Challenges and Opportunities: Lessons Learned from ADA Coordinators Working within Diverse Healthcare Organizations

DISABILITY EQUITY COLLABORATIVE

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Acknowledgement

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Agenda

- ADA Coordinators and Healthcare Organizations
- Position Titles, Departments, and Structure
- Roles, Responsibilities, and Initiatives
- Collaboration Within and Outside of the Organization
- Budget Constraints and Supports
- Barriers and Facilitators
- Leaders

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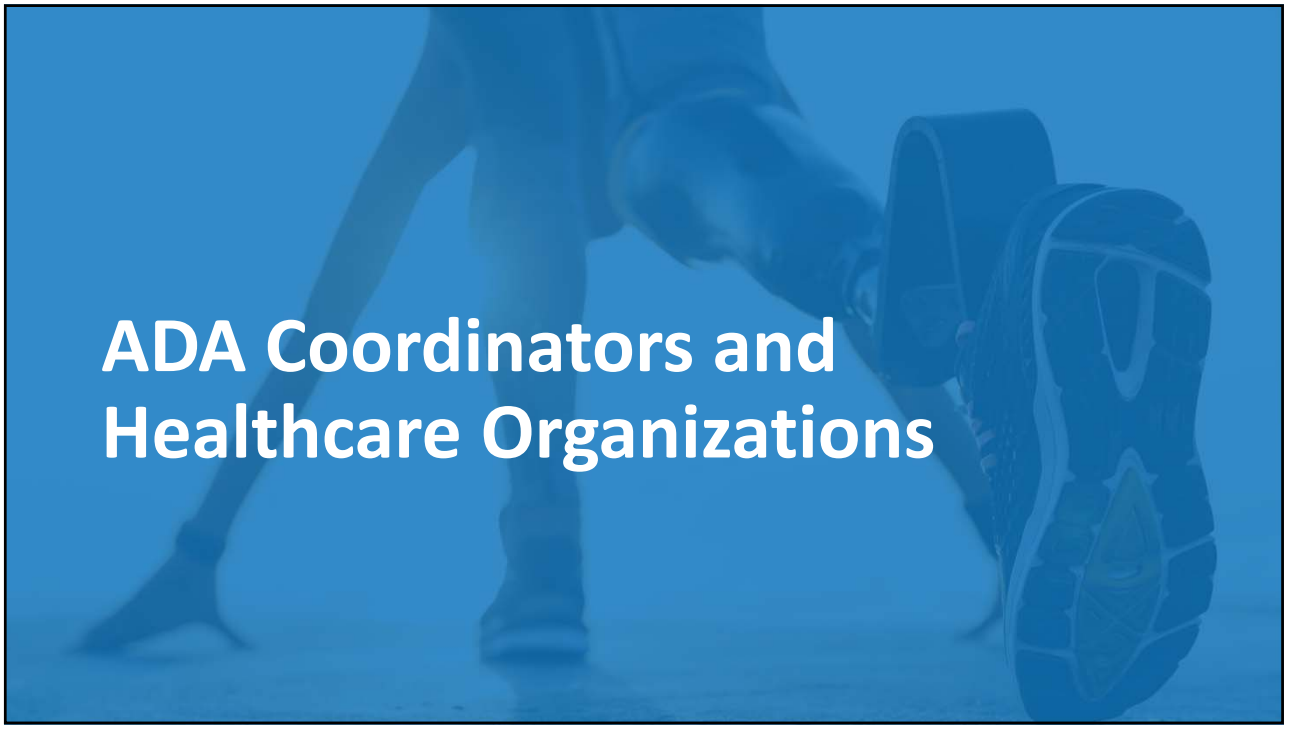

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Background

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- **Section 504 of the Rehab Act and Americans with Disabilities Act**- Requires healthcare organizations (HCOs) to provide accessible healthcare to patients with disabilities
- **Section 1557 of the Affordable Care Act** - Prohibits HCOs from discriminating against patients based on race, color, national origin, sex, age, or **disability**
  - HCOs with over 15 employees required to designate an employee to lead these efforts

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Key-Informant Interviews

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- 21 Interviews from May 2019 to January 2021
- Recruited by word of mouth
- Individuals who led disability initiatives at their healthcare organization
- Represented 18 community and academic healthcare organizations or hospitals across the United States
- Healthcare organizations varied in size and geographic location
  - Total of 200+ hospitals; ranging from 1 to 40 hospitals

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Position Titles

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504 Coordinator (2)	Program Director of Diversity and Inclusion
1557 Coordinator (3)	Inclusion Specialist
ADA Compliance Manager (2)	Medical Director of Diversity and Inclusion
Disability Access and 504 Officer	Senior Advisor for Special Projects
ADA/Accessibility Coordinator/Manager (4)	Qualities Program Manager
Disability Program Manager	Senior Manager of Patient Experience
Regional Administrator for ADA and Civil Rights	Patient Advocate
Office of Civil Rights Coordinator	Geriatric Services Director
Assistive Services Program Manager	Interpretive Services Coordinator/Manager/Director (4)
Program Manager for Facilities Compliance	Language Access Program Manager

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Departments

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Patient Care Services (2)	Ambulatory Operations
Patient Advocate	Human Resources
Quality and Safety Department (2)	Facilities Continuity
Safety Department	Call Center
Quality Management and Medical Staff Services	Strategic Planning
Disability Resource Center	Nursing Administration
Office of Health Equity and Inclusion	Compliance
Member Equity, Inclusion, and Diversity	Office of General Counsel
	Interpretive Services Department (2)

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Position History

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- Almost all were the first person in their position
- Length of time in position ranged from 6 months to 9 years
- Many of the positions began as a result of a patient lawsuit or a DOJ consent decree
- Some had position as a result of Affordable Care Act

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Position Structure and Organization

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- Varied by healthcare organization
- Many were the only position dedicated to improving disability accessibility in their organization
- Three types of models

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Position Structure: Model 1

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- One individual leading all efforts

We have a civil rights coordinator through the requirements of Section 1557, but they, again, when it comes to anything ADA or language access related, usually those individuals will come to me for guidance input and assistance in resolution. We don't have a team of ADA people.

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Position Structure: Model 2

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- Lead with team of ADA coordinators

I came in with a number of years of experience, but most of our ADA coordinators are people who have other jobs, and it's an add on.

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Position Structure: Model 3

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- Collaborative multi-discipline team
- *We have a network of ADA coordinator/managers across our system. The way that my job works, I'm the lead for my region. Then I work in a multidisciplinary fashion with facilities, safety, clinical, operations. Yeah. Everybody takes ownership and responsibility for equal access…I'm like the quarterback*

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Goal of the Position

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- To meet the requirements/remain in compliance with laws and regulations

I would say the organization views it as a position to fulfill legal requirements 'cause legally, we're required to have a coordinator for non-discrimination purposes. If there wasn't a law, I don't think there would be anybody doing anything about this at this hospital.

- To create a culture focused on equal access to healthcare for PWD

I think it's really to ensure that everybody gets the care that's commensurate with every other patient in the hospital, just to level the playing field, if you will, but every time, for everyone.

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Goal of Position

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I think the purpose of my job here is to make sure that we are as compliant with the rules and regulations as possible, but also that we're doing the right thing for our patients so that we can impact some of those other areas. It's not just legal obligations, but it's promoting exceptional patient outcomes, trying to reduce our readmission rate, making sure that our patients understand the discharge recommendations that we give them, making sure that our providers are able to communicate with people in a way that they understand.

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Responsibilities beyond Disability Role

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- Some positions were broad and focused on all disparities/populations

Grow awareness around health disparities, to create processes and systems to address those disparities, and to make sure [Hospital] is an inclusive provider and meeting the needs of all patients we serve.

- Some were focused on specific initiatives like interpretive services

I am here to provide interpreter services. I have to manage my in- house interpreters who are all Spanish speakers. I have to find contract interpreters if there are languages other than—it's very language-based, and in that I have ASL needs.

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Activities within Position

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- Develop and implement policies and procedures
- Respond to patient requests and complaints
- Assess facilities
- Purchase and/or provide accommodations
- Conduct trainings
- Provide resources and advice to staff and providers
- Ensuring organization is compliant with legal requirements

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Initiatives: Documentation of Disability

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- Ask every patient if they have a disability and need accommodations
- Proactively providing needed accommodations
- Who is impacted and how to improve care

…the feedback that we've received is that the patients are very happy that they're actually asking them what their disability is at the time of registration and that this is something that's unique to them. They actually expect, then, for us to be much more involved in their care.

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Initiatives: Training/Education

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- Often component of larger system-wide annual employee training
- How to communicate, support, identify and provide needed resources for PWD
- Some partner with community organizations and persons with disabilities

…it's not just now on disability sensitivity. It's really trying to engage the organization in thinking about implicit bias training, cultural competency training, but not making it transactional; really making it intentional.

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Initiatives: Facilities and Physical Access

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- Ensuring the new and current physical space meets ADA requirements
- Parking lots, entrances, doors, heights of tables, signage, etc.

…I personally go in and look at things from the aspect of a surveyor and just trying to make sure that we have things in place. If we don't, I document those things. I bring those—send them up the chain to see what kind of changes that we can make.

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Initiatives: Service Animals

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- Creating/updating policies specific to service animals
- Training staff on policies

Normally, we don't allow animals in our building, but of course, we want to accommodate people who use service animals, so it's important that my staff know the questions that they can ask and our responsibilities and obligations to accommodate someone who uses a service animal and to do so in a very polite and respectable way.

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Initiatives

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- **Accessible Medical Equipment**
  - Height adjustable examination tables
- **Effective Communication**
  - Effective communication toolkits or sensory toolkits
  - Large print or braille materials
  - Nurse call buttons
- **Electronic Materials**
  - Website
  - Patient portal

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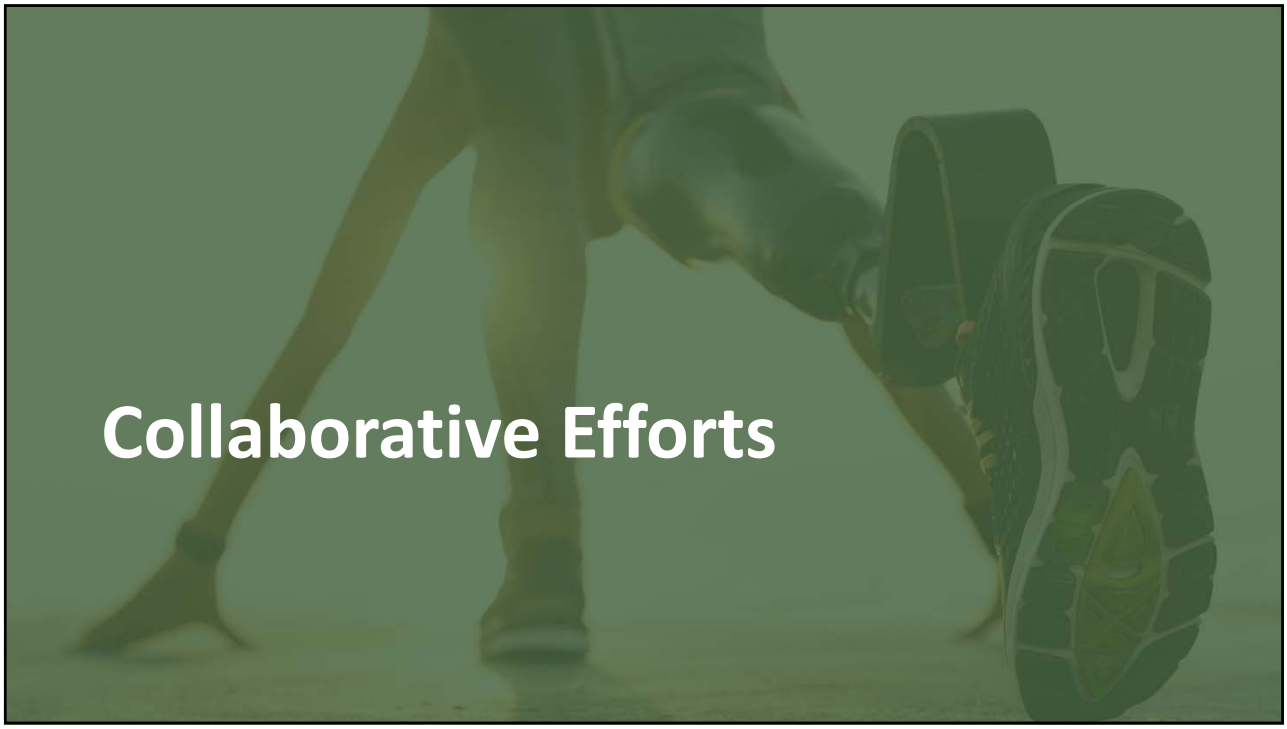

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Collaboration within Organization

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- Frequent collaboration with other departments
  - Compliance and legal
  - Patient experience
  - Facilities
  - Diversity and Inclusion
  - Environmental Health and Safety

  We implemented a system effective communication policy last year. That was the result of about almost a year's effort, really working on a policy collaboratively that would make sense and be meaningful and be applicable throughout the state.

- Buy-in from other departments "key" to success of initiatives

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Collaboration with Groups Outside of the Organization

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- Community Advocacy Organizations
- Local Centers for Independent Living
- ADA Regional Centers
- DEC: Leaders

- Collaboration in the form of grants, guidance on compliance and initiatives, resources, and lessons learned/best practices

- Involving PWD in trainings, advisory committees, developing initiatives/programs

The staff not only hears about what types of things they should do, but to hear about a patient's experience is most valuable.

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Budget Models

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- Almost all:
  - Did not have their own budget
  - Were not the final decision maker for budget requests
- Model types (these are not independent of each other)
  - Annual budget
  - Request funding for an item at a time
  - Rely on grants to support initiatives
- Confusion and variability on whose responsibility it was to fund position and initiatives
  - This goes back to the diversity of locations of the position
  - This can differ by type of accommodation

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Budget Constraints

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- One of the largest barriers/challenges
- Require money for:
  - Position
  - Equipment and renovations
  - Personnel time (e.g., attending trainings, asking disability questions)
  - Other: braille format for common forms, interpreters

That's really it [money as the most needed resource]. I think it would help if this type of position actually had its own budget, and the budget was well-enough funded that we actually had the funding that we need so that we can provide what we should be providing. We just don't have that. Every time something is needed, I'm literally going to other people and begging to spend their money. It would be fantastic if our organization actually recognized.

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Budget Constraints

DISABILITY EQUITY COLLABORATIVE

- Constantly "justifying" spending due to lack of understanding/support from leadership for funding initiatives
- Competing priorities

With my previous VP, everything was tied to money, and I had to give reports and white papers on why I had to provide a deaf interpreter.

Accessibility is expensive.

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Budget Supports

- Leadership buy-in

We earmark money at the upper—I'd say, the CEO and the board of directors for our health system, they allocate funds in the budget every year for our ADA programs.

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Budget Supports

- Pressure from leadership/organization for departments to include/approve budget requests related to disability initiatives

All of our outpatient physician groups—so all of our outpatient physician offices have purchased an effective communication kit. Their leadership basically told each site manager, "This is what we recommend. This is what you need. You need to purchase it," and they did.

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Budget Supports

- Dedicated funds in main/capital budget

…for the physical access and equipment, we have a disability funds budget or what we call ADA budget, which is a pool of money that is funded through the hospital. It's a capital budget that stays within the planning office. They actually oversee it, but I make all the recommendations for what we need.

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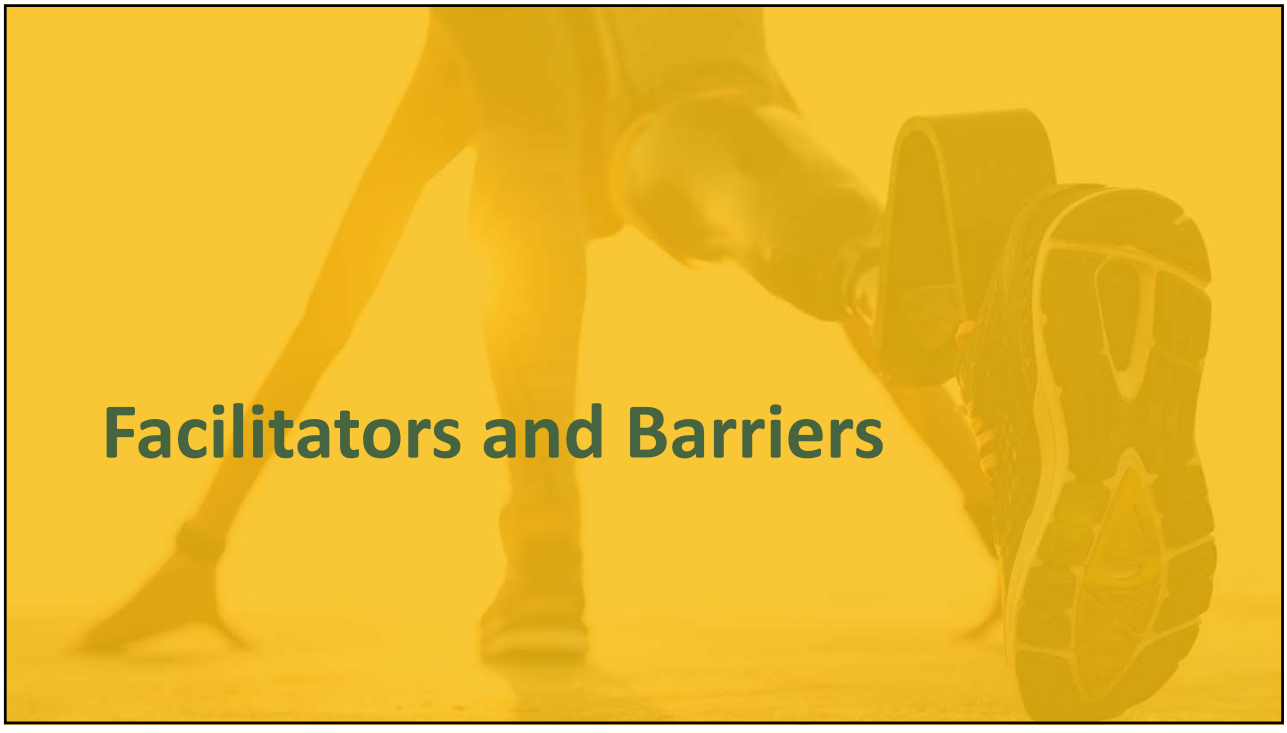

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Leadership Support

- Participants who are doing well in position report feeling as though they are viewed as experts in their organizations and have the "ear of leadership team"
- Need leadership support across different departments and domains since accessibility initiatives cross cut the organization

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DISABILITY EQUITY COLLABORATIVE

Leadership Support (cont.)

- Leadership support facilitates long term maintenance of initiatives

Leadership buy-in is huge, and I would say this is probably going to be one of the most common barriers for anyone trying to push the needle when it comes to advancing disability competent care practices. Not only having that leadership buy-in, but you need their support, and you need them to be a champion. You also need, of course, their money.

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DISABILITY EQUITY COLLABORATIVE

Leadership Support (cont.)

- Conversely, those who are continually advocating and fighting for recognition, support, and budget report frustrations
  - Leadership might not be aware of or understand why the ADA is important
- Having legal team backing up participants when they get pushback from staff and providers can be key

Leadership has to decide that this is important. If you have to have a culture, you know, you have to have a leader who's saying, "This is important. We need to be doing this," and then they have to put the resources to it to actually make it happen, and then demand accountability. It can't be the flavor of the week. This is a long-term, ongoing, just thing we do. It's not even a thing we do. It has to be who we are.

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Time, Resources, Money

- Many reported feeling overwhelmed in their position due to the wide variety of and large number of responsibilities

Lack of time, [laughter] 'cause you really do have to prioritize certain things and build on them. Some of the things that I would love to see us do—because I have to spend time bringing other people up to speed. One of the challenges is that we've had a lot of turnover.

- Many had other roles – one participant reported that she only has 1 day per week to work on disability initiatives

I feel like I wear so many hats that, sometimes, that does get put at the bottom of my to-do list. I wish I could be more available for people. The clinics don't always have the time either.

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Time, Resources, Money (cont.)

DISABILITY EQUITY COLLABORATIVE

- Many were the only person in their role, which was insufficient

I can only do so much as one person, so depends on others to carry out initiatives/policies/trainings (responsible for 5 hospitals). In my ideal world, I would have two or three of me.

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Time, Resources, Money (cont.)

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- When accessibility is prioritized, such as purchasing of accessible medical equipment, participants saw a positive result.

I think we've had a lot of success in the area of accessible medical equipment. We've bought so much equipment. We've trained our staff on how to use them. We're getting really good feedback.

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Time, Resources, Money (cont.)

DISABILITY EQUITY COLLABORATIVE

- They don't necessarily have control over what is purchased

We can always use more money. If I had more money, I could bring speakers in. I could do better training. It would be great to do partnerships with other health systems, that sort of thing. That's the higher aspiration, and we need money to do all of that. I will always say we need more money, more budget, more budget, more budget.

- Need systems in place

I think what I find most frustrating than, for challenging is the fact that we can't come up with a system on a system level to address these things. I don't care who addresses them. I don't care if they decide that it's really my job, but it would be a lot easier if there was a mechanism in place, so that I wasn't running around patching things

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Documenting Disability Status

DISABILITY EQUITY COLLABORATIVE

- Documenting was a foundational step in delivering accessible care
  - Identify who requires accommodations
  - Measure effects of initiatives
- Despite this, majority of sites struggled in this area due to:
  - Lack of buy in or support
  - Competing priorities
  - Recommendations and standards

I often get told, there's so many different types of disability...it's such a robust project that they're not interested in taking it on...

It should be if we can't document it, if we can't measure it, we can't improve it.

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Documenting Disability Status (cont.)

DISABILITY EQUITY COLLABORATIVE

- Some might have disability documented, but then connecting to accommodations is challenging – consequently accommodations are attempted to be provided "on the spot"

It [documentation] would make work flows easier…I think it would be more effective. How do I say it? If we don't know what patients need, then how can I help?

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Documenting Disability Status (cont.)

DISABILITY EQUITY COLLABORATIVE

- Need documentation to demonstrate the size of the population and therefore justify their position, budget needs, etc.

- Measuring the effects of initiatives will help with justifying their requests

…when I'm trying to go to the table and ask for $100,000.00 to improve communication access for people with disabilities, I need to be able to show that, okay, this is our member population.

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Staff and Clinician Knowledge

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- Staff and clinicians often are unaware of requirements and only see the burden of providing accommodations
- One participant described how her organization has over 25,000 employees and it is "challenging"
- Turnover with staff
- Training doesn't exist

I think educating and informing our staff that this is a new way of doing something, a new way of approaching an issue is probably the biggest barrier.

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Culture Shift and Behavior Change

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- When accessibility is a part of the overall mission of organization, participants saw more success in their initiatives
- The organization at all levels need to understand the need for and prioritize providing accessible care
- It can sometimes take a complaint or threat of litigation to convince organization to change

Even though we've been practicing and doing it for 20 plus years this way, now somebody's telling us we have to change… Sometimes, it's fighting a battle that I feel like I'm never gonna win, but hey, it's little victories that kind of keep me plugging along.

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DEC Leaders is a community of individuals who work in healthcare organizations and hospitals (e.g., ADA Coordinators, Section 504/1557 Coordinators) on disability accessibility initiatives.

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DEC Healthcare Leaders

DISABILITY EQUITY COLLABORATIVE

- Meetings
  - Every other Friday via Zoom
  - "Safe space" in which participants can:
    - Exchange ideas
    - Find solutions to problems they face in their organizations, and
    - Champion their successes
  - Subject matter experts are regularly invited as guest speakers.
- Online platform
  - Engage in real-time discussions about current issues they're facing at their organizations
  - Hosts a wide variety of resources shared internally among members

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Example Topics

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- Effective communication toolkits
- Documentation of disability status and accommodations in the EHR
- Assistive Technology resources for patients who are blind/low vision
- Service animal policies
- Identifying differential roles of ADA/504/1557 Coordinators
- U.S. Access Board Medical Diagnostic Equipment standards
- Covid-19 topics
  - Mask exemptions for patients with disabilities
  - Visitor policy exemptions for patients with disabilities who require caregiver assistance
  - Access to clear masks to accommodate patients who rely on lip reading

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Disability Equity Collaborative

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If you work within a healthcare setting leading disability initiatives and you are interested in participating in Leaders

OR

You are interested in engaging with other stakeholders on the topic of disability healthcare equity

Please email Megan Morris at: megan.A.morris@cuanschutz.edu

https://www.disabilityequitycollaborative.org/

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THANK YOU!

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