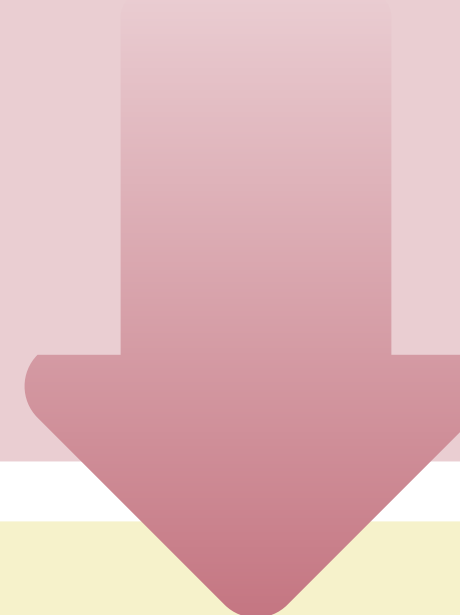
- Know the standards & requirements for treating people with IDD
- Get feedback on the care they give and how to improve

#### Learn to be self-aware

- Get training on how their own thoughts and actions affect their care
- Think about their own culture and learn to treat people from different cultures

#### Learn to communicate

- Get training on how to use simple language
- Learn different ways to communicate, such as through pictures



## During the journey

### A clinician can:

- Learn how to care for people with IDD
- Learn different cultures
- Build empathy

### Important steps for clinicians during the journey

#### Make sure patients understand

- Ask patients to explain information back to the clinician to check understanding
- Use simple language

#### Make healthcare accessible

- Make sure equipment and clinics are accessible to all people
- Use tools to help all people communicate, such as visuals or mobile phone apps

#### Support patients

- Refer patients to services with IDD experts
- Build strong relationships with people with IDD and their families to support their whole health



## At journey's end

**A clinician and people with IDD can feel ready to act, which can lead to better health!**

### Important steps for clinicians at journey's end

- Work together with nurses, social workers, and community groups to support people with IDD
- Meet people where they are by finding ways to meet their needs
- Keep practicing! Give excellent care to all patients, while recognizing it is an ongoing journey of learning



**ABC3:** Action to Build Clinical Confidence & Culture

**Clinician:** A healthcare professional who treats patients directly, such as a doctor, nurse, or physician associate.

**IDD:** Intellectual and Developmental Disabilities. This includes common conditions like autism, cerebral palsy, Down Syndrome, intellectual disability, ADHD (attention deficit hyperactivity disorder), and more rare conditions like William Syndrome or Rhett Syndrome.