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

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1:10 – 1:55 - Session 1
1:55 – 2:05 - Break
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Overview of Project to Date

In February 2019, Dr. Morris and the team at the University of Colorado Anschutz Medical Campus received funding for a 2-year Engagement Award from the Patient Centered Outcomes Research Institute (PCORI). (Additional information about the award can be found here.) The following are the objectives of the project:

1. Develop a national Learning Collaborative (LEADERs) that has the capacity to engage in Patient Centered Outcomes Research (PCOR) to address disability healthcare disparities.
    a. Progress: We currently organize a twice a month meeting of healthcare systems who are actively working on advancing disability equity in their own organization. The meeting is an opportunity for members to share experiences and resources, as well as get advice from others on how to implement accessibility initiatives. We currently have approximately 50 members from around 30 healthcare systems. The group has grown by word of mouth and significantly increased in membership since the beginning of the pandemic.

2. Identify stakeholders' priorities for PCOR to address disability healthcare disparities.
    a. Progress: Between May 2019 and August 2020, we completed 50 interviews with key stakeholders. Below is the breakdown of the categories of the interviewees. The aim of the interviews was to understand the stakeholders' perspectives of research, policy, and practice priorities to advance equitable care for persons with disabilities. The results of these interviews will inform our discussions during the Summit.

Interviewees	Number
Disability Accessibility Coordinators (DACs)	17
Researchers	9
Advocacy Organizations	10
Policy Makers	7
Payers	5
Professional Organizations	2

3. Develop a sustainable infrastructure for engaging key stakeholders (HCOs, patients, and researchers) in LEADERs through a website or web-based collaborative network.
    a. Progress: We are continuing to formalize the LEADERs learning collaborative and build a sustainability plan. Additional information and resources we have gathered throughout the project can be found here: https://advancingequitablecare.org/

In September 2020, we received a COVID-19-related Enhancement for the Award from PCORI. With the Enhancement, we conducted 4 virtual focus groups (total of 31 people) with the previously engaged stakeholders, as well as some additional DACs. The aim of the focus groups was to understand how COVID-19 and related healthcare modifications have affected the care delivered to patients with disabilities. The results of these focus groups will inform our discussions during this Summit. Additionally, as a part of the Enhancement, we are engaging communication experts to help us develop a communication and dissemination plan for LEADERs, our online platform, and resources.

Definitions and Abbreviations

Disability: For this project we are using the WHO's International Classification of Functioning, Disability and health (ICF) model of disability. The ICF states that disability is the interaction between a person's body functions and structures, activities, participation, environmental factors and personal factors. Common disability categories include: physical, visual, hearing, communication, mental health, and cognition. In this project we define disability as a population who experiences disparities in health and healthcare outcomes. Disability is not considered as an outcome measure.

Healthcare disparities: This project focuses specifically on healthcare disparities experienced by persons with disabilities. We are focused on how the healthcare system can be modified to provided equitable care to patients with disabilities. Healthcare disparities are only one of the factors that contribute to health disparities. It is beyond the scope of this project to focus on all of the factors that contribute to health disparities.

Healthcare systems: Throughout this document we refer to healthcare systems, which is inclusive of healthcare organizations, clinics and hospitals.

Disability Accessibility Coordinator: These are individuals who work within healthcare systems and are involved in or lead accessibility initiatives at their organizations. They have a wide variety of titles (e.g., ADA Coordinators, Section 504 or 1557 Coordinator) and work in a variety of departments within their organization. We suspect that there is a growth in the number of these individuals due to Section 1557 of the Affordable Care Act, which states that healthcare systems with 15 or more employees need to designate one individual to oversee non-discrimination efforts.

Abbreviations:

Person with a disability: PWD
Disability Accessibility Coordinator: DAC
Electronic health record: EHR
Learning CollaborativE to Advance Disability Equity in HealthcaRe: LEADERs

Disability Language and Participation Guidelines for the Meetings

1. Language
    a. Disability language can be complex and potentially nuanced, as such, we will work to extend understanding to one another. We will work within the assumption that no one means to offend and is trying their best.
    b. As a default, we will use person-first language, acknowledging that there are certain disability communities that might prefer other language.
    c. Participants will help one another understand preferred language or specific preferences by sharing known preferences.
    d. Appropriate language examples:
        i. Person with disability
        ii. Autistic/on the Autism spectrum
        iii. Child with complex healthcare needs
        iv. Uses a wheelchair/wheelchair user
        v. Has cerebral palsy (or other condition)
        vi. Person with a mental illness
        vii. Person who has epilepsy
        viii. Person who is hard of hearing
        ix. People who are blind
    e. Words/phrases to avoid:
        i. Disabled
        ii. Special needs
        iii. Normal (when referring to person without a disability)
        iv. Handicapped
        v. Wheelchair-bound
        vi. Crazy, psycho, mental case
        vii. The mentally ill
        viii. A victim of/ suffers from
        ix. The blind

2. Participation
    f. Participants will respect the opinions and experiences of one another.
    g. Participants will acknowledge and respect that a range of disabilities are represented within the group and our goal is to promote accessible healthcare for individuals will all types of disabilities.
    h. Participants will work to be sensitive to intersections of disability, race/ethnicity, gender, and sexual orientation.
    i. All will work towards an environment of collaboration and an atmosphere of respect.

3. Accommodations
    j. To accommodate those with hearing disabilities, please use video during the call when possible and appropriate.
    k. To accommodate those with communication disabilities, members will speak one at a time, will not interrupt someone while speaking, and allow others extra time to talk when needed.
    l. At least once per session, the moderator will allow an opportunity for participants who have not spoken up yet a chance to express opinions if they would like.

Topic Area #1: Disability Data Collection

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 #2: Transforming Healthcare Organizations and Clinics to be Accessible

Little evidence and few standards exist to inform how to provide accessible healthcare to patients with disabilities. (*See Page 13 for a list of examples.)

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 #3: Healthcare Leadership, Providers and Staff: Changing the Culture of Healthcare

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
    e. 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.
    f. 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.
    g. Providers and staff need education on what they are required to provide under the ADA.
    h. Need to increase the number of providers and staff who have disabilities.

3. Medical and Healthcare Professional Education
    i. Many participants thought we need to start early in educating healthcare providers and staff about disability.
    j. There are currently no requirements for including disability in medical education.
    k. 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.
    l. 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
    m. 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 #4: Patients, Family Members and Caregivers

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
    d. 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.
    e. Research is needed to determine whether engagement with family members improves patient care.
    f. More defined roles of caregivers and family members during appointments need to be identified and documented.
    g. Caregivers’ disabilities need to be reported in the EHR.
    h. 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
    i. Many of the DACs reported working with their local disability community to assist in identifying ways to improve their healthcare system.

Topic Area #5: Intersectionality

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:
    f. Income level
    g. Educational opportunities
    h. Occupation, employment status, and workplace safety
    i. Gender inequity
    j. Racial segregation
    k. Food insecurity and inaccessibility of nutritious food choices
    l. Access to housing and utility services
    m. Early childhood experiences and development
    n. Social support and community inclusivity
    o. Crime rates and exposure to violent behavior
    p. Availability of transportation
    q. Neighborhood conditions and physical environment
    r. Access to safe drinking water, clean air, and toxin-free environments
    s. 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 #6: COVID-19

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

List of Disability Accommodations and Accessibility Initiatives

Below are categories or groups of accommodations and initiatives that the DACs reported working on. With each category, we provided several examples. This is by no means an exhaustive list of the types of accommodations in these categories.

1. Physical access
   a. Ramps and elevators in buildings and parking lots
   b. Room and doorways large enough to accommodate someone in a wheelchair
   c. Equipment (weight scales, radiology equipment, examination tables, Hoyer lifts)

2. Effective communication (communication and visual disabilities)
   d. Providing auxiliary aids and services (e.g., Pocket Talkers)
   e. Communication kits
   f. Amplified phones
   g. Magnifiers
   h. Communication boards

3. Policies and procedures
   i. Early rooming for patients with autism
   j. Service animals

4. Providing communication access to Deaf and hard of hearing patients
   k. Sign language interpretation
   l. CART
   m. Remote interpreting

5. Documenting disability status
6. Training staff and clinicians about accessibility and accommodations
7. EMR accessibility
   n. Patient portal accessibility
   o. Printing patient after visit summaries in large print

8. Telehealth accessibility
9. Sensory accommodations and toolkits for patients with autism or other disabilities
10. Accommodations for patients with cognitive disabilities
    p. Informed consent

11. Accessibility of the healthcare system's website

Important Outcomes Identified by Participants

The majority of the DACs reported that they do not systematically collect outcomes. They reported believing that their role was critical to "exceptional patient outcomes", but often do not have a good measure of this.

1. Patient outcomes
    a. Patient reported
        i. Experience
        ii. Satisfaction
        iii. Quality of Life and Health Related Quality of Life
        iv. Unmet healthcare needs
        v. Whether accommodation needs were met
    b. Patient self-efficacy
    c. Patient is able to identify who to contact if he/she has a question about accessibility
    d. Adherence to care because patient understood the recommendations

2. Staff outcomes
    e. Satisfaction
    f. Attitudes towards PWD
    g. Burnout
    h. Comfort with caring for PWD
    i. How comfortable and confident they are about being able to meet the needs of PWD
    j. Whether staff think they have had adequate training and equipment
    k. Number of staff and providers with disabilities

3. Accommodation process outcomes
    l. Do staff report having a point person to ask questions if they have them
    m. Patient received the accommodations they needed
    n. Efficiency in providing accommodation - Staff not scrambling to provide accommodations

4. Safety of patients and staff
5. Cost effectiveness and cost benefit
6. Effective communication
7. Quality outcomes
    o. Clinical outcomes
        i. Hypertension
        ii. Blood pressure control
        iii. Diabetes management
        iv. Whether progressive conditions, such as Parkinson's disease are slowed
        v. Disease specific clinical outcomes (e.g., asthma outcomes)
        vi. Infectious disease exposure
    p. Healthcare utilization
        i. Preventative care
            1. Cancer screening
            2. Screening for chronic conditions
            3. Monitoring for medications and multiple medication interactions
        ii. Reducing
            1. Readmissions

        2. Reoccurring emergency visits
        3. Hospitalizations
    - iii. Behavioral health use
    - iv. Reduce barriers to care
    - v. Reduce unnecessary care
    - vi. Efficient access to care (e.g., can get a mammogram in the same timeframe as others)