LEADERs Summit:
Working Together to Advance Equitable Healthcare for Persons with Disabilities

October 19th and November 9th, 2020

Organized by Megan A. Morris, PhD, MPH, CCC-SLP, Kori Eberle, Steve Lockhart, and the team at the University of Colorado Anschutz Medical Campus

Table of Contents

Schedule for November 9th

Eastern Time
12:00 – 12:15 – Introductions and overview
12:15 – 12:25 – Speaker
12:25 – 1:00 – Overview of findings from Day 1 of the Summit
1:00 – 1:10 – Break and transition to breakout groups
1:10 – 2:10 – Breakout groups
2:10 – 2:30 – Break
2:30 – 3:45 – Presentation and discussion of breakout groups
3:45 – 4:00 – Conclusion, next steps and wrap up

Central Time
11:00 – 11:15 – Introductions and overview
11:15 – 11:25 – Speaker
11:25 – 12:00 – Overview of findings from Day 1 of the Summit
12:00 – 12:10 – Break and transition to breakout groups
12:10 – 1:10 – Breakout groups
1:10 – 1:30 – Break
1:30 – 2:45 – Presentation and discussion of breakout groups
2:45 – 3:00 – Conclusion, next steps and wrap up

Mountain Time
10:00 – 10:15 – Introductions and overview
10:15 – 10:25 – Speaker
10:25 – 11:00 – Overview of findings from Day 1 of the Summit
11:00 – 11:10 – Break and transition to breakout groups
11:10 – 12:10 – Breakout groups
12:10 – 12:30 – Break
12:30 – 1:45 – Presentation and discussion of breakout groups
1:45 – 2:00 – Conclusion, next steps and wrap up

Pacific Time
9:00 – 9:15 – Introductions and overview
9:15 – 9:25 – Speaker
9:25 – 10:00 – Overview of findings from Day 1 of the Summit
10:00 – 10:10 – Break and transition to breakout groups
10:10 – 11:10 – Breakout groups
11:10 – 11:30 – Break
11:30 – 12:45 – Presentation and discussion of breakout groups
12:45 – 1:00 – Conclusion, next steps and wrap up

Topic Area #1: Disability Data Collection – Summary from Stakeholder Interviews

To advance disability equitable healthcare, systematic collection of patients' disability status needs to occur both at the healthcare system level and at the population level. This was the top research priority identified by our stakeholders and advisory committee. Across the interviewed DACs, virtually all were actively working on collection of patients' disability status at some level. In our COVID-19 focus groups, documenting disability status at both the healthcare system and the public health level continued to be a top priority.

Healthcare system
1. There are two purposes for disability data collection at the healthcare system level: 1) track quality of care delivered to PWD at the system level and 2) identify patients who require healthcare accommodations.
2. Without documenting disability status, it is unknown how many patients require accommodations and what specific accommodations they need. Healthcare systems need this information in order to make decisions regarding purchasing of equipment and investment in disability resources.
3. Challenges to systematic data collection include:
    a. Lack of standard language for documenting disability in electronic health records (EHR), which consequently makes it difficult to search for disability status within or across health systems.
    b. Disabilities can change over time.
    c. Accommodations vary within disability groups. For example, someone who affirms a hearing disability could be Deaf and require an ASL interpreter, or they could have a moderate hearing disability and benefit from a sound amplifier.
    d. Lack of standards or evidence on how to train staff to collect disability status.
    e. A disability field is often not available in the EHR. Work needs to be done to determine what specific functions (e.g., ability to track needed accommodations over time) are needed to be built into the disability field.
    f. No evidence or standards of where and how to best collect the information: patient registration, patient portals, time of check-in, etc.
    g. Once data is collected, evidence and standards are needed to inform how to use the data meaningfully.
4. It can be difficult to convince health systems to be an "early adopter" of documenting disability status as changing the EHR and clinical workflow can be onerous.
5. There are concerns with alert fatigue and that staff and providers will ignore the disability field.

Population level:
1. PWD are underrepresented in national surveys. Improved and increased systematic data collection at both the state and federal public health levels, which will provide evidence of disparities is needed.
2. There are federal mandates for collection in national surveys (e.g., Section 4302 of the ACA).
3. Need to determine ways to identify disability status in claims data.
4. Funding is needed to help incentivize healthcare systems to collect and share data with public health programs and organizations such as the CDC.
5. Alternative response modalities for surveys are needed to ensure accessibility.

Topic Area #1: Disability Data Collection – Summary from Summit Breakout Groups

1. Successes and existing initiatives
    a. Surveillance data:
        i. National Child Health Data Survey
        ii. Centers for Disease and Prevention: 9 questions (functional based not diagnostic) to include learning, mental health, and communication disabilities; collected at state level
        iii. HHS question set (self-report); although don't directly ask about disability (instead are ADL language questions)
        iv. Oregon Health Authority will prioritize this next year
    b. Health care organizations
        i. Multiple health systems actively working on implementation of documenting patients' disability status, including: Yale New Haven Health and Northwestern
    c. Evidence exists for *which* questions to ask
        i. Legal mandates exist to document disability status and accommodate PWD
        ii. New interoperability rules could drive information exchange forward

2. Challenges
    a. National data sources don't have detailed info/hasn't been collected
        i. Push for requirement to ask these questions, possibility embedded in technology/EHR
    b. Difficult to measure outcomes of initiatives without data collection
    c. Child vs. adult disability status
    d. Disclosing disability
        i. Self-report, as individuals may not identify with their disability
        ii. Concerns about patient comfort with disclosing
        iii. Stigma with use of disability language
    e. Payer/claims data
        i. Could be beneficial, although additional work needed
        ii. Currently not self-reported
    f. Need to determine how organizations, providers and staff can make the data actionable and provide accessible accommodations
    g. Asking the questions on a national level is incredibly expensive and challenging
    h. Need disability data to measure the effects of COVID-19

Topic Area #2: Transforming Healthcare Organizations and Clinics – Summary from Stakeholder Interviews

Little evidence and few standards exist to inform how to provide accessible healthcare.

1. No "gold standard" or minimum standards exist for disability accessible care
   a. Current laws and regulations can be vague and leave room for interpretation.
   b. While regulations mandating accessible care exist, there are little standards on *how* to implement accessible care.
   c. Healthcare settings are diverse. As such, recommendations are needed on how to provide accessible care in each setting.
   d. The consequence of no standards:
      i. Can encourage doing very little and to do the bare minimum.
      ii. Wide variety in what healthcare systems provide
   e. Unclear who should be developing and enforcing standards for accessible care
2. Need evidence that providing disability accommodations improves outcomes (*See Page 14)
   a. Need evidence that *not* providing accommodations leads to worse outcomes.
   b. Need better measures of accessibility
3. One way for healthcare systems to track patient-reported outcomes is through national quality measures such as the HCAHPS. Currently, there are no specific disability questions in the HCAHPS or other quality measures.
4. Resources are needed for informing *how* to implement accessible care. This includes toolkits and tangible solutions, which should be stored in a central location for these resources.
5. Paying for accessibility
   a. There is interest and need for determining the cost and cost effectiveness of accommodations.
   b. Many of the costs are not necessarily equipment, but staff and providers' time.
   c. Mixed beliefs on who should financially contribute to providing accessible care. Potential funders include: federal agencies, state agencies, healthcare systems, and insurance providers.
6. There is interest and some efforts by federal agencies and insurance provider to create directories of the accessibility features a clinic/hospital provides. Currently, this is self-report and minimal validation efforts.
7. The DAC role is ill-defined. These individuals have a wide variety of job titles, are in diverse departments within their organizations, often have additional roles, and have mixed support from their leadership. Some work alone while others have teams of DACs within their organization. Their job duties are wide reaching, and with COVID-19, the scope and amount of work increased significantly.
8. Challenges with conducting research to measure the effects of accommodations
   a. Need the infrastructure in place, namely health systems collecting and documenting disability status, to be able to carry out intervention studies.
   b. Difficult to get clinical staff to buy into interventions due to competing demands
   c. Often need to pick one population for study due to funder, (e.g., foundations for specific disabilities or condition-specific NIH institutes) which limits generalizability of findings.
   d. Health systems want to implement changes now, but research to develop evidence is lengthy and can be incremental.
   e. Some funders, including federal and foundation funders, do not consider disability a disparity population.

Topic Area #2: Transforming Healthcare Organizations and Clinics– Summary from Summit Breakout Groups

1. <u>Successes and existing initiatives</u>
   a. Accessible medical diagnostic equipment (MDE)
      i. Multiple research studies in this area
      ii. Report through the Access Board in January 2017
         1. Rule-making rescinded
         2. Some organizations have adopted standards (VA)
         3. Medicare regulations already require this/specific equipment
   b. Laws requiring accessible care are available
      i. Potential legal ramifications may help push action forward on the part of providers
      ii. Increased litigation and enforcement of standards
   c. Initiatives for providers/clinics to declare what accessible equipment and features are available
   d. Resources
      i. ADA centers across the country
      ii. Some websites have been curated about equipment
   e. Centene: provides funds to increase accessibility (e.g. Barrier Removal Fund which is a part of Provider Accessibility Initiative)
   f. Increased focus on injury prevention; incentive of avoiding employee injury

2. <u>Challenges</u>
   a. Medical equipment
      i. Gap in what's being made and what clear standards are
         1. Standards don't apply to all groups (children, extremely heavy patients)
      ii. Many health systems and clinics don't have accessible equipment
         1. Equipment often purchased based on aesthetics
      iii. Some MDE exists in HCO but lack patient-centered usability approach
   b. Health care providers expect accessibility will be too expensive; don't want to engage
      i. Lack of consensus about who should be contributing to cost
      ii. Large cost differential between 'old' and new equipment
   c. Organizations don't follow regulations/law, including CMS regulations
   d. Difficult to get people/groups to change
      i. Accessibility is a culture change; number of steps needed for change can be huge
      ii. Difficult for providers to figure out what action is needed/what they need to do (e.g., "effective communication")
         1. Unsure how to disseminate resources; verifiable information that meets accessibility standards

Topic Area #3: Healthcare Leadership, Providers and Staff: Changing the Culture of Healthcare - Summary from Stakeholder Interviews

Participants believed that a culture change in healthcare is needed to make significant changes. This often starts with changing the attitudes, knowledge, and practices of the people who work within healthcare, including leadership, providers and staff.

1. Leadership
   a. Disability is sometimes not on the radar of healthcare providers and leadership
   b. Healthcare systems often are unaware of their legal requirements and how to best provide accessible care
   c. There are many competing demands as well as limited time and resources
   d. Persons with disabilities can be considered a small but expensive population already, and so it can be difficult to convince leadership to spend more time and resources on the population.

2. Providers and staff
   a. Need to demonstrate that staff and providers have explicit and implicit biases, attitudes and assumptions about persons with disabilities, and that these biases can affect the quality of care delivered to PWD. Additionally, we need evidence-based interventions to address these biases.
   b. Need improved training on how to interact and provide patient-centered care to patients with disabilities. This includes topics such as how to effectively communicate with patients with communication disabilities to providing primary care to patients with spinal cord injuries.
   c. Providers and staff need education on what they are required to provide under the ADA.
   d. Need to increase the number of providers and staff who have disabilities.

3. Medical and Healthcare Professional Education
   a. Many participants thought we need to start early in educating healthcare providers and staff about disability.
   b. There are currently no requirements for including disability in medical education.
   c. Need to increase the number of students who have disabilities.

4. Healthcare systems and providers need encouragement to provide accessible care as currently there is little pressure on health systems to be accessible. There is little enforcement if a system or provider is not meeting requirements.
   a. Potential incentives
      i. Improved outcomes and cost effectiveness (once demonstrated)
      ii. Financial – reimbursement, tax credits, etc.
      iii. "It is the right thing to do" - this is a social justice issue
      iv. Competition: ranking or grading systems for hospitals and clinics on accessibility
      v. Awareness of how large the disability population actually is
      vi. Align accessibility with existing mission and priorities
   b. Potential disincentives
      i. Litigation, which is rare and so might not be a strong motivator
      ii. Tie accessibility to reimbursement or accreditation
      iii. Increased enforcement of federal and state regulation

Topic Area #3: Healthcare Leadership, Providers and Staff: Changing the Culture of Healthcare - Summary from Summit Breakout Groups

1. <u>Successes and existing initiatives</u>
    a. Disability competency curriculum is implemented at some institutions
    b. Recent research findings on provider attitudes and beliefs
    c. Healthcare organizations and payer organizations have disability advisory committees
        i. Example: Centene
    d. LEADERs
        i. Summit – interdisciplinary collaboration
        ii. Learning collaborative
    e. Advocacy groups have training resources
    f. Increased MDs with disabilities (#docswithdisabilities)
    g. AMA would be on board for more rigorous cultural competency in disability standards in med school curricula
    h. Standards developed for disability in healthcare education
    i. ACA requirements for:
        i. Training
        ii. ADA Coordinators

2. <u>Challenges</u>
    a. Staff/organizations have poor perception of quality of life for PWD
        i. Falsely equate health status with disability
    b. Unless provider and staff perceptions and attitudes are addressed, available accommodations won't be used
    c. Few PWD work within the healthcare setting – need to create pipeline and mentorship
    d. Culture change is required but difficult
    e. Lack of funding and resources to adequately train health care professionals
    f. AAMC has pushed back on rigorous cultural competency in disability standards in med school curricula

Topic Area #4: Patients, Family Members and Caregivers - Summary from Stakeholder Interviews

While the focus of the project was to identify ways to improve the healthcare system for persons with disabilities, there were some areas that participants reported that are specific to patients with disabilities and their caregivers.

1. Patients
   a. Patients experience or perceive societal stigma regarding living with a disability. As a result, many might be reluctant to disclose (especially those with mental health disabilities), or identify with the term "disability". This is likely true with older adults. As a result, it is difficult to identify patients who require accommodations and track the quality of care delivered to patients with disabilities.
   b. Patient might be unaware of their rights under the ADA, what accommodations are even an option, and how to request accommodations. This might be especially true for those with newly acquired disabilities.
   c. Increased research and resources are needed to determine how to effectively communicate health information to patients with disabilities, particularly those with cognitive disabilities.

2. Family members and caregivers
   a. More research and resources are need to inform how to integrate caregivers into patient-centered care. This includes training providers on how to talk with family members and how to handle situations in which the patient has a cognitive disability.
   b. Research is needed to determine whether engagement with family members improves patient care.
   c. More defined roles of caregivers and family members during appointments need to be identified and documented.
   d. Caregivers' disabilities need to be reported in the EHR.
   e. Caregivers are sometimes not allowed into clinical encounters. This has both worsened with COVID-19 due to restricted visitor policies, and improved with the HHS bulletin stating that patients with disabilities should be granted exceptions to restricted visitor policies.

3. Community members
   a. Many of the DACs reported working with their local disability community to assist in identifying ways to improve their healthcare system.

Topic Area #4: Patients, Family Members and Caregivers - Summary from Summit Breakout Groups

1. <u>Successes and existing initiatives</u>
    a. Current research on dementia care could be exchanged/collaboration with that group
    b. Very active dementia care community
    c. Caregivers know patients very well and can be an asset in clinical encounters

2. <u>Challenges</u>
    a. Differences in how individuals perceive disabilities
    b. Resources are fragmented and can be difficult to access/find/navigate
    c. Lack of awareness about what resources are available, especially if patient is new to location or system
    d. Rigid standards can be just as harmful as not having resources
    e. Transition from pediatric to adult care is more difficult for patients with disabilities
    f. Not enough NIH research applications for this type of research
    g. Caregivers
        i. Lack of resources and evidence for integrating the caregiver into the team
        ii. Provider communicating to caregiver instead of talking to the patient – not providing patient-centered care
        iii. Terminology (e.g. the term *caregiver* is inappropriate – should be talking about *care partner*)
        iv. Caregivers are expected to provide accommodations during medical appointments
        v. Caregivers need to ask questions in order to learn about resources
        vi. Visitor policies – caregivers are part of care team, not just visitors. This has an impact on how the patient is receiving care and how well patients can comply with the treatment, and also as advocate for patient to get the care they need

Topic Area #5: Intersectionality - Summary from Stakeholder Interviews

This section has the least amount of information. This gap is telling in and of itself. Participants and the advisory committee believed it is critical area in need of additional research and resources. Many highlighted the increased and unique disparities in health and healthcare outcomes of people who experience intersectionality. The role of social determinants of health and how the determinants effect the lives and health of persons with disabilities was also highlighted. As some mentioned, it is imperative when looking at improving health outcomes for people with disabilities, to understand all needs, barriers, and experiences, which may be increased if they are from an additional marginalized population.

1. Other identities to consider include but are not limited to:
   a. Race/ethnicity
   b. Rurality
   c. Gender
   d. Sexual orientation/gender identity
   e. Veteran status

2. Social determinants of health can include:
   a. Income level
   b. Educational opportunities
   c. Occupation, employment status, and workplace safety
   d. Gender inequity
   e. Racial segregation
   f. Food insecurity and inaccessibility of nutritious food choices
   g. Access to housing and utility services
   h. Early childhood experiences and development
   i. Social support and community inclusivity
   j. Crime rates and exposure to violent behavior
   k. Availability of transportation
   l. Neighborhood conditions and physical environment
   m. Access to safe drinking water, clean air, and toxin-free environments
   n. Recreational and leisure opportunities

3. Some of the DACs reported that the recent attention and focus on addressing systemic racism in the United States has had both positive and negative impacts for PWD in their organizations. Some felt it has increased awareness and incentivized organizations to act more swiftly to address accessibility. Others, specifically those who were also in charge of addressing racial discrimination in their organization, felt that it increased their workload, leaving less time to focus on disability accessibility.

4. Conducting research on intersectionality of disability and other demographic characteristics (e.g., race) can be difficult due to small sample sizes.

Topic Area #5: Intersectionality - Summary from Summit Breakout Groups

1. <u>Successes and existing initiatives</u>
    a. Intersectionality is an easy topic for people to understand even when they are not familiar with it, research needs to begin acknowledging these components

2. <u>Challenges</u>
    a. Concern that different demographics groups perceive and define disability differently
        i. Answer disability questions differently
        ii. Might be reluctant to disclose
    b. Lack of awareness of intersectionality across all groups (e.g., researchers, healthcare systems, public, policy makers, etc.
    c. Not sure who will fund this research
    d. COVID-19
        i. Lack of data from surveys and COVID-19 reporting and so cannot look at how COVID is impacting PWD of color – there is enough data to say it is impacting the black committee, needs to be more messaging around this
            1. How are we addressing this disparity?
        ii. Disproportionate disparities around the availability of care affecting support workers with disability, specifically those of color
        iii. Telehealth
            1. People with lower economic circumstances or rural communities may not have as much accessibility

Topic Area #6: COVID-19 - Summary from Stakeholder Interviews

Participants reported that COVID-19 has exacerbated disparities in care experienced by persons with disabilities. They anticipate that health and healthcare outcomes will worsen for persons with disabilities during the pandemic. Below are some of the new challenges that have arisen due to COVID-19. Despite these challenges, there are some silver linings. Disability Accessibility Coordinators (DACs) have reported that there has been increased awareness of needs of persons with disabilities by their leadership. As such, there have been more opportunities to train staff and providers and implement some accessibility initiatives, particularly communication initiatives. Additionally, the DACs report increased collaboration within their organization, including with their offices of equity and inclusion. Finally, they report that more patients seem empowered to ask for accommodations. There are questions of how to sustain these "silver linings" following the pandemic.

1. Masks
   a. Concerns regarding patients with disabilities who request exceptions to wearing a mask, and those without disabilities using this as a reason to not wear a mask.
   b. Need for clear masks for those with hearing and other communication disabilities
2. Visitor policies
   c. Most hospitals have now adapted visitor policies to accommodate PWD, but concerns still remain on how to best support patients and their caregivers.
3. Telehealth
   d. Telehealth developed rapidly overnight out of necessity. Many obstacles, such as reimbursement disappeared.
   e. Unfortunately, telehealth is often not accessible for PWD.
   f. Effective communication via telehealth was and still is challenging
   g. Concern that moving to telehealth means providers are becoming less familiar with providing hands-on care PWD
   h. Access to Patient Portals can be challenging as the programs are not always compatible with accessibility programs such as screen readers.
4. Crisis triage plans and medical rationing of COVID-19 testing, treatment and vaccines
   i. Concerns that medical rationing will occur or is currently occurring
   j. Concern that decisions are made based on the devaluing the lives of PWD
   k. Concern that teams are not equipped to identify and address implicit and explicit biases and assumptions that affect care decisions.
5. Challenge of providing accommodations with social distancing guidelines
   l. Blind/visually disabled persons are not able to touch surfaces
   m. COVID has created physical barriers between PWD and healthcare teams. For so long we have worked to increase people's comfort with physically touching PWD
   n. Safety first vs. accessibility
6. Under recognized population
   o. Disability itself is not considered a risk factor for COVID (although many underlying factors cause them to be at high risk)
   p. PWD still largely invisible in COVID discussions
   q. More persons identifying as having a disability. For example, people are recognizing that their mild/moderate hearing disability makes it challenging to communicate with people wearing masks.
7. Access to COVID testing and testing sites can be challenging for PWD
8. Mental health impact of COVID-19 and socially distancing on PWD and caregivers

Topic Area #6: COVID-19 - Summary from Summit Breakout Groups

1. Successes and existing initiatives
    a. Policies previously discriminated against PWD are changing
    b. Since everyone is impacted, potentially more interest and more advocacy in this area
    c. Increased understanding of the challenges faced by persons with disabilities now (e.g., not being able to hear as well during telehealth visits)
    d. Telehealth
        i. Open up opportunities for accessibility and future research
        ii. Professionals are licensed state-by-state, not nationally – with telehealth, state lines are much less relevant. May give someone who needs special treatment better access to the necessary subspecialists for their condition without traveling
    e. Federal funding specific to COVID, can have many uses/broad opportunities for funding to improve infrastructure, etc.
        i. Inclusion of PWD in drug/vaccine trials
        ii. Underrepresented populations – new NIH initiative RAD x-UP, $500 million to address disparities to testing for COVID-19
        iii. Goal to move this into the mainstream with regard to research investment
2. Challenges
    a. Inclusion of PWD, including those who are people of color, in drug/vaccine trials is low due
    b. Concern regarding discrimination and unequal treatment during COVID
        i. Equal access to treatment – will they treat me because of my disability?
        ii. Role of implicit bias during the pandemic determining who gets treated and who doesn't is poorly understood and recognized
    c. Testing centers and treatment for PWD has not been accessible for everyone
    d. Healthcare modifications
        i. Problems with the visitation policies
        ii. Masks
            1. Issues around medical staff needing to wear clear masks for those who would benefit from lip-reading
            2. Some disabilities make it difficult or prevent ability to wear a mask
        iii. Telehealth
            1. May be inaccessible or present barriers for PWD, esp. people who are deaf and those who would need face to face exams
            2. Providers had to jump in to providing telehealth = learning curve
            3. Many people do not have the resources to engage in telehealth
    e. Providing direct care to PWD
        i. Availability of PPE for care workers
        ii. Plans for care if care worker gets COVID
    f. Focus has been on nursing home, not PWD
        i. Intermediate Care Facilities with individuals with intellectual disabilities have had major outbreaks
    g. Impact on preventive care
        i. Primary care and dental care offices closed for a long period of time, routine care did not happen because providers were not open

    h. Healthcare systems are overwhelmed: how do we make this an issue to focus on?

General Action Priorities Identified by Summit Breakout Groups

1. Disaster preparation and disaster relief for people with disabilities
2. Need additional researchers - pipeline issue
3. Additional research needed in prevention and treatment for people with disabilities
4. Be more explicit about stigma and ableism as well as tools to address it in an effective way
5. Might be great resources available; dissemination needed
6. Ensuring that PWD are considered a "disparity population"
7. Include the voices of PWD across all stages and initiatives
   a. Sufficient and accurate representation of PWD is needed in all sectors
   b. Continued collaboration across disciplines is necessary
8. Cultural competency training is necessary for providers, researchers, health administrators
9. Develop standards for accessible healthcare that go beyond legal requirements
10. Increase awareness of the implications and importance of intersectionality

Advocacy Action Priorities Identified by Summit Breakout Groups

1. Communication/outreach to PWD
2. Improve advocacy for PWD during COVID
3. Educate patients on knowing their rights/self-advocacy
4. Health systems need to have relationship/connections within community

Research Action Priorities Identified by Summit Breakout Groups

1. Disability Data Collection
    a. Determine best practices for data collection at a practice-level
        i. Develop pre-screener and script before asking disability questions
        ii. Develop evidence for who should ask, what time point should questions be asked, and how often it should be asked
            1. Patient portal
            2. Schedulers/at time of registration
            3. Provider (would allow for more conversation around disability)
    b. Evidence for linking accommodations to patient requests
    c. Engage with funders and policy makers to advocate for routine collection of disability status in national surveys and research studies
    d. Develop and implement alternative response modalities for surveys to ensure accessibility
2. Transforming Healthcare Organizations and Clinics to be Accessible
    a. Identify funders who are interested in supporting this work
    b. Develop instruments to measure accessibility
    c. Measure effects of healthcare accessibility initiatives on quality, safety, patient-reported outcomes, provider/staff reported outcomes, cost effectiveness, etc.
    d. Assess the implementation of laws and policies mandating accessibility
    e. Develop evidence-based standards for accessible healthcare that go beyond legal requirements
3. Healthcare Leadership, Providers and Staff: Changing the Culture of Healthcare
    a. Provide evidence to support education and training that incorporates discussion of attitudes and biases
4. Patients, Family Members, and Caregivers
    a. Explore how different demographic groups, including different race/ethnicity, define disability
    b. Explore how to effectively engage family members and caregivers to improve patient outcomes
5. Intersectionality
    a. Funding for pilot grants around intersectionality
    b. Include collection of disability status in existing studies just like collection of race/ethnicity. This would allow for secondary analyses.
    c. Explore how to increase understanding and comfort with disclosing disability status
    d. Describe disparities in the context of COVID-19, including focus on populations that experience intersectionality
6. COVID-19
    a. Measure short- and long-term health outcomes for PWD who contract COVID
    b. Understand effects of healthcare modifications (e.g., telehealth, masks, decreased preventative services) on healthcare and health outcomes of PWD
        i. Impact post-COVID – everything can't be moved to telehealth just because it's "easier," not a substitute for office-based care, especially for PWD
    c. Systematic analysis on whether residential setting matters
    d. Assess best practices for treating PWD during COVID
    e. Measure and address biases in care provided to PWD

Policy Action Priorities Identified by Summit Breakout Groups

1. <u>Disability Data Collection</u>
   a. Continue to increase policies and mandates for collection of disability status by national surveys and national networks (e.g., FHQCs)
   b. Standardized discrete field for documentation and functionality in EHR
      i. Develop functional workflow in EHR
      ii. Develop possibility for back end linkage of codes to extrapolate data
      iii. Disability information needs to be highly visible in the EHR, as there is more of a focus around providing accommodations than the actual disclosing of the disability
      iv. Develop standards across EHRs, not just EPIC
   c. Funding to incentivize healthcare systems to collect and share data with public health programs and organizations such as the CDC.
2. <u>Transforming Healthcare Organizations and Clinics to be Accessible</u>
   a. Incentivizing health systems to be accessible
      i. Health plans can incentivize meeting accessibility requirements
   b. Incorporate ADA requirements in accreditation
   c. Educate health systems, hospitals and clinics of the requirements for accessibility
   d. Develop, incentivize and enforce evidence-based standards for accessible healthcare that go beyond legal requirements
   e. Explore models to help reimburse paying for disability accessibility initiatives
   f. Promote competition for accessibility (awards, recognition, US News & World Report uses it)
   g. Integrate disability into HCAHPS scores
   h. Promote resources for how to implement accessible care.
   i. Promote directories of providers who are accessible
   j. DOJ and HHS to adopt Medical Diagnostic Equipment standards/set standards for HCOs
   k. A CPT code modifier that would pay an additional amount for services to PWD; may spur attention to codes for documenting level of disability, incentivize providers to include more PWD on their panels
3. <u>Healthcare Leadership, Providers and Staff: Changing the Culture of Healthcare</u>
   a. Accountability for healthcare organizations to train staff and providers
   b. Medical education needs to incorporate disability education into training (e.g., standard codes of conduct; ADHCE Core Competencies on Disability for Health Care Education)
4. <u>Patients, Family Members, and Caregivers</u>
   a. Resources for patients and caregivers on ADA requirements for accessible care
   b. Educate health systems on visitor exception policies for PWD
5. <u>Intersectionality</u>
   a. Increase collection of disability data across systems (research, national surveys, health systems, etc.)
      i. Create resources for people who are collecting the questions
6. <u>COVID-19</u>
   a. Telehealth regulations, payment, and standards – may need to be refined if permanent
   b. Strategy/policy for ensuring direct care service worker pipeline and how to strengthen it
   c. Ensure that disability is included in public health, state and national policies related to COVID-19 testing, treatment and vaccines.

Practice Action Priorities Identified by Summit Breakout Groups

1. Disability Data Collection
    a. Prioritize capturing data in a standardized way
    b. Develop list of health systems currently working on this initiative (beneficial for networking/problem-solving and also to increase strength in approaching EPIC or other EHR)
2. Transforming Healthcare Organizations and Clinics to be Accessible
    a. Increase buy-in from healthcare systems, including C Suite; spend money to save money
        i. Work to promote clinical providers and staff buy in to accommodations
    b. Tie documented disability to accommodations
    c. Someone within the organization should be responsible for ensuring they are meeting these standards (Section 1557)
3. Healthcare Leadership, Providers and Staff: Changing the Culture of Healthcare
    a. Highlight bright spots (i.e. organizations where leadership is supportive)
    b. Address knowledge gaps, biases and attitudes of providers and staff (anyone who has contact with patients)
        i. More culturally competent training
        ii. Address myth that patients with disabilities are a 'low' percentage of the population
        iii. Improve understanding around what ADA standards mean
        iv. More education on how to include caregivers in appointments
        v. Increase value and understanding of people with disabilities
        vi. Make trainings mandatory
        vii. Include disability in standard diversity trainings
    c. Workplace diversity: increased number of employees with disabilities
        i. Decrease stigma with identifying as having a disability
4. Patients, Family Members, and Caregivers
    a. Assistance with navigation needs to be a standard of care
    b. Connect patients to others in order to facilitate pediatric to adult care transition
    c. Improve relationships between healthcare providers to facilitate coordination of care
    d. More user-friendly patient portals that provide guidance on how to interpret records
    e. Include people with disabilities in the way practices are set up and that care is provided
    f. Patient and family engagement in the process – affinity groups, engagement groups
    g. Obtain consent from individuals with disabilities, not just their caregivers. Important not to remove agency from people with disabilities
    h. Provide staff with guidelines on what they should consider when patients ask for support person to be allowed to join patient, both for visits and admissions.
    i. Need to have multiple modalities/different ways of getting clinical and medical information across due to wide variety of abilities and needs
    j. Health systems need to have relationship/connections within community
    k. Allow for and engage with caregivers and family members in clinical encounters
    l. Report caregiver needs in EHR
5. Intersectionality
    a. Increase collection of disability data across systems (research, national surveys, health systems, etc.)
        i. Create resources for people who are collecting the questions
    b. Incorporate disability in organizations' conversations and efforts for equity

6. <u>COVID-19</u>
    a. Develop and implement non-discriminatory triage policies
    b. Provide care in a non-discriminatory manner
    c. Take lessons learned and applying them to preparedness for the future
    d. Determine way to document in patients' charts that they need COVID-19 related adaptations (e.g., they are approved to bring a caregiver or not wear a mask)
    e. Ensure testing sites are accessible