LEADERs Summit Day 2:
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
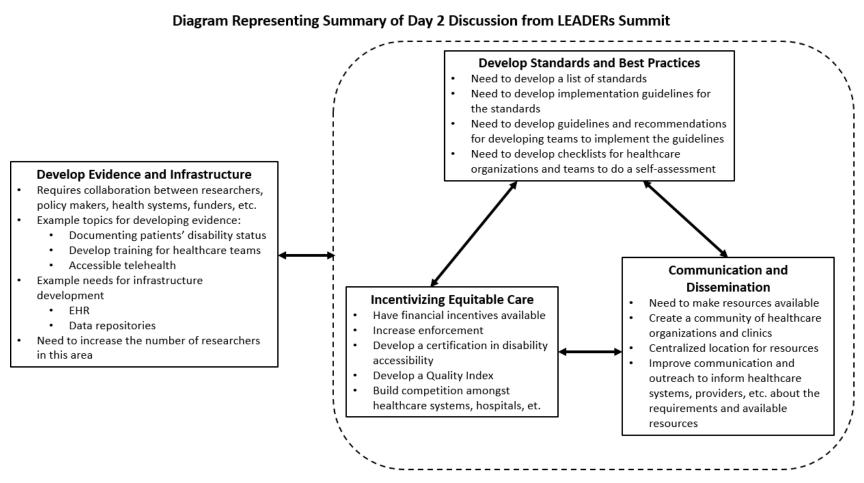
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Summary of the Breakout Group Discussions

Below is an attempt of a graphical representation of a summary of the discussions from the breakout groups during the second day of the Summit. Research evidence as well as infrastructure (e.g., data repositories) need to be developed to inform 1) standards and best practices, 2) communication and dissemination, and 3) incentivizing equitable care. You will note that all of the arrows in the diagram are bi-directional. All of these areas need to work together in order to advance equitable healthcare for persons with disabilities. Following the diagram is a more detailed outline of the discussion.

Diagram Representing Summary of Day 2 Discussion from LEADERs Summit

Develop Standards and Best Practices
- Need to develop a list of standards
- Need to develop implementation guidelines for the standards
- Need to develop guidelines and recommendations for developing teams to implement the guidelines
- Need to develop checklists for healthcare organizations and teams to do a self-assessment

Develop Evidence and Infrastructure
- Requires collaboration between researchers, policy makers, health systems, funders, etc.
- Example topics for developing evidence:
  - Documenting patients' disability status
  - Develop training for healthcare teams
  - Accessible telehealth
- Example needs for infrastructure development
  - EHR
  - Data repositories
- Need to increase the number of researchers in this area

Incentivizing Equitable Care
- Have financial incentives available
- Increase enforcement
- Develop a certification in disability accessibility
- Develop a Quality Index
- Build competition amongst healthcare systems, hospitals, et.

Communication and Dissemination
- Need to make resources available
- Create a community of healthcare organizations and clinics
- Centralized location for resources
- Improve communication and outreach to inform healthcare systems, providers, etc. about the requirements and available resources

- **General**
  - Inclusion of persons with disabilities needs to occur across all stages and initiatives
  - Sufficient and accurate representation of persons with disabilities is needed in all sectors
  - Persons with disabilities need to be considered a "disparity population"
  - Be more explicit about the presence of stigma and ableism
  - Cultural shift is required to bring attention to this issue

- **Develop Evidence and Infrastructure**
  - Research collaboration
    - Need an annual "conference" with broad representation of researchers/partners
    - Create researcher working group
      - share current data and research aims
      - share current research and literature around relevant topics for future research
      - current findings
    - Data
      - Create community-based linkages for care
      - Both for patient/client-level data and for recruitment
        - Would help diversify participants geographically and in other ways
      - Shared network that could be tied to PCORnet
    - Recruitment
      - University sites advertising/informing individuals of research participation opportunities
      - Both for patient/client-level data and for recruitment
    - Would help diversify participants geographically and in other ways
    - Innovative/ creative design strategies to address the need for evidence-based intervention; do we really need to have multiple RCTs to demonstrate the effectiveness of "obvious" accommodations (i.e. do we need to "prove" that height-adjustable exam tables improve quality of healthcare for PWD?)
  - Research and infrastructure building topics
    - *Training for healthcare teams*
      - Cultural competency training for providers, trainees and nonclinical staff across multiple types of settings
        - Include actionable steps and tools, and regular, consistent trainings to facilitate a level of accountability
      - Tools that address stigma and ableism
      - Identify easily digestible material that can reduce implicit bias
      - Identify funding sources
      - Identify where to house and share the trainings
    - *Telehealth*
      - Continue to work to make interface for visits accessible (EHR, etc.)
      - Need solution for billing structure that do not cover telehealth if only over the phone
      - CART vendor availability
      - Best practices
      - Insurance structure is limiting when patients do not have the technology to do video visits (i.e. telephone visits not covered, video visits covered)
      - Accessibility concerns: Nonverbal, ASL, screen reading

- Consent forms to do the visit are only through the patient portal, which is not accessible
  - *Collection of patients' disability status*
    - Standardized data collection around documenting disability status
    - Collect more data from people with disability to create better accommodations
    - Epic is a critical partner
      - Being able to field test projects, having a clearinghouse of research that is ongoing
    - We still need a universal way to capture disability status before we can create a universal way to report and evaluate ourselves on it
    - Engage EPIC and other EHR vendors
    - Create workgroup to develop standards
  - *Population level data collection*
    - Accessing data from existing surveys (national, state, and individual groups') is challenging
    - Time is a barrier and the lack of proximity to other researchers makes sharing of current data difficult
    - Medicaid and bureaucracy are an issue with linkages to care
    - Statewide issues
  - *Other research questions*
    - Evidence that benefits outweigh the cost for providing appropriate accommodations
    - Limited diversity/representation of intersectionality in many studies (small Ns)
    - Work with researchers to identify if barriers are financial or need further research
    - We need longitudinal outcomes and funding for this
    - Evidence needed for safety and quality and how it improves outcomes
    - Quantify the cost of <u>not</u> providing appropriate accommodations
- Research funding
  - Identification of funding opportunities
    - Other sources of funding (foundations, managed care organizations, etc.)
    - NOT-HD-20-031 – Research on Rehabilitation Needs Association with the COVID-19 Pandemic
    - NOT-MD-19-007 – Notice of NIMHD's Interest in Research on Disability in Health Disparity Populations
    - PAR-20-250 – NICHD Research Education Programs R25
  - Address the lack of understanding of the NIH funding process
  - Specific processes required to inform funding priorities within federal funding agencies
  - RFA's aren't always needed to fund accommodations; can apply to parent announcement as well. Reach out to program officers to get questions answered around funding.
  - Challenge of NIH being organ/disease based due to Congressionally dictated structure.
  - Progress in this area – NIH collaboration across institutes RADx, COVID supplements, etc.
  - Diverse streams of funding

- o <u>Increase number of researchers</u>
  - Identify and address pipeline issues
  - Support career development awards, including diversity supplements
  - Recognize that PWD are under-represented group in research

- **Develop Standards and Best Practices**
  - o Environmental scan of organizations where innovation is currently happening – need funding to do this
  - o Create a set of best practices at the *operational* level for health system accessibility
    - Need a digestible set of guidelines of how to successfully meet these standards as current lists are not necessarily digestible
  - o Create a set of best practices for accommodation implementation
    - Need financial support and champions within health system organizations to create significant change
  - o Create a Healthcare Quality Index equivalent for rating health systems on accessibility
    - Needs to be representative of multiple settings
  - o Standardized checklist for organizations to evaluate themselves on their accessibility and progress towards it
  - o Create recommendations for models of how healthcare organizations can create teams to do the work

- **Dissemination and Communication**
  - o Create a way to connect with each other
  - o Create living documents/resources for accessible healthcare
  - o Make great resources available
  - o Improve communication strategies
  - o Technical assistance
  - o Disseminating resources specific to healthcare settings
  - o Disseminating best practices around current standards
  - o Centralized location to disseminate resource

- **Incentivizing accessibility**
  - o Financial
    - Increase financial support and have champions within health system organizations to create significant change
    - Tax credits could provide resources for some clinics in need
    - Funding for implementation
  - o Certification
  - o Building competition amongst hospitals/health systems
  - o Federal support
  - o Improved enforcement of current standards

Next Steps

Below are immediate next steps we plan to take over the next few months. We invite you to participate in these steps, specifically the working groups. If you have any steps you or your organization are planning to take, we invite you to share those steps. Finally, if there are other ideas you would like to work on with others in this group, please let us know.

- Working Groups – the format and content of each group is TBD. Please complete the survey to indicate your interest in participating in an informational meeting for one or more of these workgroups.
    1. Research
        - Might include: works in progress, connect with funders, develop new researchers, share findings, etc.
    2. Documenting disability status in the EHR
    3. Standards for providing accessible care

- Newsletter
    - We will be developing a quarterly newsletter. The goal of the newsletter is to maintain momentum and collaboration while sharing updates. The content is TBD and we would appreciate your input. Potential items could include:
        - Summary of topics from LEADERs meetings (the community of disability accessibility coordinators)
        - Any policy updates
        - Any research updates
        - Research opportunities
        - Research funding opportunities

- Bi-monthly community of healthcare systems that involves disability accessibility coordinators at health systems
    - We will continue to meet every other week and provide a space for healthcare systems/hospitals to share ideas with each other on providing accessible care
    - A summary of topics discussed to be shared in the newsletter
    - We are continuing to develop a platform for members to share resources, ideas, questions, etc., as well as curate materials that they develop
    - While this group is a community for healthcare systems, we are always open to other individuals attending occasionally to present to get input or share policies, research, etc. Please contact Dr. Megan Morris and Kori Eberle if you have any questions.

- Website
    - We are working on developing a website with resources for healthcare systems, providers, etc. We plan to have a public area of resources (please send us links of resources you have!), and a private area in which the Community members can share items such as hospital policies, proprietary materials, etc.