



SC Disability Public Health Task Force

1.11.23

1-3pm

[Via Zoom](#)

- I. Welcome** **Kimberly Tissot, President & CEO**
- II. Introductions**
 - a. In Attendance: Mandy Halloran, Kimberly Tissot, Annie Foster, Beth Franco, Ann Warner, Alexis Smith, Anna Guryan (DEI Specialist with SCDEC), Anni Crook, Catherine Graham (ED for Spinal Cord Research Fund), David Rotholz, Elizabeth Childers (DHEC), Donna Mack (SCCHWA), Felicia Johnson, Eric Bellamy (Children’s Trust of SC), Jessica Seel (SC Office of Rural Health), Joyce Davis (Brain Injury Association of SC), Janet Priest (DDSN), Karma Marshall, Kaylee Quintanilla-Caro, Mckenzie Watson, Megan Branham (Family Connection), Megan Johnson (SCDOA), Justina Siuba (IMPH), Megan Weis, Russell Morrison, Spencer Dickey, Valarie Bishop, Naomi Lett, Rebecca Williams-Agee, Mike Leach, Reba Landry, Julia Martinelli, Amy Holbert, Stacey Seipel (MUSC), Terrance Middleton (DEI Specialist with Pee Dee area DHEC), Lawson Clubb (Walton Options), Rachell Johnson (SCATP), Margaret Alewine.
- III. Overview & Purpose of the SC Disability Public Health Task Force** (Refer to PowerPoint slides for additional details)
 - a. Kimberly provided information about Able SC’s mission as a disability-led organization.
 - b. Kimberly shared about Able SC’s work related to Public Health. It is important to remember that disability intersects with all

other identities, and when we say disability, we mean all types of disabilities. While leading vaccination efforts during the pandemic, we learned that people with disabilities are often excluded from these efforts. Under the CDC BIPOC program, we learned that when people are part of multi-marginalized communities, there can be many hesitancies. This program worked to address these hesitancies for vaccination.

- c. Advocacy and Education during the pandemic: people with disabilities were dying and becoming very sick at higher rates, and we did a lot of advocacy work, press releases, interviews, etc., to ensure that people with disabilities were being included. This task force will continue to address this to ensure that people with disabilities are included.
 - d. Kimberly discussed Public Health Funding: We received a small portion of the funding awarded to aging and disability networks across the country to expand the public health workforce. We do not want to be a watchdog group but, unfortunately, must do that to address gaps. Organizations like the Center for Disability Resources, AccessAbility, and Walton Options are also participating.
 - e. Kimberly addressed the overview & purpose of the task force outlined in the PowerPoint. We want to ensure that people are included in life-saving policies and activities in our state.
- IV. Health Equity** (Refer to PowerPoint slides for additional details)
- a. Kimberly answered the questions, “What is health equity?” and “Why is disability left out of health equity?”
 - i. One of the reasons disability is left out of health equity is a lack of data. We haven’t had access to data on the number of people with disabilities who died or were impacted by COVID.
 - ii. Another reason disability is excluded is due to not understanding barriers. For example, many videos came out during the pandemic but lacked ASL interpretation or other necessary accommodations.

iii. There is also no clear definition of disability or understanding of the laws. We must educate people in the medical world on this and ensure we have a clear definition of disability.

- b. What is a disability? The legal definition differs from the definition given by the Social Security Administration or Medicaid Waivers.
- c. Kimberly reviewed examples of major life activities, disabilities, and relevant disability rights laws.
 - i. When people think of the ADA, they often think it's only about employment, but it relates to public access.

V. **The status of South Carolinians with Disabilities**

- a. Kimberly discussed the many ways we are left out. Regarding physical accommodations, even very new buildings are often not accessible.
- b. People with disabilities are one of the most marginalized communities. Kimberly discussed the “how” and “why” of this.
 - i. One reason why is systemic ableism. Ableism is when you see non-disabled people as having a hierarchy. We will continue to address this if you're not familiar with this term.
- c. Medical Knowledge of individuals with disabilities: a majority of physicians did not know who determines reasonable accommodations or felt they were at risk for an ADA lawsuit. There is a need to educate physicians in addition to service providers.
- d. Disability and health: barriers look different for everyone (transportation, finding a healthcare provider, etc.)
 - i. People with disabilities are likelier to have poorer health because it is more challenging to access preventative health measures such as mammograms.

VI. **Lessons learned & solutions from COVID-19 pandemic**

- a. Kimberly discussed the impact of COVID on people with disabilities and the medical bias towards disability.

- i. We sent many letters to hospitals and others to prevent medical rationing and, luckily, didn't have any deaths related to this reported in SC.
- ii. Michael Hickson's death: Michael died in Texas after being denied a ventilator when he had COVID-19. He had a spinal cord injury, and the hospital deemed his life less worthy of saving. This is why we want to bring more people into this conversation and continue this work.

VII. How can your agency benefit from this task force, or how can this work be included in the work your organization is already doing? Open Discussion / Goal development:

- a. Beth Franco: DRSC works closely on the standard of care, and Beth is not convinced we are where we need to be. DRSC is still following this and is interested in continuing to focus on this. If we have another pandemic and there are concerns about rationing care or not allowing caregivers to enter hospitals, these things need to be addressed upfront.
- b. Julia Martinelli: AccessAbility has concerns with long-haul COVID. Many think COVID is over, and AccessAbility is dealing with cases of people being mistreated and left in hospitals indefinitely. Families are having a hard time getting systems in place to help. She is also concerned about government funding being withdrawn and not increased.
- c. Catherine Graham: Catherine spent years trying to increase access to health care. In the past, she has worked with DHEC and primary health care providers, with the mindset that we are a rural state and not everyone can be in one of the urban areas. She doesn't feel that we've made much progress outside of making groups aware of the lack of access. They are aware but haven't taken steps to address the gaps. Healthcare centers and doctors' offices need to be made accessible on the basic level so that this is already ingrained when we have a pandemic. When we do it while reacting in an emergency, it only addresses short-term solutions. Agencies represented in this meeting (DHEC, DHHS, etc.) already have great health

programs being promoted; they need to be tweaked to communicate to the right groups in an accessible fashion and in accessible locations.

- d. Kimberly: we need to think about both long-term solutions and how we can help people now, especially since COVID is not going away. What tools can we create?
- e. Beth Franco: DRSC has been working on effective communication. People who don't have an interpreter or an effective interpreter may reach out. If they don't have access to this accommodation, they aren't getting what they need.
- f. Kimberly: when someone isn't being appropriately served, they aren't able to go to work, to be parents, etc. This is a safe space. We know there are great intentions among many of these programs in our state, but many are missing inclusion pieces.
- g. Rebecca Williams asked if there had been a statewide needs assessment.
 - i. Kimberly replied that there had been state and national needs assessments. Standard of care and access are some of the significant issues. Regarding access, this applies to people needing help to get where they need to be or have accommodations when they get there. Medical clinics are often not accessible (exam rooms, not having access to accessible scale, etc.).
- h. Kimberly: At our next meeting, we will set some goals, assign committees, etc. What does your organization need to work on these changes?
- i. Rebecca Williams: Is there a need to separate into workgroups to focus on individual groups such as youth?
 - i. Kimberly responded that there are many subgroups we can divide into (accessibility, communications, etc.)
- j. Catherine Graham added that we could take a population approach and look at needs as a whole and then at target populations. For example, we could start with adults ages 18 to

65. Then add the additional criteria for youth, young children, seniors, etc.

- k. Kimberly asked the group if everyone feels that they've learned today about disparities in public health for people with disabilities. And how can this group impact each person's actions within their agencies?
 - i. Eric Bellamy: At Children's Trust, our target population is providers, but the end goal is improving children's and families' outcomes. Looking forward to seeing how we can have more of a collective impact. There is a lot of misinformation and people coming from different perspectives.
 - ii. Kimberly: We plan to bring in national speakers to these meetings to help inform us on how to achieve our goals.
 - iii. Jessica Seel: Remember that specific issues might be amplified even more in rural areas. They encouraged everyone to look at things from a geographic perspective.
 - iv. Kimberly: we saw the impact of gaps in rural areas when advocating for home-based vaccination and other access to vaccinations due to lack of transportation.
 - v. Megan Johnson (SCDOA): Not even factoring in disability, there are already so many disparities in housing, transportation, healthcare, etc. Half of the senior population has at least one disability.
- l. Julia Martinelli asked the group if anyone is missing whom we can add to this task force.
- m. Kimberly shared that we are planning to bring in legislators to discuss how to address these issues. During COVID, we had a youth in foster care who advocated not to go to school but to instead get home-based school because their foster parent had a medical condition that put them at risk. We've seen how this pandemic impacts all ages.
 - i. Mike Leach added that the Family First Preservation Services Act was passed in 2018 at the federal level. States have had several years to implement all the

pieces; DSS has discussed whom we need to have at the table to implement this. Mike shared that he sees much room for improvement and a need to ensure everyone is at the table.

- VIII. Future Meetings: meet monthly to get started and will have ongoing training and technical assistance.
- IX. Adjournment