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)

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Seeking Support

The ABC3 Coalition seeks support for the National Roadmap for Disability-Inclusive Healthcare from both healthcare and disability organizations, and to grow the coalition itself.

The purpose of the ABC3 Coalition is to coordinate national strategies that aim to prepare general clinicians in multiple health professions to serve people with intellectual and/or developmental disabilities (IDD) equitably and effectively.

We believe that sustained and meaningful change requires building a movement of people and organizations with the shared goal of creating a healthcare workforce that is committed and fully prepared to serve this growing and vulnerable population that deserves the best health possible so they can thrive.

We invite you to join us.

[**CLICK HERE TO SUPPORT THE ROADMAP**]

Executive Summary

Action to Build Clinical Confidence and Culture (ABC3) is a coalition established by Institute for Exceptional Care (IEC). Its purpose is to coordinate national strategies that aim to prepare general clinicians in multiple health professions to serve people with intellectual and/or developmental disabilities (IDD) equitably and effectively. The IDD population includes people with conditions such as Down syndrome, autism, fetal alcohol syndrome, and cerebral palsy.

ABC3's member organizations and self-advocate leaders are uniquely positioned to effect change on a national scale because they represent or can partner with organizations such as clinical professional societies, clinical education associations, and healthcare accrediting and regulatory bodies. Each of these sectors wield significant influence through their policies, programs, and thought leadership, to motivate clinicians and healthcare facilities to become better prepared to serve people with IDD.

Through foundational discussions, the coalition developed a formal charter and identified the types of general clinicians to prioritize – physicians, nurse practitioners, and physician associates in the areas of primary care, mental/behavioral health, emergency care, sexual/reproductive health, and dentistry. These clinicians are most likely to encounter people with IDD in daily practice and hold important influence through their ability to make referrals and write prescriptions.

With support from the WITH Foundation, the ABC3 coalition developed a National Roadmap for Disability-Inclusive Healthcare (the Roadmap) of goals and action steps to achieve clinical preparedness at scale. The Roadmap was premised on the coalition's conception of the factors that help a general clinician "journey" from an initial stage of limited awareness of IDD and under-confidence in serving people with IDD, to a middle stage of having appropriate knowledge, attitudes, and skills, then ultimately to the final desired state of also having the resources and infrastructure to act. The ABC3 Clinician Journey can be viewed in Appendix B.

The coalition also sought input from informants through focus groups with 87 clinicians recruited from around the country. All focus groups included multiple health professions, but each targeted a different type of clinician: (1) clinicians who received no IDD exposure during their formal clinical training but who became committed and prepared to serve the IDD population through other means ("converted generalists"); (2) clinicians who neither had any IDD exposure during formal clinical training nor obtained it through other means ("unconverted generalists"); (3) clinicians who themselves have developmental disabilities (DD); (4) clinicians of color; and (5) clinical education leaders. Focus group participants identified the types of organizations (sectors) that could influence general clinicians, as well as the specific actions each sector might take, and helped to refine the ABC3 Clinician Journey.

IEC conducted an analysis of focus group themes to distill the most cited sectors and actions. The ABC3 Steering Group then came to consensus on the four highest priority sectors (ABC3/IEC, professional societies, education associations, and accrediting/regulatory bodies), specific goals for each sector, and specific action steps to achieve every goal.

The selected goals and action steps are deliberately sequenced, to align across sectors and in recognition of how the different sectors typically relate to one another. An example of alignment is planning for simultaneous engagement of educational associations across different health professions, as such inter-professional coordination already exists and can accelerate action on IDD education. An example of sequencing is the coalition's decision to invest first in driving culture change in a sector, before promoting actual training through that sector. This is based on the Steering Group's deep experience with training initiatives that fail or do not have lasting impact because there was no effort to first "soften the ground" with culture change that gives clinicians the desire to learn about a topic.

The resulting National Roadmap for Disability-Inclusive Healthcare prioritizes four sectors, listed in the proposed order of engagement:
• The ABC3 Coalition and IEC
• Professional Societies
• Educational Associations
• Accrediting/Regulatory Bodies

The Roadmap identifies specific goals for each sector, as seen below and in Appendix F: ABC3 Sector Overview.

ABC3 Sector Overview

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

The Steering Group identified specific action steps to achieve each goal, informed by insights from focus groups as well as the following key guiding principles:

- Keep the perspectives of people with IDD central by involving self-advocates as key partners in all work.
- Leverage and promote IDD training resources and lessons learned from other initiatives.
- Engage each sector representing all the targeted professions simultaneously (e.g., educational associations for medicine, nursing, and physician associates) to produce coordinated, unified messaging to clinicians.
- Offer clinicians multiple, incentivized, and guided options for learning.
- Engage the targeted sector leaders early and often, to grow buy-in and momentum.

A summary of each sector's goals and action steps can be found in Appendices G, H, I, and J.

The Need: A National Strategy For Better IDD Healthcare

For 16 million people with intellectual and/or developmental disabilities (IDD) such as Down syndrome, cerebral palsy, and autism, the services available and delivered by clinical teams in general healthcare practice settings are too often under-prepared, ineffective, and/or unsafe. While clinicians who specialize in treating IDD conditions provide critical services, people with IDD need a much broader array of healthcare services and available supports. The life expectancy for people with IDD has steadily increased and now exceeds 72 years. However, a July 2023 report indicated that people with learning disabilities and autism from ethnic minority groups were found to have a median age at death of 34 years, which is significantly lower than the comparable white population. As they age, people with IDD will develop common chronic conditions like cancer, heart disease, diabetes, and dementia that require thoughtful care from all clinicians.

Unfortunately, people with IDD face significant barriers to accessing care and achieving their desired outcomes. Such barriers include inadequate accommodations to support communication between individuals and clinicians, a lack of formal training in IDD provided to healthcare professionals, and complex financing systems that limit or create confusion surrounding access to local providers who are prepared to provide appropriate and culturally competent care. People with IDD can receive insurance through Medicaid, Medicare, and private insurance. Some individuals with IDD may be dually eligible beneficiaries who are enrolled in both Medicare and Medicaid, whose eligibility rules create potential for significant overlap and complexity, particularly with managing Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) payments, and a lack of coordination between programs for primary, acute, and home and community-based services (HCBS).

People with disabilities are more likely than the general population to have unmet healthcare needs, receive lower quality healthcare and fewer preventative services, and are less likely to be offered equal treatment. The CDC reports 1 in 4 adults with a disability do not have a primary healthcare provider, have an unmet health need due to cost, and 20% have not had a routine check-up within the past year. On top of struggles with healthcare affordability and access, people with IDD face physician bias and avoidance, as a recent Harvard study found that only about half of doctors (57%) strongly agreed that they "welcomed people with disabilities into their practices".

Healthcare professionals across the United States struggle with the lack of knowledge and level of comfort needed to provide high quality care to people with IDD. A study from 2017 reported that only 52% of medical schools include a "disability awareness program." Medical students receive an average of 11 minutes of exposure to IDD throughout their four-year clinical training and research has shown that eight out of ten physicians harbor negative views of people with disabilities, including the belief that disability leads to worse quality of life. In an October 2022 New York Times story, a person with disabilities recalled a doctor who said, "I really don't know what to do with you. Maybe you should go elsewhere."

Gaps in healthcare services for people with IDD are multi-factorial and can be exacerbated when they need accommodations for communication, accessibility, emotional and/or behavioral triggers, and other individual needs. Healthcare facilities can be a place of harm for people with IDD, where policies, physical designs, clinician attitudes, use of physical and chemical restraints, and other factors impact their comfort or ability to receive care. Clinical communications involving people with IDD were examined in a study that indicated physicians often have unstandardized approaches; clinicians prefer to communicate with caregivers despite concerns over individual consent, visual aids to assist in communication are not widely used, and physicians frequently do not directly engage with an individual with IDD due to their estimation of the individuals' decision-making ability. A study in 2022 found that people with IDD were 2.7 times as likely to experience harm when admitted to the hospital compared to the general population, with patient safety incidents leading to lengthened stays and increased mortality risk. A similar study found that over 30% of people with IDD experienced adverse events during their hospital visits, compared to less than 10% of other individuals.

As a consequence, people with IDD experience avoidable mortality and morbidity. They have higher rates of diabetes, depression, and anxiety. Incidence of maternal mortality for women with IDD is nearly threefold higher than the general population. A study of obstetric care and pregnancy health among autistic individuals found that 31% had delayed or missed screenings, 16% began prenatal care after the first trimester, 65% were diagnosed with depression during pregnancy, 39% were diagnosed with post-partum depression. Gestation complications were relatively common, with 23% of individuals receiving a diagnosis of gestational hypertension, 10% of pre-eclampsia, and 10% of gestational diabetes. Over 25% of autistic youth experience suicidal ideation and nearly one in ten will attempt suicide before the age of 25. Aside from age, intellectual disability (ID), was the strongest predictor of death from COVID-19. Outcomes for people with IDD who are Black or Brown are even worse.

At the same time, general clinicians are hindered in practicing at their desired level of effectiveness. The vast majority receive little to no training in disability values or history, IDD, its implications for treatment of other health conditions, or the concrete methods and strategies for supporting people with IDD. Without adequate training, reports show, providers lack comfort in their ability to effectively examine and interact with people with disabilities, often leading to poorer outcomes, difficulty establishing trust, and reluctance to work with this population. Physicians face additional barriers to meeting the needs of individuals with IDD when it comes to having accessible equipment, financial resources to obtain equipment, enough space to meet accommodation needs, and tailored payment for the time required to care for individuals with complex needs. A 2019 survey in the state of California found that less than 20% of doctor's offices had adjustable exam tables, only 10.9% are equipped with wheelchair accessible scales, and just 5.9% were supplied with a lift to assist staff and individuals with transfers to an examination table. Lack of communication skills, situational awareness, environmental preparedness, and clinical knowledge about IDD create unnecessary stress for clinicians. They are left feeling helpless and unconfident.

Initiatives to Improve Traning Among General Clinicians

Numerous curricula concerning IDD and other disabilities are already available and serve as useful tools for setting core competencies and providing instructional content that can be used to educate clinicians in practice or clinicians in training in how to better serve people with IDD.

The Alliance for Disability in Health Care Education (ADHCE) partnered with The Ohio State University's Nisonger Center to establish core competencies based on guiding principles and shared values for providing care to people with disabilities. Their core competencies include contextual and conceptual frameworks on disability, professionalism, patient-centered care, legal obligations and responsibilities for caring for individuals with disabilities, teams and systems-based practice, clinical assessment, and clinical care over the lifespan and during transitions.

PATH-PWIDD is a consortium funded by the U.S. Department of Health and Human Service's Administration for Community Living to implement IDD curricula in more than thirty clinical training programs. PATH-PWIDD is working to introduce an interprofessional health education curriculum for pre- and post- licensure clinical students. Their goal is to develop and integrate high-impact and inclusive learning activities.

The Vanderbilt University Medical Center's Consortium LEND program has worked with experts to create curriculum resources for training programs on more than 30 neurodevelopmental disability topics. These include reading materials, assignments, discussion prompts, case studies, and other resources for facilitating training.

IntellectAbility is a company committed to improving understanding of IDD. It has created e-learning curricula, available to clinicians from any healthcare profession, that provide fundamentals in understanding IDD healthcare. Its six modules include real world case studies.

Special Olympics International and the American Academy of Developmental Medicine and Dentistry (AADMD) also sponsor training initiatives at undergraduate clinical schools. Free healthcare screenings are provided to athletes participating in Special Olympics events.

Ability Central is a nonprofit and philanthropic organization that promotes healthcare solutions for people with communication disabilities. It has created training and advocacy resources available to both healthcare professionals and community members, with a focus on communication strategies, accommodations, and tools and technology.

ECHO Autism is a voluntary network of clinicians, individuals, and families that meet virtually in a collaborative learning environment to share resources and spread clinical expertise. ECHO Autism's initial focus was on the pediatric population, with expansion planned into adult clinical care and care of other IDD conditions.

These initiatives have sparked incredible improvements in care provided to the IDD community, but they all face challenges to scaling and sustained impact because they rely on time-limited grant funding and/or a limited pool of motivated participants. Lasting change requires the additional engagement of organizations that have the policy and/or programmatic influence to "hard wire" demand for training among clinicians at all levels of practice experience. National clinical societies, educational associations in different health professions, and accrediting bodies can sponsor programs like free IDD-related continuing education, policies such as inclusion of IDD-related material on certification exams, and campaigns supported through webinars and policy positions that leverage both existing and new training resources to drive permanent change on a national level.

To catch clinicians when they are most open-minded, many previous and current initiatives addressing the preparation of clinicians to better serve people with IDD have understandably focused on clinicians in training. (ECHO Autism, Ability Central, and IntellectAbility are notable exceptions). However, clinicians in practice are more numerous and can wield disproportionate influence on new clinicians whom they supervise or train. Their mentorship can motivate or demotivate younger clinicians to better serve people with IDD. Thus, it is also critical to prepare clinicians in practice, at scale.

The ABC3 Coalition & IEC

Institute for Exceptional Care (IEC) is a nonprofit founded by healthcare leaders who also have the lived experience of supporting loved ones with IDD. Its mission is to make healthcare better for people with IDD so they can have the best health possible to live life to the fullest. IEC works in partnership with people with IDD (self-advocates) to inform strategies for evolving care models, training general clinicians, and designing better methods of financing and paying for services.

IEC established the ABC3 coalition in 2021 to ensure the preparation and motivation of clinicians across the U.S. to serve people with IDD. The coalition brings together self-advocates, family care partners/givers, and healthcare experts who share a common understanding of the problem to create a shared vision for change. ABC3 and its member organizations will design and implement campaigns and programs and develop materials and curated resources to drive culture change and relevant knowledge and skills at scale among clinicians.

The founding Steering Group includes self-advocates, family members, clinicians, and leaders from clinical professional societies, disability organizations, clinical educational organizations, and accrediting bodies. We seek to grow the coalition over time with others committed to collective action to achieve shared goals. Please see Appendix A: ABC3 Charter for more information on membership and the governance processes for the coalition.

Initial ABC3 Coalition Members:
• 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 on 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)
• Center for Dignity in Healthcare for People with Disabilities, Kennedy Krieger Institute
• Developmental Disabilities Nurses Association (DDNA)
• ECHO Autism
• IntellectAbility
• Nisonger Center, The Ohio State University
• Special Olympics International (SOI)
• Kayte Barton, IDD Self Advocate
• Dena Gassner, Autism Researcher, IDD Self Advocate, and Care Partner
• BJ Stasio, IDD Self Advocate

Building a National Roadmap for Disability-Inclusive Healthcare (The Roadmap)

Priority Clinician Audiences

The Steering Group centered on the types of clinicians who are most likely to encounter people with IDD in daily practice, and who wield influence over a person's care through medication prescriptions and referrals. The coalition thus decided to prioritize physicians, nurse practitioners, and physician associates in the clinical fields of primary care, mental/behavioral health, emergency care, sexual/reproductive health, and dentistry.

Conceptual Model: The ABC3 Clinician Journey

The ABC3 Steering Group first developed a "clinician journey" graphic to conceptualize the change process that a generalist clinician experiences as they transition from an initial stage of limited understanding of IDD, to a middle stage of having knowledge, skills, and cultural understanding, to a final stage of feeling motivated, prepared, and confident that they have the appropriate resources and infrastructure to provide equitable care. The ABC3 Clinician Journey identifies factors – internal to the clinician or external influences – that are likely to motivate and facilitate this evolution, refer to Appendix B.

Participant Input

The Steering Group then sought input from clinicians through a series of focus groups. Participants were sought from physicians, dentists, nurse practitioners, and physician associates in the areas of primary care, mental/behavioral health, emergency care, sexual/reproductive health, and dentistry.

IEC recruited clinicians for focus groups using tailored invitations and an electronic flyer shared nationally with more than 100 clinical and disability organizations, with individuals, and on social media. We deliberately sought partnerships to help recruit clinicians of color, clinicians with developmental disabilities (DD) including cerebral palsy and autism, and other gap areas of clinician representation in geography and discipline. We ensured that only qualified registrants could join meetings and accommodated all participants' accessibility and communication needs.

Between May 2022 and February 2023, the ABC3 team facilitated six focus groups that engaged 87 clinicians in training and in practice. Focus groups were organized by participant type; converted generalists, clinical educators, generalist clinicians, clinicians of color, and clinicians with DD. Participants represented different types of practice settings, racial/ethnic groups (see Table 1), geographic areas, and the targeted health professions. Discussion guides included common questions for all focus groups, and several questions tailored to each clinician type, refer to Appendix C: Clinicians with DD Focus Group Protocol.

Table 1: Participant Demographics

RACE/ETHNICITY	PERCENTAGE
American Indian or Alaskan Native	2.1%
Asian/Pacific Islander	6.4%
Black/African American	37.2%
Hispanic/Latinx	7.4%
White/Caucasian	40.43%
Another Race	6.4%

Both in-person and virtual focus groups were held. In-person focus groups with converted generalist physicians and dentists took place at the 2022 AADMD conference and with converted generalist nurse practitioners and nurses at the 2022 DDNA conference. Focus groups with clinical educators, clinicians with DD, and clinicians of color took place virtually, with additional individual interviews as needed to accommodate clinicians' schedules. Focus group participants were split into breakout rooms to allow adequate time for discussion.

The discussion topics during focus groups followed in the order of exposure to people with IDD, exposure to training, barriers to improving clinical confidence, facilitators to developing clinical skills and preparedness, influential organizations or motivators, and lastly a review of the ABC3 Clinician Journey. Most participants shared common experiences with a lack of exposure to people with IDD and during training. One clinician informant described their lack of exposure and training this way:

> **"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." – General Clinician**

Potential barriers to equitably serving people with IDD shared during focus groups included lack of awareness and training, insufficient communication structures, trouble accessing and receiving appropriate treatment, resistance to changing clinical structure, lack of workplace support, and the medical system structure. Focus group participants shared the following:

> "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." – Converted Generalist

> "Our healthcare systems are not set up, how we train, how we train everyone in the hospital, to manage ID and DD 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, whether it is the space, whether it is the expectation of being able to see volume." – Clinician of Color

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

Focus group participants also identified several facilitators to support clinical confidence and culture, such as additional exposure to people with IDD, training opportunities, understanding individual health needs, workplace support, and shared characteristics or lived experiences. Participants reflected on their experiences, noting:

> "The one thing that I wish is that everyone had exposure, because I feel like if you have exposure, and that is why I think so many people who knew somebody who was part of a family - it was not scary, it was not anything abnormal. You realize these are people just like you, maybe [they] have some different needs, but that exposure was what definitely led to my revelation."
> – Converted Generalist

> "Our healthcare systems are not set up, how we train, how we train everyone in the hospital, to manage ID and DD 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, whether it is the space, whether it is the expectation of being able to see volume." **– Clinician of Color**

> "There needs to be advocacy at the legislative level that coordination of care is really important. If you want clinicians to turn into it, the work has to be valued for the time that gets put in." **– General Clinician**

Participants completed a post-survey following their participation in the focus group to rank factors they perceived to be most influential in motivating clinicians in practice and clinicians in training to achieve confidence and competence in serving people with IDD. Broader cultural norms and signals, as well as diversity, equity, and inclusion (DEI) initiatives were ranked as the most influential factors for clinicians in training. Focus group informants ranked self-assessments and feedback on performance and access to supports and tools as the top motivators for clinicians in practice. Examples of motivating factors can be found in Appendix D: ABC3 Participants Infographic.

Thematic analyses of ABC3 focus groups and surveys found exposure to individuals with IDD, training exposure, and the influence of educational associations, professional societies, accrediting bodies, licensing bodies, and IEC/ABC3 coalition as key themes; refer to Appendix E: ABC3 Thematic Analyses.

ABC3 Clincian Journey: Revisons

We solicited reactions to the draft Clinician Journey graphic from each focus group after the main discussion to avoid anchoring participants' responses with the factors already included in the graphic. Although themes in the Clinician Journey often paralleled those raised during the small group discussions, each focus group pinpointed specific factors they considered most influential, identified notable gaps, and added at least one new motivating factor to the map. The ABC3 Clinician Journey graphic in Appendix B reflects this evolution.

Building Consensus on Key Sectors, Goals, and Action Steps

We utilized a modified-Delphi approach to develop consensus among ABC3 Steering Group members on the elements of a Roadmap. The Delphi process is widely regarded as a preferred "consensus development technique" to reach rapid consensus, prevent dominant individuals from taking control of the group, and avoid conformity invoked by group pressures. First, experts are asked to respond to tailored questions. Then, their responses are presented to the contributor panel. Members are asked to express their preferences, typically through a voting format, followed by additional rounds of responses and voting that continue until a consensus is achieved.

For this initiative, focus group participants served as the experts and the Steering Group served as the contributor panel. Expert responses were collected during the clinician focus groups. The contributor panel portion of the Delphi process spanned the first two quarterly meetings of 2023. Members of the ABC3 team met individually with self-advocate members of the Steering Group to review meeting content, answer questions, and collect their perspectives for which actions they would vote to prioritize.

During the first meeting, the Steering Group previewed the four sectors prioritized by focus group participants – ABC3 Coalition/IEC, professional societies, educational associations, and accrediting bodies – as well as goals and action steps proposed for each sector by focus groups. Steering Group members then voted to select no more than four goals for each sector. To ensure all members could provide their thoughts, we created small breakout groups to allow for more in-depth conversations and welcomed them to share additional ideas by email.

We completed the Delphi process at the second quarterly meeting. The IEC team synthesized input from the first meeting and developed a plain-language slide deck, which summarized the priority sectors, goals, and actions. Steering Group members voted to first target clinicians in practice through professional societies, then clinicians in training through educational associations, on the assumption that funding and bandwidth may not allow the coalition to address both simultaneously. In July 2023, Steering Group members reviewed and approved the proposed Roadmap.

Key Sectors

The National Roadmap for Disability-Inclusive Healthcare focuses on four sectors that will have the greatest potential to influence clinical confidence and culture among general clinicians to better serve people with IDD. These sectors include the ABC3 coalition and IEC, professional societies, educational associations, and healthcare accrediting/regulatory bodies.

Professional societies are organizations representing clinicians from the same health profession that promote the goals and interests of their members, for example AAP, DDNA, and AAPA. Professional societies have influence with their member clinicians, other peer professional societies, accrediting bodies, healthcare policymakers, and other experts.

Educational associations develop recommendations and resources on the content that healthcare professionals learn during their pre-licensure and post-graduate training. Examples include the Association of American Medical Colleges (AAMC) and the American Dental Education Association (ADEA). Membership in educational associations includes clinical schools, clinical students, professors, academics, researchers and leaders of clinical education journals and other educational publications.

Accrediting bodies and regulatory bodies both aim to ensure high quality of care. Some accrediting bodies focus on individual clinicians, while others focus on healthcare facilities and training programs. Examples of accrediting bodies include accreditors of clinical training programs (ACGME), and accreditors of healthcare facilities (The Joint Commission). Regulatory bodies are government agencies that set standards for the licensure of qualified health professionals and facilities, for example state medical and facility licensing boards. In addition, government agencies such as the Centers for Medicare and Medicaid Services, the CDC, and Occupation Safety and Health Administration set national standards for systems, facilities, and individual practice.

Priority Goals by Sector

The sequence below summarizes the goals identified for each of the four sectors. While a given goal may take several years to achieve, ABC3 coalition members felt strongly that early and deep engagement of sector leaders in this systematic way would ultimately lead to meaningful change on a large scale.

The Roadmap sectors and goals can be found below and in Appendix F: ABC3 Sector Overview.

ABC3 Sector Overview

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

The goals for sectors are interdependent. The ABC3 coalition must act first by establishing key partnerships with educational associations, professional societies, and, at a later stage, accrediting bodies. ABC3 and IEC must also develop the foundational resources for other sectors to use, including a "culture change campaign toolkit" and "training package" with multiple elements and recommended approaches to using them. Engaging leaders in other sectors throughout this early stage of work will help develop buy-in for the later work that professional societies and educational associations must do to promote culture change campaigns and educational programs among their members. As importantly, encouraging organizations governing different health professions (medicine, nursing, dental, physician assistants) to coordinate with one another on developing materials and programs will improve efficiency and result in clinicians hearing consistent messages.

IEC will coordinate many of these activities. Understanding that IEC will not be able to engage all other sectors at once, the ABC3 Steering Group voted to prioritize professional societies over educational associations first, and then target accrediting bodies in a later phase of work. The coalition reasoned that professional societies influence many more clinicians than educational associations do (1.5 million clinicians in practice vs. fewer than 300,000 trainees), and that other large IDD clinical training initiatives have not targeted clinicians in practice, leaving an important gap for ABC3 to address. Accrediting bodies historically follow the lead of professional societies and educational associations in addressing new areas of clinical focus; first creating clinical champions for better care of people with IDD will also help ABC3 advocate with accrediting bodies.

Table 2: Goals for Each Sector

SECTOR	GOALS	DESCRIPTION
ABC3 Coalition & IEC	Use data & stories to illustrate the need for action	Target audience includes educational associations, professional societies, and accrediting/regulatory bodies
	Advocate for educational associations and professional societies to include IDD in curricula and continuing medical education (CME)	Target audience includes the individual associations and societies in the priority professions (medicine, nursing, physician assistants)
	Advocate for inclusion of IDD content in licensure, initial certification,recertification, and accreditation	Target audience includes accrediting and regulatory bodies
Professional Societies	Change clinical culture to see people with IDD as individuals rather than a medical diagnosis	Drive culture change campaigns in partnership with IEC/ABC3, that target society members (individual clinicians)
	Create quality measures specific to IDD care	Partner with IEC to apply the IIDDEAL Health Outcomes Framework in selecting what measures to develop
	Incentivize continuing clinical education for IDD learning	Through strategies such as free CME
	Promote clinical environments that are supportive for people with IDD	Through spreading best practices, peer-to-peer training, and other means
Educational Associations	Sponsor or support culture change campaigns	Targeting members, in partnership with IEC/ABC3
	Support curricular development of clinical skills for supporting diverse cultural backgrounds in graduate and prelicensure programs	Ideally all key health professions (medicine, nursing, physician assistants) collaborate to co-develop consistent curricula
	Include IDD content in training programs for trainers & learners	Through promotion by the educational associations
Regulatory Bodies for Clinicians	Require IDD learning through licensing renewals	Through requiring specific types or amounts of IDD continuing education
	Require IDD learning through board (re)certification	Through questions on board exams about IDD or involving cases of people with IDD
Accrediting Bodies for Clinicians	Sponsor culture change campaigns among facility leaders	In partnership with IEC/ABC3 and bodies such as the American Hospital Association or the American Medical Group Association
	Incorporate requirements into facility accreditation	Through standards for how facilities are designed (e.g., with quiet rooms), equipped (e.g., with accessible exam tables), staffed (e.g., with someone who can offer communication support), and run (e.g., with longer appointments for people with IDD)

Priority Action Steps by Sector

The coalition identified key action steps for the sectors to achieve each of their goals, informed by insights from focus groups as well as the following key guiding principles:

- Keep the perspectives of people with IDD centralized by partnering with lay people with IDD and clinicians with DD as key partners in all ABC3 initiatives. We will thus leverage the genius of their lived experience and ensure that the coalition's work remains aligned with core disability values.
- Leverage and promote IDD training resources and lessons learned from other initiatives including those cited in the Background section. We aim to promote and leverage these immensely valuable resources and not reinvent the wheel, but rather develop a curated compilation of such resources to amplify through ABC3 sponsored campaigns.
- Engage each sector representing all the targeted professions simultaneously (e.g., educational associations for medicine, nursing, and physician associates) to produce coordinated, unified messaging to clinicians.
- Offer clinicians multiple, incentivized, and guided options for learning.
- Engage the targeted sector leaders early and often, to grow buy-in and momentum.

The graphics below (also found in Appendices G, H, I and J) describe action steps for each sector in approximate sequence of when each would occur. The actual ordering of steps may vary depending on funding and what areas of work receive the most positive engagement from sector leaders.

The ABC3 Coalition and IEC sector graphic below (also found in Appendix G: ABC3 Coalition and IEC) summarizes the goals and action steps for members of the ABC3 coalition, IEC, and other disability partners, who are positioned across the target sectors and have deep connections with the IDD community.

The ABC3 Coalition & IEC

GOALS	ACTION STEPS
GOAL #1: Use data & stories to illustrate the need for action	• Gather health stories from people with IDD • Find production partners to create video profiles of people with IDD • Collect published data on IDD • Build a culture change campaign toolkit to give clinicians positive exposure to people with IDD • Partner with 3 other sectors on culture change campaigns • Educate lawmakers on the need for culture change and training
GOAL #2: Advocate for educational associations and professional societies to include IDD in curricula and continuing medical education (CME)	• Identify and gather leaders in educational associations and professional societies to ask what they need to reach our goal • Create learning objectives and curriculum content for these sectors • Develop clinical case scenarios from the perspective of people with IDD • Collect and build interactive and virtual training modules • Make a training package with step-by-step map for using curricula, videos, case scenarios, engaging people with IDD, and an audit tool to help practices assess their readiness for serving people with IDD • Partner people with IDD and sector leaders to design and run "train the trainer" programs
GOAL #3: Advocate for inclusion of IDD content in licensure, initial certification, recertification and accreditation.	• Identify high-priority accrediting bodies to engage • Ask accrediting bodies what they need to reach our goal • Help accrediting bodies identify people with IDD and clinical experts as partners in designing IDD components

Professional Societies

The Professional Societies sector graphic below (also found in Appendix H: Professional Societies) summarizes the goals and action steps for professional societies, who are best positioned to influence clinicians in practice at scale.

GOALS	ACTION STEPS
GOAL #1: Change clinical culture to see people with IDD as individuals rather than a medical diagnosis	• Partner with ABC3 to map IDD competencies for societies and specialty boards • Partner with ABC3 to run culture change campaigns • Leverage ABC3's culture change campaign toolkit • Pass society resolutions on the importance of inclusion for people with IDD and of clinical training in IDD • Promote ABC3 audit tools among members • Promote use of ABC3 training package • Develop more learning material for sub-specialties
GOAL #2: Create quality measures specific to IDD care	• Partner with ABC3 to develop quality measures that align with the IIDDEAL Health Outcomes Framework • Get IDD quality measures endorsed by Medicare & Medicaid • Promote use of quality measures with clinical practices, insurers, and government
GOAL #3: Incentivize continuing clinical education (CCE) for IDD learning	• Partner with ABC3 to create IDD-related CCE • Offer free CCE credit for clinicians to attend IDD-related sessions at society conferences • Map consensus IDD competencies with educational associations for CCE test items to be used as a focus for learners and educators • Promote IDD continuing education opportunities
GOAL #4: Promote clinical environments that are supportive for people with IDD	• Promote The Joint Commission's requirements for clinical practice sites to be IDD-friendly • Create checklist for clinical practices to build IDD friendly environments • Educate clinicians on ADA compliance • Educate clinicians on legal risk for mistreatment of people with IDD

Educational Associations

The Educational Associations sector graphic below (also found in Appendix I: Educational Associations) summarizes the goals and action steps for educational associations, who are best positioned to influence clinicians in training across medical specialties and physician types.

GOALS	ACTION STEPS
GOAL #1: Sponsor or support culture change campaigns	• Partner with ABC3 and people with IDD on culture change campaigns • Involve leaders from clinical schools and graduate training programs in campaigns
GOAL #2: Support curricular development of clinical skills for supporting patients of diverse cultural backgrounds in graduate and prelicensure programs	• Partner with ABC3 to develop curriculum standards • Reach agreement on knowledge and defined outcomes for skill competencies in team-based care • Promote integration of IDD material into existing courses to train the trainers and train the learners • Encourage the use of ABC3 training package among association members to train the trainers and train the learners • Track use of training package and collect feedback • Expand competencies to standardized and real patients • Utilize education networks for trainers and collaborate with existing IDD educators • Host symposium of key education leaders and community members to share lessons learned
GOAL #3: Include IDD content in training programs for trainers & learners	• Use ABC3 training packet • Include people with IDD in training to share lived experiences • Target primary care before expanding to other specialties • Engage accrediting bodies to align on IDD learning priorities and skills-based competencies for clinicians in training in medicine, nursing, and physician assistants • Include IDD items in recommended and/or required curricula

Regulatory Bodies for Clinicians

The Regulary and Accrediting Bodies sector graphics (also found in Appendix J: Accrediting Bodies) summarizes the goals and action steps for regulatory and accrediting bodies. Some bodies focus on accrediting individual clinicians through specialty boards and licensing agencies. Other bodies focus on accrediting healthcare facilities.

GOALS	ACTION STEPS
GOAL #1: **Require IDD learning through licensing renewals**	• Set minimum level of IDD-related continuing clinical education (CCE) for renewal • Encourage the creation of more IDD content in CCE
GOAL #2: **Require IDD learning through board (re)certification**	• Partner with ABC3 to map how IDD competencies can be used in certification exams and requirements • Reach agreement among accreditors of graduate training programs for EACH profession on core set of skills-based competencies • Use training package developed by ABC3

Accrediting Bodies for Healthcare Facilities

GOALS	ACTION STEPS
GOAL #1: Sponsor culture change campaigns among facility leaders	• Partner with ABC3 and people with IDD on culture change campaign
GOAL #2: Incorporate IDD-related tools and processes into requirements for facility accreditation	• Partner with people with IDD and ABC3 to identify what facilities should be prepared to do to support people with IDD • Build off existing tools to certify facilities as IDD-inclusive • Include IDD-supportive elements in requirements for healthcare facilities

Next Steps: Seeking Support

The ABC3 Coalition is committed to moving forward with efficient and bold action guided by the Roadmap. We have already begun to identify potential funders and partners to engage on early projects.

We also invite additional individual experts and self-advocates and influential disability and healthcare organizations to join the coalition and share their support of the Roadmap, understanding that doing so entails making a commitment to act.

People with IDD deserve safe, inclusive, and equitable healthcare and other support from their clinical partners, so they can have the best possible health to live life to the fullest.

Clinicians deserve access to the training, resources, and supports they need to best partner with people with disabilities in reaching their desired outcomes.

We hope you will join us in this movement. Fill out this short survey to indicate your support of the Roadmap.

Stay up to date on our progress by visiting the ABC3 page or the Roadmap page.

Appendix

Appendix A: Action to Build Clinical Culture & Confidence (ABC3) Charter

OUR MISSION AND WHO WE ARE

ABC3 is an action collaborative to ensure the preparation and motivation of, and resources available to clinicians across the U.S. to serve people with intellectual and developmental disabilities (IDD).

WHAT WE DO

ABC3 designs and implements campaigns, programs, and the development of materials or other resources that have the potential to drive culture change and relevant knowledge and skills at scale among clinicians. ABC3 also promotes policies with potential for similar impact.

HOW WE WORK TO MAXIMIZE IMPACT

ABC3 works within a collective impact framework. We share a common agenda, approach to measuring progress, and supportive resources through Institute for Exceptional Care. Through co-creating a Strategic Plan, we develop a common understanding of the problem, create a shared vision for change, and identify priority goals. We seek always to leverage the unique talents, resources, and influence of individual members. We rely on consistent, open communication and a strong foundation of trust to learn from one another and create greater openness to change. We assume good intent while validating experiences of harm as an impact.

MEMBERSHIP GUIDELINES

EDI Statement: We strive for an inclusive membership within bounds, in terms of size, of what IEC has the capacity to support administratively, and to ensure a cohesive and collaborative culture. We aim for diversity among members in terms of race/ethnicity, gender, geographic location, healthcare discipline. Among members who are self-advocates and/or family or other care partners, we also aim for diversity of underlying IDD conditions.

INDIVIDUAL CONTRIBUTORS

Roles for individual experts (including researchers), self-advocates, or other stakeholders, while not currently available, are anticipated as ABC3 matures.

MEMBER ORGANIZATIONS OF ACTION COLLABORATIVE (NON-STEERING)

New members are identified annually and invited to join the ABC3 based on alignment with priorities in the Strategic Plan. ABC3 revisits memberships on a regular (annual) basis as its work evolves to ensure inclusion of partners critical for achieving short- and long-term goals. Membership is evergreen unless the member wishes to withdraw, or the Steering Group determines that a member organization no longer has a good fit with respect to achieving ABC3's goals. Member organizations commit to advocating for ABC3's goals and promoting its initiatives through their own organizations and channels.

Stay up to date on our progress by visiting the ABC3 page or contact IEC at info@ie-care.org.

STEERING GROUP

The Steering Group is responsible for developing and refining the Charter and Strategic Plan, setting membership priorities and advising IEC on business decisions. Steering Group members are also expected to be advocates for ABC3's goals within their own organizations, and to help promote ABC3 initiatives through channels where they have influence. The Steering Group consists of 12-20 member organizations serving for terms of 2-3 years on a staggered schedule, with a Chairperson who serves for the length of their organization's usual membership term.

DECISION-MAKING

A two-thirds majority vote of the Steering Group is required for a motion to carry; however, ABC3 strives to achieve consensus among Steering Group members on strategic and policy decisions.

POSITION STATEMENTS

ABC3 makes judicious decisions in developing position statements and in endorsing the positions of others, limiting its position statement activities to instances where they will materially advance its strategic goals. When ABC3 develops position statements, member organizations have the opportunity to review and comment and to endorse or decline to endorse the statement and/or be listed as a co-signatory.

FUNDING

ABC3 is a voluntary affiliation of its member organizations that operates under the umbrella of IEC, who serves as the accountable entity for initiatives and operations with financial support. The IEC President is solely authorized to accept funds, donations, or in-kind services on behalf of the ABC3. At present, membership organizations are not expected to make financial contributions to the ABC3; however, all members are expected to contribute to and disseminate materials related to ABC3's campaigns and programs.

BRANDING AND AUTHORITY

ABC3's logo does not include elements of the logos of its member organizations and any similarities are purely coincidental. The design of ABC3 letterhead or similar materials for the collaborative's operations does not incorporate the names or logos of the members, steering committee, or chairperson. Neither ABC3-branded business cards nor email addresses are provided to members of the ABC3.

Letters on behalf of the ABC3 may be signed by the Steering Group Chairperson. Grant proposals or instruments that encumber the IEC financially or with the performance of deliverables may only be signed by the IEC Chief Executive Officer.
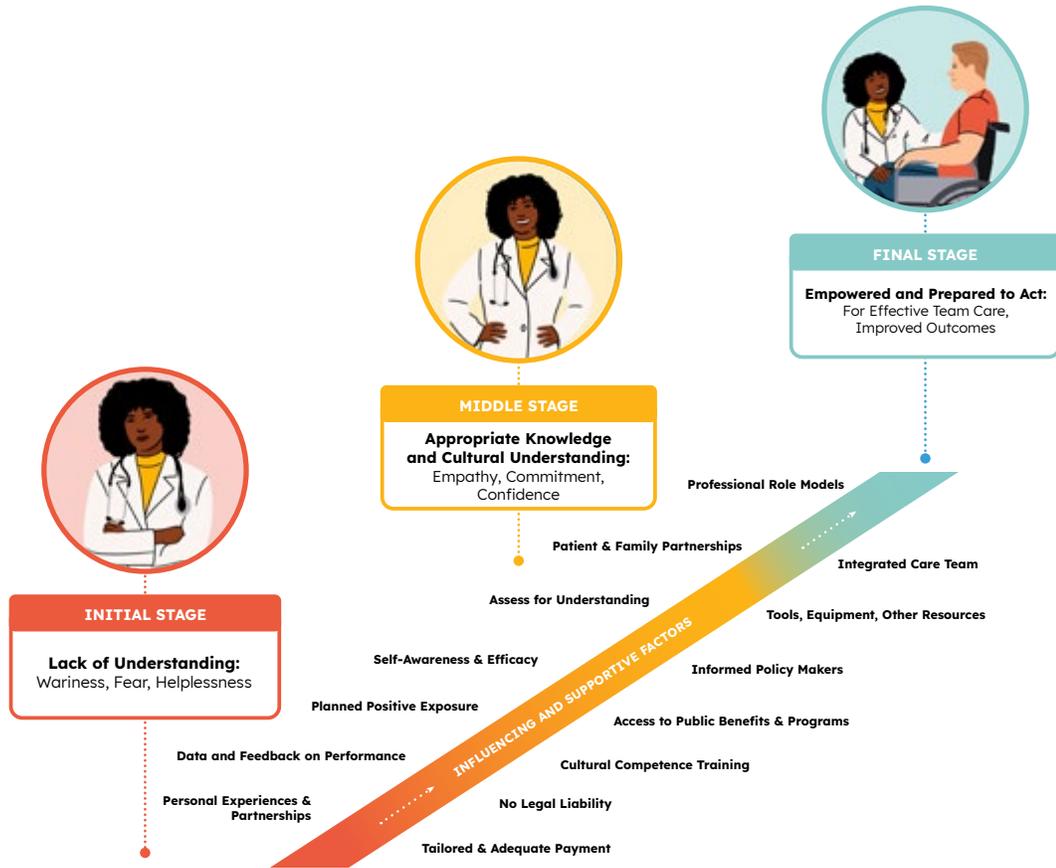
- Accreditation Council on Continuing Medical Education
- Accreditation Council on Graduate Medical Education
- American Academy of Developmental Medicine and Dentistry
- American Association on Intellectual and Developmental Disabilities
- American Academy of Pediatrics
- American Academy of Physician Associates
- American Association of Medical Colleges

- Association of American Medical Colleges
- American College of Physicians
- American Dental Education Association
- Autistic Doctors International
- The Center for Dignity in Healthcare for People with Disabilities
- Developmental Disabilities Nurses Association
- ECHO Autism Communities
- Institute for Exceptional Care
- IntellectAbility
- Nisonger Center
- Special Olympics International

STEERING GROUP MEMBERS

- Kara Ayers
- Kayte Barton
- Kathy Brown
- Meelin Dian Chin Kit-Wells
- Craig Escude
- Dena Gassner
- Bernadette Grosjean
- Gul Gulsun
- Susan Havercamp
- Susan Hingle

- Eric Holmboe
- Lisa Howley
- Graham McMahon
- Margaret Nygren
- Kitty O'Hare
- Hoangmai Pham
- Kristin Sohl
- BJ Stasio
- Anne Williams

Appendix B: ABC3 Clinician Journey

FINAL STAGE

Empowered and Prepared to Act:
For Effective Team Care,
Improved Outcomes

MIDDLE STAGE

**Appropriate Knowledge
and Cultural Understanding:**
Empathy, Commitment,
Confidence

INITIAL STAGE

Lack of Understanding:
Wariness, Fear, Helplessness

INFLUENCING AND SUPPORTIVE FACTORS

Professional Role Models

Patient & Family Partnerships

Assess for Understanding

Integrated Care Team

Tools, Equipment, Other Resources

Self-Awareness & Efficacy

Informed Policy Makers

Planned Positive Exposure

Access to Public Benefits & Programs

Data and Feedback on Performance

Cultural Competence Training

No Legal Liability

Personal Experiences &
Partnerships

Tailored & Adequate Payment

KEY: Influencing and Supportive Factors

INITIAL STAGE

- **Personal Experiences & Partnerships:**
  Family or friends with IDD, school or volunteer experiences with IDD
- **Data and Feedback on Performance:**
  Quality reports from your organization, insurers, or regulatory bodies with respect to care for patients with IDD
- **Planned Positive Exposure:**
  Positive exposure to people with IDD - first as people with full and complex lives
- **Self-Awareness & Efficacy:**
  Ability to reflect and recognize how actions, thoughts, and emotions impact ability to perform effectively
- **Professional Standards & Requirements:**
  Knowledge to provide care to patients with IDD from the educational opportunities and clinical training available through curriculum, licensure, and residency training
- **Tailored & Adequate Payment:**
  Incentivizing the engagement and frequency of serving patients with IDD by lengthening appointment times and offering appropriate payment
- **No Legal Liability:**
  Avoiding medical malpractice for special patient populations
- **Cultural Competence Training:**
  General training to improve skills for treating patients from culturally, linguistically, and socio-economically diverse backgrounds
- **Access to Public Benefits & Programs:**
  National and state-level benefits that patients with IDD qualify for, and access to other programs available under the Medicaid umbrella
- **Informed Policy Makers:**
  Legislators and politicians who are informed on disparities in healthcare for people with IDD and can influence policies to support their needs

MIDDLE STAGE

- **Assess for Understanding:**
  Talking points for clinicians to check for patients' understanding of the meaning of diagnoses, procedures, medical terms, etc; comfort with explaining medical terms in plain language
- **Patient & Family Partnerships:**
  Developing relationships with patients with IDD and their families to support health and decision-making
- **Professional Role Models:**
  Healthcare thought leaders, healthcare data or articles, professional associations, someone you work with and respect
- **Tools, Equipment, Other Resources:**
  Access to, and availability of, equipment, translators, adapted exam tables, transportation services, home and community-based services, and IDD clinical experts for referrals and consultations
- **Integrated Care Team:**
  Interprofessional care team (nurses, social workers, physicians, home and community-based services, etc) that supports the needs of patients with IDD

Appendix C: Clinicians with DD Focus Group Protocol

INTRODUCTION AND WARM-UP: (15 MINUTES)

- Thanks for joining us, especially at the end of a long workday. We're so appreciative of your willingness to share your unique perspectives as clinicians who also have the lived experience of having a developmental disability (DD). We're interested in learning about the exposure you had to patients with I/DD during undergraduate clinical education, post-graduate training, and now as a professional. And to understand what you think are the most effective ways to ensure that all clinicians are adequately prepared and committed to serving people with I/DD.
- As a reminder, ABC3 is a collaborative…
- We're going to go around the zoom room to introduce ourselves, please share your name, current position(s), and specialty. We'll cover the details of your training in our discussion.

QUESTIONS: (30 MINUTES)

To begin, we'd like to ask about your training.

1. Throughout your clinical training, what coursework or experiences, if any, helped you to gain either exposure to or knowledge in providing clinical support to patients with I/DD?
Prompts:
   a. [If yes], was it specific to caring for people with I/DD?
      i. Did your desire come first, or did the opportunity to take a course present itself, that is, was it deliberate or opportunistic?
   b. [If they have past exposure] Has your interest focused on a particular aspect of people with I/DD (i.e., health disparities, living with I/DD, genetics, and I/DD)?

2. Along your journey to becoming a clinician, do you feel you have had enough guidance on how to serve people with I/DD successfully?
   a. [If they mentioned they have taken prior coursework] Have you had access to any formal training (e.g., coursework or mentorship opportunities) that was tailored to caring for people with I/DD?
   b. [If formal training] Can you tell us more about the specific courses you took and some of the strengths, weaknesses, and gaps within your coursework?
   c. What types of supports or resources, if any, do you wish you had better access to?

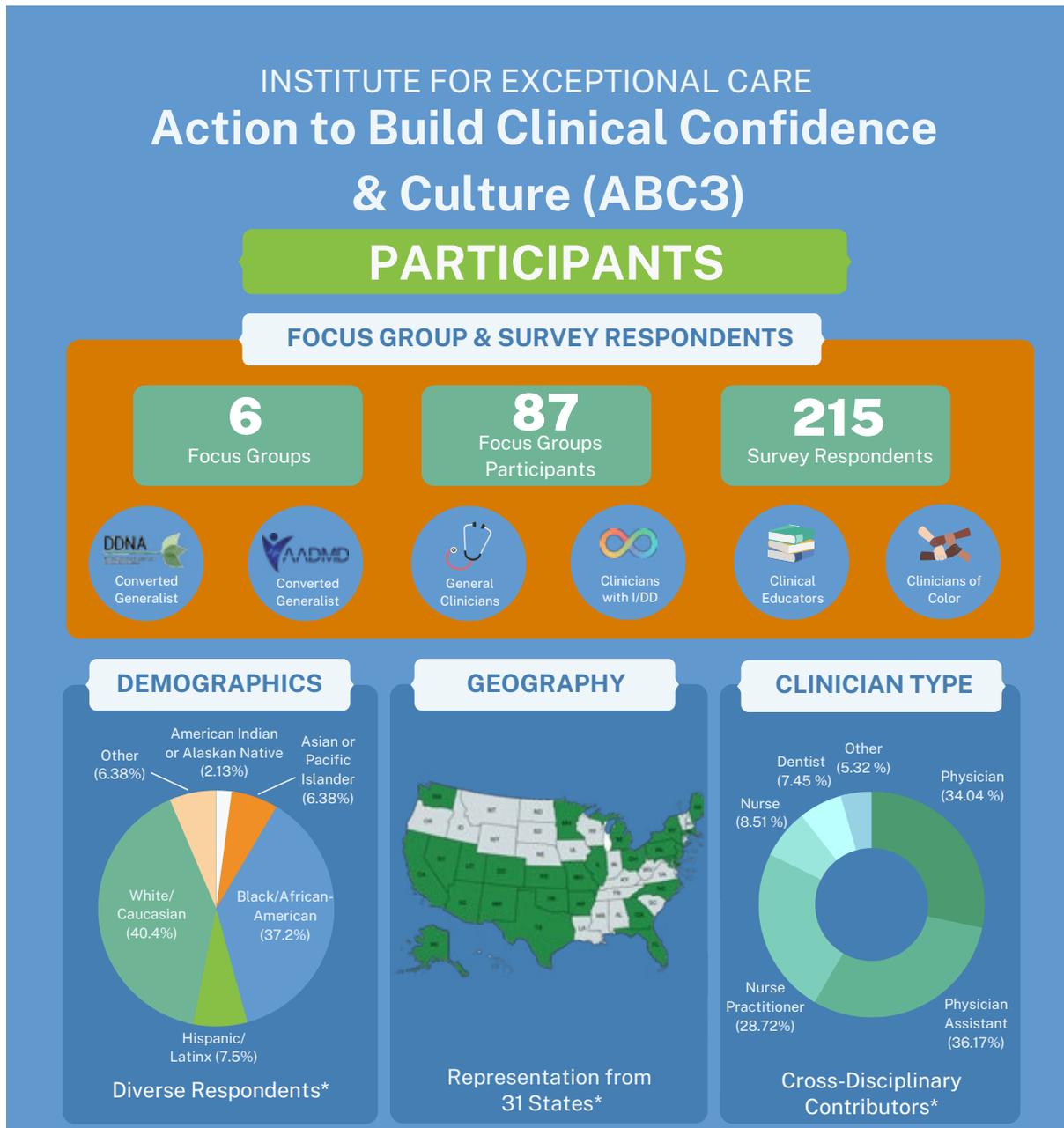Now, let's talk a little about your role as a clinician with DD.

3. How, if at all, did your personal lived experience as an individual with DD influence you to become a clinician?

4. In your opinion, what if any particular challenges are there that patients with I/DD face in accessing and receiving appropriate treatment?

5. What if any preconceptions among clinicians and other health personnel that you have encountered regarding serving people with I/DD?
   a. Do you have any suggestions on how these preconceptions could be addressed?

6. As a clinician with DD, what if any additional benefit do you think your patients get from your clinical support due to shared lived experiences?

7. What if any barriers have you faced in serving people with I/DD?
   a. Do you have any suggestions on how these barriers could be addressed?

8. In your opinion, what would be the most successful format to teach clinicians about people with I/DD (i.e., required course, elective, workshop, webinar, conferences, general media)?
   1. How available were courses or other clinical opportunities regarding caring for people with I/DD to you?
      1. [If yes] Can you walk me through what that opportunity looked like?
      2. [If no] Why do you think that is?

9. What kinds of organizations (e.g., licensing bodies, professional societies, accreditation bodies, etc.) or influencers (e.g., your attendings, professors, hospital leaders, celebrities, people with IDD and their families, professors, hospital leaders, etc.) do you believe would most effectively influence clinicians in training and/or practice to seek more preparation in serving people with I/DD?

10. Now we'd like to show you the journey map we've developed to identify opportunities to influence clinicians' commitment and preparedness to serve people with IDD.
    1. One of the group leaders quickly walks through the fishbone pause to let the group read on-screen (should send via email ahead of time as well).
    2. How, if at all, would you edit, click down or re-arrange this depiction? What specific drivers do you think are particularly important to prioritize?

11. Do you have any suggestions for roles that clinicians with DD in particular can play in advancing understanding of and clinical competency in caring for people with I/DD?

CLOSING: (10 MINUTES)
Thank you for your invaluable help today. We would like to continue to tap your experience as we finalize this framework and then move into action. This might include a second group to comment on our action plan, providing comments on curricula for pilots, or providing your advice on other initiatives. There is much good work being done, so we're always looking to connect with fellow travelers. As we come to an end, I'd like to go around the room for final comments and suggestions.

Appendix D: ABC3 Participants

INSTITUTE FOR EXCEPTIONAL CARE

Action to Build Clinical Confidence & Culture (ABC3)

PARTICIPANTS

FOCUS GROUP & SURVEY RESPONDENTS

6
Focus Groups

87
Focus Groups Participants

215
Survey Respondents

DDNA — Converted Generalist

AADMD — Converted Generalist

General Clinicians

Clinicians with I/DD

Clinical Educators

Clinicians of Color

DEMOGRAPHICS

Other (6.38%)
American Indian or Alaskan Native (2.13%)
Asian or Pacific Islander (6.38%)
White/Caucasian (40.4%)
Black/African-American (37.2%)
Hispanic/Latinx (7.5%)

Diverse Respondents*

GEOGRAPHY

Representation from 31 States*

CLINICIAN TYPE

Dentist (7.45 %)
Other (5.32 %)
Nurse (8.51 %)
Physician (34.04 %)
Nurse Practitioner (28.72%)
Physician Assistant (36.17%)

Cross-Disciplinary Contributors*

Note: This appendix uses old branding for IEC that was relevant for the Roadmap's initial creation. This graphic will be updated in April 2024.

FINDINGS

MOTIVATING FACTORS

Top motivators in achieving confidence and competence in serving people with I/DD.**

Clinicians in Training

Broader cultural norms and signals
Examples: Movies, social media, celebrities, or political leaders

Diversity, Equity, and Inclusion (DEI)
Example: Desire to be inclusive of the IDD population

Clinicians in Practice

Self-assessments and feedback on performance
Example: Quality reports with respect to care of patients with IDD

Access to supports and tools
Examples: remote monitoring equipment, adapted exam tables

INFLUENCERS

Influencers clinicians identified would be most effective in driving clinicians to train or seek more preparation in serving people with I/DD.**

IEC ABC3 Collaborative → Educational Associations *(e.g., clinical schools & AAMC)* → Accrediting Bodies *(e.g., NCQA & The Joint Commission)* → Licensing Bodies *(e.g., State Board of Nursing & Medicine)* → Professional Societies *(e.g., DDNA & AADMD)*

FACILITATORS

> The one thing that I wish is that everyone had exposure. They are people just like you, maybe [they] have some different needs, but that exposure was what definitely led to my revelation.
> - Converted Generalist

Additional Training

Understanding Patient's Health Needs

Exposure to People with I/DD

Workplace Support

Shared Characteristics

BARRIERS

Lack of Awareness & Training

Lack of Communication Structures

Accessing & Receiving Appropriate Care

Medical System Structure

Resistance to Change

Lack of Workplace Support

> Our healthcare systems are not set up, how we train.. 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, the space, or the expectation of being able to see volume.
> – Clinician of Color

institute for **exceptional** care

Note: The ABC3 Project Team facilitated focus groups in-person and via Zoom and denoted responses from participants with *. The ABC3 Project Team disseminated surveys using online survey tool, SurveyMonkey, and denoted respondents with **.

Appendix E: Thematic Anyalsis of ABC3 Focus Groups and Surveys

Recruitment efforts for focus group participants were ongoing until February 2023. Tailored invitation letters and flyers were created for each focus group to aid in recruitment of eligible participants. The project team disseminated recruitment materials with IEC partners, ABC3 Steering Group members, internal contacts, and over 100 organizations ranging from professional societies to local disability organizations. Interested individuals received a prompt to complete a pre-survey about their scope of practice, credentials, and demographic information, see Appendix D: ABC3 Participants infographic. Next, screened registrants received condensed protocol questions, as listed in Table 1. Discussion guides were tailored to the specific types of clinicians in each focus group.

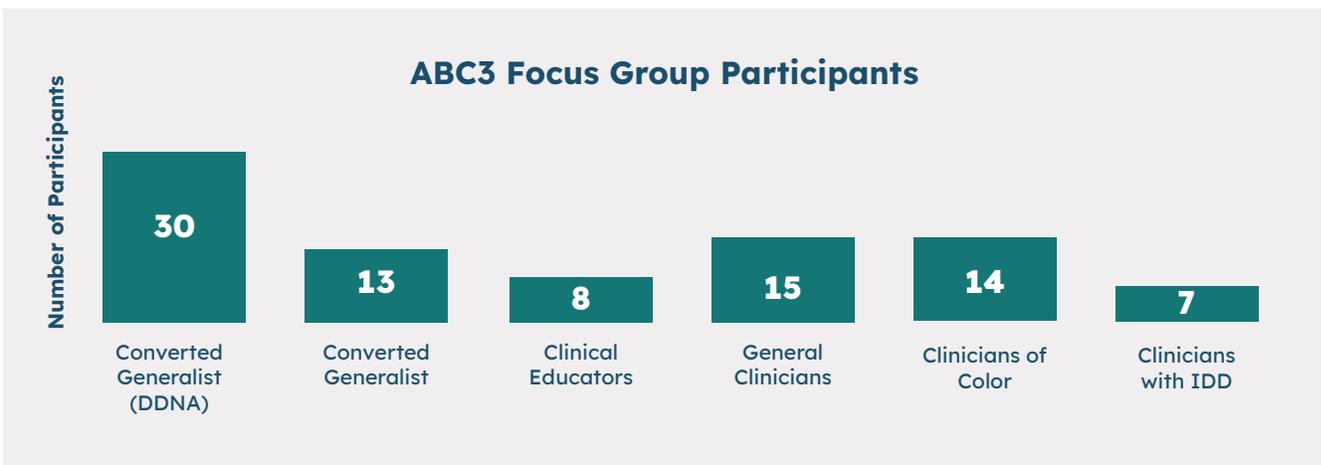| TOPIC	QUESTION (CONDENSED)
Exposure to People with IDD	1. What has been your exposure to people with intellectual and/or developmental disabilities (IDD)? For instance, were you exposed to IDD during: • pre-licensure coursework? • in past or current clinical practice? • a personal connection with an individual with IDD? 2. Was your exposure to IDD deliberate or opportunistic? • Did others influence you? • Did your understanding or attitudes towards IDD change as you gained exposure? • Has your past exposure focused on a particular aspect of people with IDD?
Exposure to Training	3. Do you feel you had enough guidance to learn how to serve people with IDD successfully? • Have you had access to formal training to care for people with IDD? • What are some courses you took? • What types of support or resources do you wish you had better access to?
Barriers	4. What have been barriers to improving your confidence regarding serving people with IDD? • Do you feel these barriers are unique to you or common among clinicians? • Do you have suggestions for mediating barriers?
Facilitators	5. In your opinion, what would be the most successful format to teach clinicians about people with IDD?
Influencers	6. What kinds of organizations or influencers do you believe would be most effective in driving clinicians in training and/or practice to seek more preparation in serving people with IDD?
Clinician Journey graphic (Appendix B: Journey Graphic)	7. We will show you the ABC3 Clinician Journey graphic developed to identify opportunities to influence clinicians' commitment and preparedness to serve people with IDD. What stands out as important to prioritize and/or what edits would you make?

After completing the focus group, participants received an electronic post-survey listing various factors that may serve as intrinsic or extrinsic motivators in helping clinicians in practice and training to achieve confidence and competence in serving people with IDD. The top-ranked motivating factors and influencers can be seen in Appendix D: ABC3 Participants infographic. A summary of pre- and post-survey respondents is shown in Table 2; some registrants completed the pre-survey but did not attend the focus group. The project team received a total of 215 pre-surveys and 73 post-surveys.

TABLE 2 SURVEY RESPONDENTS

RACE/ETHNICITY	PRE-SURVEY	POST-SURVEY
Converted Generalist (DDNA)	N= 79	N= 30
Converted Generalist (AADMD)	N= 37	N= 13
Clinical Educators	N= 5	N= 8
General Clinicians, Clinicians of Color, &	N= 94	N= 22
Total	N= 215	N= 73

Focus groups targeted four types of clinicians: (1) Converted generalists, who are clinicians that received no IDD exposure during formal clinical training but became committed and confident in welcoming and serving patients with IDD; (2) Clinicians of color, who were diverse in race/ethnicity and gender; (3) Clinicians with DD had a range of DD types, from cerebral palsy to autism; and (4) Generalists who are clinicians who do not yet feel skilled or confident in providing care to people with IDD, but are aware of at least some patients with IDD in their practice. Converted generalists focus groups convened at the annual meetings of the Developmental Disabilities Nurses Association (DDNA) and American Academy of Developmental Medicine & Dentistry (AADMD). Other focus groups took place virtually over Zoom where meetings could be recorded for later analysis. Individual interviews were offered to several clinical education leaders to accommodate their schedules. The number of participants within all focus groups is shown in Figure 1, amounting to 87 unique respondents.

FIGURE 1: FOCUS GROUP PARTICIPANTS

ABC3 Focus Group Participants

	Number of Participants
Converted Generalist (DDNA)	30
Converted Generalist	13
Clinical Educators	8
General Clinicians	15
Clinicians of Color	14
Clinicians with IDD	7

The transcription service otter.ai was used to capture all comments, supplemented by team notes. Transcripts were reviewed and coded. Given the different types of clinicians across focus groups, codebooks were tailored for clinician type and then merged into a master codebook with overarching themes. Themes were itemized using a framework matrix to organize coded data (Gale et al., 2013) and using the memoing approach (Birks et al., 2008).

Key Themes

I. EXPOSURE TO INDIVIDUALS WITH IDD

Across the six focus groups, most general clinicians, clinicians of color, and clinicians with IDD mentioned that their first exposure to people with IDD was through clinical experience. For instance, practicing clinicians mentioned providing care to patients with IDD, through their experiences in neurosurgery, with patients with neurological-related developmental disabilities or other traumas, radiology, specifically patients with traumatic brain injuries or those with cerebral palsy, and through past work within a rehabilitation center or through the K-12 public school system. Many clinicians also spoke candidly about the uncertainty they felt in providing care to people with IDD due to their lack of training. Some clinicians gained exposure to this population through clinical rotations, particularly psychiatric and pediatric rotations. A clinician with IDD described their limited exposure:

> **"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." - Clinician with IDD**

In contrast, the vast majority of converted generalists were first exposed to IDD through an affected family member, commonly a child or a sibling, a friend, or someone close to them with another disability. Many described how these personal connections to people with IDD motivated their journey to becoming a clinician and, ultimately, seeking additional training opportunities to serve people with IDD.

Converted generalists also spoke of other personal experiences that gave them foundational experiences and knowledge about people with IDD, such as through work with a faith-based organization, a legal requirement (e.g., a class action lawsuit against the state or to abide by state requirements), and volunteering opportunities during their youth. One clinician spoke of her innate desire to support this population since her youth.

> **"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 actually 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." – Converted Generalist**

When prompted to describe the cultural preparedness of clinicians in training and practice, clinical educators expected that clinicians with personal connections to individuals with IDD would likely bring those experiences to their clinical practice. Conversely, clinicians with on-the-job training, depending on the populations they typically serve, over time, would become more confident if they saw a meaningful number of patients with IDD regularly and become "trained on the job."

II. TRAINING EXPOSURE

We asked participants about their past training experience, including through pre-licensure coursework (e.g., medical school, nursing school, dental school), clinical rotations, or residency. Practicing clinicians reported frequently treating patients with IDD with minimal to no training. Most clinicians received no training during pre-licensure coursework. Clinical educators believe that most clinicians had little to no training or had only general knowledge about treating patients with IDD; educators assumed they were not adequately prepared. Clinical educators further described how some clinicians might not even be aware when interacting with peers who have IDD. Clinicians who reported getting on-the-job training experiences typically got them through a psychiatry or pediatrics rotation.

> **"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. " – General Clinicians**

A few current medical students and recent graduates spoke about recently revamped curricula at their schools, which purposefully included disability content. Students and clinicians noted that their updated curricula were in response to requests from students to ensure they gained exposure to diverse patient stories and standardized patients, particularly for populations with special healthcare needs, such as the geriatric population. Some institutions also made deliberate changes in coursework to address diversity, equity, and inclusion.

> **"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." – Clinician with IDD**

Due to lack of training and exposure to patients with IDD, converted generalists and clinicians with IDD sought additional training opportunities. Clinicians with IDD spoke about applying to fellowship opportunities, to seek supplemental training from institutions with a dedicated curriculum, such as the University of Michigan's MDisability program (2023). Converted generalists at the AADMD conference also used continuing education opportunities, took non-required coursework, and aligned available research or clinical projects to improve their knowledge and skills. Among converted generalists, nurses in particular discussed being motivated to seek additional training after witnessing other clinicians poorly treating patients with IDD.

Despite lack of formal recognition for a developmental nursing specialty, converted generalist nurses decided to focus their practice on developmental disabilities, which led them to find community in DDNA. One additional burden of developing new knowledge was that other clinicians then expected developmental disabilities nurses to "know everything" about caring for people with IDD.

III. INFLUENCERS

When asked about the organizations or individuals that would best influence them to seek more preparation in serving people with IDD, clinicians most often cited educational associations, accrediting bodies, professional societies, and licensing bodies. Other notable influencers included advocates and peer practitioners who served as role models.

EDUCATIONAL ASSOCIATIONS

Educational associations are organizations that develop and recommend the content and topics healthcare professionals learn during their training. For instance, the Association of American Medical Colleges recommends the topics and competencies for medical students to master. Focus group participants described optimal scenarios of educational associations first promoting that clinical schools and training programs embed IDD content in learning curricula. The next step proposed by focus group informants was for licensing bodies, such as the National Medical Board of Examiners, taking action to include IDD-related questions in accreditation examinations, such as the Step 1 or 2 USMLE (United States Medical Licensing Examinations). Clinicians noted that such a process would ensure teaching staff prioritized these topics to prepare students for assessments and motivate students to learn.

The Facilitators section below describes additional suggestions for educational associations to address IDD learning.

ACCREDITING BODIES

Accrediting Bodies are private entities that set quality standards, evaluate, and accredit clinical training programs, continuing clinical education programs, healthcare facilities, such as hospitals, or other healthcare entities, like insurance plans. Examples of accreditors include the Accreditation Council for Graduate Medical Education, Accreditation Council for Continuing Medical Education, The Joint Commission, and the National Committee for Quality Assurance. Clinicians of color identified accrediting bodies as notable influencer organizations, due to their ability to provide incentives to clinical training programs for addressing IDD-related competencies. National accrediting bodies can also ensure uniform standards across various states.

> **"Through the accrediting bodies because that will give you the reciprocity so that every time you go to a different state, you do not have to either redo or it is slightly different requirements or anything like that." – Clinicians of Color**

Clinicians across multiple focus groups recommended for other disability organizations, beyond IEC, to partner with professional societies and leverage their national platforms to spread awareness. One clinician suggested offering a conference solely focused on disability topics with educational sessions related to clinical scenarios and case-based learning that can be applied to various medical specialties. Many other clinicians suggested that professional societies integrate disability sessions into broader conferences.

> **"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." – Clinician with IDD**

Clinical educators encouraged the creation of IDD interest groups within professional societies, to allow clinicians interested in improving care for this population to network with peers and share best practices.

IEC ABC3 COALITION: SOCIAL MEDIA

Focus group participants also advised IEC and the ABC3 Coalition to engage social media influencers and platforms that engage clinical audiences in an effort to advocate for additional training in caring for people with IDD. Specific suggestions included creating engaging and comedic videos to spread awareness. General clinicians specifically noted that many professional societies use Audio Digest, which offers audio CME opportunities and has a deeply engaged interdisciplinary clinical audience across multiple specialties. Other platforms mentioned included LinkedIn and Doximity, a networking service for medical professionals (Doximity, 2023)

> **"Go with more of a social media type of thing. We do a lot of marketing with LinkedIn. Doximity is another one that you know. If there are articles and I have a few minutes, I am scrolling through those. That is a good way to impact clinicians." – General Clinicians**

Clinical educators discussed challenges in changing public discourse and noted that major culture change sometimes only occurs after horror stories in public media, such as a death due to a medical error. Given that there have been many instances of people with IDD experiencing bad health outcomes due to failures in the system, they encouraged engagement of celebrities with large audiences to leverage those incidents as wake-up calls among clinicians and the general public.

IEC ABC3 COALITION

Advocates at the Legislative Level & Peer Clinicians to increase awareness and participation from other organizations, clinicians encouraged the ABC3 coalition to engage the [Centers for Medicare & Medicaid Services](#) (CMS). CMS wields tremendous influence through connections with over 60 million beneficiaries, payment policies, and regulatory powers. If CMS makes IDD a priority, clinical organizations will respond.

> **"There needs to be advocacy at the legislative level that coordination of care is really important. If you want clinicians to turn into it, the work has to be valued for the time that gets put in." – General Clinicians**

Clinicians with IDD noted that the number of clinicians and patients with disabilities has increased exponentially, and their intersectional perspectives would be beneficial in guiding future work of ABC3. Additionally, one clinician described how clinicians with IDD might serve as role models and influence their peers.

> **"People who genuinely care and who are gentle, who will watch them in their setting and see how they do what they do. It takes time. You have to listen. You have to make people with IDD feel comfortable enough to let their guard down so that they will essentially become effective patients. And, you know, that is something that probably is hard to learn unless you have a good role model for it." – Clinician with IDD**

IV. FACILITATORS

Clinicians identified several supports and resources to facilitate clinical confidence and culture. The most prominent themes were related to exposure to people with IDD and additional training opportunities. Other motivators include a greater understanding of the health needs of people with IDD and a supportive workplace that promotes policies and opportunities for improving clinical skills. Clinicians of color and clinicians with IDD noted that shared identities and lived experiences with vulnerable patient populations often helped their patients establish deeper trust and achieve improved outcomes.

ADDITIONAL EXPOSURE TO PEOPLE WITH IDD

Nearly all clinician types felt that additional exposure to people with IDD in medical and non-medical settings would improve clinical confidence. Participants discussed the importance of providing forums to seek input on clinical care design from self-advocates and caregivers, such as by establishing patient and caregiver panels or increasing planned face-to-face interactions with people with IDD and their support persons. Clinicians also recommended creating IDD-specific clinical rounds with individuals with IDD as simulated patients and exposing pre-licensure students to patients with IDD in a group home setting to learn aspects of their daily lives and community resources for families.

Other ideas for offering IDD exposure included pre-clinical coursework, partnerships with clinicians with IDD, including disability within DEI initiatives, and implementing mandatory CME for all clinician types.

> **"The one thing that I wish is that everyone had exposure. Because I feel like if you have exposure, and that is why I think so many people who knew somebody who was part of a family- it was not scary, it was not anything abnormal. You realize these are people just like you, maybe [they] have some different needs, but that exposure was what definitely led to my revelation."**
> **– Converted Generalist**

ADDITIONAL TRAINING OPPORTUNITIES

Clinicians shared the importance of behavior management and communication training for clinicians and direct support staff, as well as gaining exposure to people with IDD before medical students enter clinical training. Clinicians with IDD identified ECHO Autism, a peer-to-peer learning community where clinicians participate in case-based learning, and similar learning networks as an exemplary format for clinicians to gain more experience working with patients with IDD.

For pre-licensure coursework, some clinicians recommended stand-alone IDD courses, but others noted the challenge of adding to the already dense and time-restricted curriculum requirements, suggesting the implementation of elective coursework instead. However, participants were cautious in the scaled impact of utilizing elective coursework, as clinicians who are already interested in serving the IDD population would be most likely to self-select such course opportunities. General clinicians noted that regardless of whether courses are required or elective, they should be interdisciplinary. Converted generalists advocated for the inclusion of health equity and the impact of the social determinants of health on the IDD population in coursework. Multiple focus groups recommended creating a short clinical rotation for disability care and creating an IDD-specific rotation. One general clinician noted the importance of collaborating with other clinicians treating patients with IDD and provided examples of topics that should be covered in training.

> **"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 - psychologists, psychiatrists, social workers, special education teachers, all of us to communicate effectively with all populations. And the inclusion of successful outcome stories in the curriculum."– General Clinician**

UNDERSTANDING PATIENT'S HEALTH NEEDS

Clinicians across focus groups shared their desires for increased access to information for understanding the needs of patients with IDD. They would like to identify user-friendly resources that explain the prevalence of IDD, as well as the need and value in seeking additional training. Participants added that new approaches to care are most frequently welcomed, particularly if such strategies would help clinicians efficiently get through their workday. For instance, clinicians shared recommendations for a needs assessment of practices, a gap analysis of what is missing in the field, creating user-friendly technical assistance tools, and data on how to improve outcomes.

Converted generalists also discussed the need for clinicians to learn about IDD etiquette, including skills such as speaking directly to the patient, listening to the individual needs of the patient, implementing shared and/or supported decision-making, and recognizing behaviors as a form of communication. A common desire among clinicians was more training and guidance on communication strategies to improve the healthcare experience of their patients, such as plain language technical assistance tools. One general clinician asked for a primary care checklist to review symptoms and milestones for various IDD types. Supplemental to this, clinicians spoke of the positive impact of a knowledgeable support person that regularly monitored the health of the individual with IDD seeking care.

WORKPLACE SUPPORT

Converted generalists were asked during focus groups on their perceptions of feeling supported in their workplace to achieve clinical competency and to identify facilitating factors. One developmental disabilities nurse described a boss that "listens, advocates, elevates and respects all nurses," while other nurses identified superiors that support additional training. Other participants discussed the importance of having access to a mentor to serve as a role model – clinicians that treated all patients with "respect and dignity" and made the extra effort to ensure individuals with IDD felt supported in their life goals.

SHARED CHARACTERISTICS OR LIVED EXPERIENCES

Clinicians of color and clinicians with IDD referenced the sense of responsibility they felt to be attuned to marginalized patients, given their dual identities. They discussed the importance of representation among their clinical peers and the benefits of having shared lived experiences with their patients, which gave them greater empathy and motivation for improving care.

> **"And the only reason why I knew what to do is because of my own experience. And that is part of why I was sent into 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." – Clinician with IDD**

A common theme among both of these groups was empathy and shared cultural competency. For many clinicians, fluency in a non-English language proved instrumental in bonding with patients who are not native English speakers, allowing the clinicians to explain treatment plans in the patient's preferred language and serve as an advocate for cultural accommodations. Clinicians of color shared how patients of color typically connected with them faster and often led to better adherence to care recommendations.

> **"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 be 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." – Clinician of Color**

Conversely, clinicians of color and those with IDD also spoke about the discrimination they face. Some clinicians with IDD initially kept their IDD hidden from peers and teachers to avoid biased treatment in their training programs, as one clinician termed it, "being weeded out." They recalled microaggressions from other physicians due to their disability, implying that they lacked the ability to be good clinicians; additional professional barriers were shared by clinicians with intersectional characteristics, such as being Black/Brown or queer.

> **"[Referencing a surgical rotation] I have had residents tell me, you cannot stand up. Why are you a doctor? You cannot do rounds. Go back downstairs and sit down." - Clinician with IDD**

V. BARRIERS

Among the most common barriers to clinical confidence and culture that clinicians cited was the lack of available resources for people with IDD to access and receive appropriate care. Moreover, some clinicians alluded to the potential logical basis for this because of the current medical system structure, resistance to changing clinical culture, and lack of workplace support.

LACK OF AWARENESS & TRAINING

Participants uniformly agreed that many clinicians lack the proper training and exposure to effectively treat and communicate with patients with IDD. They believe that unless clinicians have personal connection with an individual with IDD, they are unlikely to know how to communicate with people with IDD appropriately. A clinician of color pointed out how everyone with IDD is unique.

> **"The most challenging to me appears to be that each individual experience with IDD is different; it depends on what condition they have. So even if you have been exposed to Down Syndrome during your medical education, it does not mean you will effectively treat someone with like Williams Syndrome or something so, and it is not feasible to actually have exposure to have like universal exposure to everything."**
> **– Clinician of Color**

Clinicians of color also identified lack of training as a barrier in the ability to assess whether patients required further treatment for their specific IDD diagnosis. And general clinicians admitted to feeling discomfort, uncertainty, and lack clinical confidence when treating patients with disabilities.

> **"And just having the confidence that I do not know how you get this, but I feel like sometimes there is a barrier in in some, I do not know what I do not know. And I think sometimes you have to spend time really asking them a sensitive way about, you know, because best practices are probably going to be very different depending on the disability." – General Clinician**

General clinicians also found it difficult to gauge what success should look like for patients with a particular type of IDD; they were not aware of data on which interventions have shown impact or metrics that allow them to track health benefits for patients with IDD.

LACK OF COMMUNICATION STRUCTURES

Focus group participants acknowledged communication barriers in providing adequate care to people with IDD. Such barriers included lack of training in communication strategies, particularly for understanding behaviors, such as among non-speaking IDD patients. Clinicians found communication even more challenging when patients with IDD arrive without a well-informed support person. For instance, when individuals with IDD do not have a legal guardian or family member to serve as a caregiver, that creates additional barriers to the patient getting assistance with taking medication appropriately or adhering to other treatment recommendations.

> **"The challenge we face is communication, you have someone who comes in with a problem, and most times, they are not actually able to express what the problem is and or what you could actually appreciate. At that point, it is visual, you know, your patient visually, might not be able to get there, the details, the clinical details from them, you have a patient struggling, you have a patient staring at you, and you do not even know what to do. And basically, you rely on information that caregivers and parents actually give, which might actually differ from what the person is facing, you know, you have a problem."– Clinician of Color**

However, a clinician of color discussed some of the issues with relying too much on caregivers or family members.

> **"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." - Clinician of Color**

Many focus group participants also experience frustration in trying to collaborate with other clinicians involved with a patient's treatment plan. One clinician described their dissatisfaction with the current communication structures among clinicians.

> **"I cannot get in contact with her PCP, the group home is not helping her be compliant with her medication, it has been difficult to provide her with the care she needs because there is not enough professional communication and collaboration."– Clinician with DD**

ACCESSING AND RECEIVING APPROPRIATE TREATMENT

Focus group participants have witnessed patients with IDD have trouble accessing quality care and receiving appropriate treatment. They cited barriers such as lack of access to reliable transportation, knowledgeable healthcare providers, and telemedicine. Participants further felt that individuals with intersecting characteristics experienced even more barriers and inappropriate treatment. A general clinician declared that people with IDD are an underserved population that is equally deserving of the "same high quality of care as any other patient."

> **"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."**
> **– Clinician of Color**

Other clinicians felt access barriers are driven by low payment rates, especially in Medicare and Medicaid. Converted generalists also believed access was limited in part because many clinicians view their patients merely as a diagnosis instead of as an individual.

> "For clinicians to know and understand a person's overall life and to have the bent to really understand what is happening in that person's life, what their critical life domains are, and what is really important to them is a little bit of a paradigm shift for patients or for clinicians who see their people their patients as patients versus seeing their patients as partners in the care that people are making choices about." – Converted Generalist

HEALTHCARE SYSTEM CHALLENGES

Clinical educators noted that multiple competing priorities meant clinicians currently lack sufficient exposure to IDD in formal educational programs and must rely on post-graduate experiences and training to expand their knowledge and skills. They believe that without a personal connection, clinicians might lack motivation to make meaningful efforts to provide quality care to patients with IDD and may instead try to avoid this patient population. Furthermore, all focus group participants cited a lack of time, in or out of training, to become competent in aspects of caring for every population, particularly special needs groups.

> "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. And it is very frustrating that there are no requirements that these appointment times need to be longer and that you just have no say as, as a clinician." – General Clinician

> "Our healthcare systems are not set up, how we train, how we train everyone in the hospital to manage ID and DD 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, whether it is the space, whether it is the expectation of being able to see volume." – Clinician of Color

In addition, clinicians found the number of medical records that a single patient might have to be overwhelming, and they would prefer a condensed version to track their patient's health needs. Clinicians also discussed the countless clinical touch points a patient may have, yet appropriate communication accommodations are not widely available. These combined barriers lead to endless "systemic dead ends."

RESISTANCE TO CHANGING CLINICAL CULTURE

Clinicians acknowledged the need to shift healthcare culture from the medical model to the social model of disability, but also noted that some clinicians lack the motivation to seek additional training to improve the treatment of this population. Participants felt this could be due to outdated assumptions about the IDD population being small, attitudes about it being "unsavory to work with the population", and false assumptions about their ability to create effective clinical relationships with people with IDD.

LACK OF WORKPLACE SUPPORT

Many converted generalists lacked supportive policies and resources in their workplace, including underfunding and superiors with biased mindsets. Clinicians with IDD commonly found misconceptions among colleagues, such as the belief that individuals with autism cannot feel empathy, that disabilities should be fixed, and that patients with IDD cannot adhere to treatment plans.

> **"Part of the coursework that we received is just like the medicalization of disability, and how all disability is just looked at as something that it is a problem that needs to be fixed. And I definitely think even I had that sort of notion coming in with someone who has been around disabled people and is disabled themselves. I still had those preconceived notions. And it was like a revelation when I was like, Oh, wait, not all disability. All disability and an illness are two separate things. And sometimes, there is overlap, but it is not always the case. I still think that disability is seen as a barrier to overcome in medicine; it is something that we need to heal." – Clinician with DD**

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Appendix F: ABC3 Sector Overview

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

Appendix G: ABC3 Coalition and IEC

GOALS	ACTION STEPS
GOAL #1: Use data & stories to illustrate the need for action	• Gather health stories from people with IDD • Find production partners to create video profiles of people with IDD • Collect published data on IDD • Build a culture change campaign toolkit to give clinicians positive exposure to people with IDD • Partner with 3 other sectors on culture change campaigns • Educate lawmakers on the need for culture change and training
GOAL #2: Advocate for educational associations and professional societies to include IDD in curricula and continuing medical education (CME)	• Identify and gather leaders in educational associations and professional societies to ask what they need to reach our goal • Create learning objectives and curriculum content for these sectors • Develop clinical case scenarios from the perspective of people with IDD • Collect and build interactive and virtual training modules • Make a training package with step-by-step map for using curricula, videos, case scenarios, engaging people with IDD, and an audit tool to help practices assess their readiness for serving people with IDD • Partner people with IDD and sector leaders to design and run "train the trainer" programs
GOAL #3: Advocate for inclusion of IDD content in licensure, initial certification, recertification and accreditation.	• Identify high-priority accrediting bodies to engage • Ask accrediting bodies what they need to reach our goal • Help accrediting bodies identify people with IDD and clinical experts as partners in designing IDD components

Appendix H: ABC3 Professional Societies

GOALS	ACTION STEPS
GOAL #1: Change clinical culture to see people with IDD as individuals rather than a medical diagnosis	• Partner with ABC3 to map IDD competencies for societies and specialty boards • Partner with ABC3 to run culture change campaigns • Leverage ABC3's culture change campaign toolkit • Pass society resolutions on the importance of inclusion for people with IDD and of clinical training in IDD • Promote ABC3 audit tools among members • Promote use of ABC3 training package • Develop more learning material for sub-specialties
GOAL #2: Create quality measures specific to IDD care	• Partner with ABC3 to develop quality measures that align with the IIDDEAL Health Outcomes Framework • Get IDD quality measures endorsed by Medicare & Medicaid • Promote use of quality measures with clinical practices, insurers, and government
GOAL #3: Incentivize continuing clinical education (CCE) for IDD learning	• Partner with ABC3 to create IDD-related CCE • Offer free CCE credit for clinicians to attend IDD-related sessions at society conferences • Map consensus IDD competencies with educational associations for CCE test items to be used as a focus for learners and educators • Promote IDD continuing education opportunities
GOAL #4: Promote clinical environments that are supportive for people with IDD	• Promote The Joint Commission's requirements for clinical practice sites to be IDD-friendly • Create checklist for clinical practices to build IDD friendly environments • Educate clinicians on ADA compliance • Educate clinicians on legal risk for mistreatment of people with IDD

Appendix I: ABC3 Educational Associations

GOALS	ACTION STEPS
GOAL #1: Sponsor or support culture change campaigns	• Partner with ABC3 and people with IDD on culture change campaigns • Involve leaders from clinical schools and graduate training programs in campaigns
GOAL #2: Support curricular development of clinical skills for supporting patients of diverse cultural backgrounds in graduate and prelicensure programs	• Partner with ABC3 to develop curriculum standards • Reach agreement on knowledge and defined outcomes for skill competencies in team-based care • Promote integration of IDD material into existing courses to train the trainers and train the learners • Encourage the use of ABC3 training package among association members to train the trainers and train the learners • Track use of training package and collect feedback • Expand competencies to standardized and real patients • Utilize education networks for trainers and collaborate with existing IDD educators • Host symposium of key education leaders and community members to share lessons learned
GOAL #3: Include IDD content in training programs for trainers & learners	• Use ABC3 training packet • Include people with IDD in training to share lived experiences • Target primary care before expanding to other specialties • Engage accrediting bodies to align on IDD learning priorities and skills-based competencies for clinicians in training in medicine, nursing, and physician assistants • Include IDD items in recommended and/or required curricula

Appendix J: ABC3 Regulatory and Accrediting Bodies

GOALS	ACTION STEPS
GOAL #1: Require IDD learning through licensing renewals	• Set minimum level of IDD-related continuing clinical education (CCE) for renewal • Encourage the creation of more IDD content in CCE
GOAL #2: Require IDD learning through board (re)certification	• Partner with ABC3 to map how IDD competencies can be used in certification exams and requirements • Reach agreement among accreditors of graduate training programs for EACH profession on core set of skills-based competencies • Use training package developed by ABC3

GOALS	ACTION STEPS
GOAL #1: Sponsor culture change campaigns among facility leaders	• Partner with ABC3 and people with IDD on culture change campaign
GOAL #2: Incorporate IDD-related tools and processes into requirements for facility accreditation	• Partner with people with IDD and ABC3 to identify what facilities should be prepared to do to support people with IDD • Build off existing tools to certify facilities as IDD-inclusive • Include IDD-supportive elements in requirements for healthcare facilities

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