

Minutes of 3/31/20

Phone call between Representatives of the Department of Health (DOH), Washington State Developmental Disabilities Council (DDC), The Arc of Washington State (Arc) facilitated by Governor's Policy Director, Amber Leaders.

Present: Representatives from the DDC (Jeremy Norden-Paul, Adrienne Stuart), DOH (Secretary Wiesman, Paj Nandi, Kathy Lofy), Governor's Office (Amber Leaders), The Arc of Washington State (Sue Elliott, Stacy Dym), Dr. Mimi Fields

This meeting was requested by disability advocates at The Washington State Developmental Disabilities Council and The Arc of Washington State in response to a recent complaint to HHS filed by Disability Rights Washington. The purpose of the meeting was to discuss language for care rationing in the "Scarce Resource Management & Crisis Standards of Care" document, and more specifically issues related to the novel COVID-19 virus.

The DD community expressed concern over the triage worksheet language regarding "baseline functional status" as a factor in determining whether or not a person with disabilities would benefit from treatment.

Background provided by DOH:

- Secretary Wiesman: The state has been planning for a pandemic influenza for a number of years, anticipating a shortage of staff, supplies, or space. He explained the number one priority is to prevent ever needing to ration care. Dr. Wiesman emphasized that we are not currently rationing care in our state and none of the guidance has been implemented. The idea is that when faced with a shortage of resources, to make decisions as ethically as possible without discrimination toward any groups.
- Kathy Nofy: A group of clinicians and ethicists has been working on these guidelines as part of two disaster advisory committees. Currently no community members are involved. Have put together guidelines for what to do if resources become scarce. Follows principles of who benefits most from limited resources and how to achieve the greatest good for the greatest number of people, not just individual patients. Developed a number of scarce resource cards (e.g. staff shortage, PPE shortage, algorithm for ICU space limits).
- Paj Nandi: Small team was engaged by emergency preparedness response office 2.5 years ago. Conversations in 7 communities across the state, did not focus as much on King County. Bellingham, Yakima (also in Spanish), Wenatchee, Spokane, Vancouver, Tumwater/Olympia, Aberdeen/Grays Harbor. Outreach included community-based organization and focused on reaching diverse groups (socioeconomic, faith, language, gender, disability). Community meetings were open and accessible to all groups.

Kathy agreed that our specific concerns related to the "baseline functional status" in the triage worksheets required a review of the language and changes. There are two groups responsible for writing and implementing the guidance to hospitals – the "Disaster Clinical Advisory

Committee” and the “Disaster Medical Advisory Committee”. The document originally had a “frailty score” that would predict outcomes and prognosis for ICU and other interventions, but the committees didn’t really like the frailty language. So they borrowed some more neutral language from a Canadian document that replaced frailty with baseline functional status. Kathy shared that she can see how the language is problematic from our perspective and the committees are going to reconvene and look at new language. Kathy stated that the healthcare community wants guidance and standards – but hospitals can’t be “compelled” to follow the guidance. The DOH Secretary can issue proclamations but still can’t really tell every hospital exactly what to do.

DOH explained that they also have an equity task force/review committee which examines how health care is delivered to all sorts of marginalized groups, that they held listening sessions around the state in accessible locations, and that they synthesized feedback and produced what they felt was responsive and inclusive guidance. Paj suggested that the equity task force look at the issues being raised about patients with disabilities. Kathy agreed and said she was emailing about it now.

There was some discussion of treatment scenarios for patients with developmental disabilities who may need treatment for COVID-19. DOH explained that the biggest impact on prognosis for the COVID-19 virus is advanced age and lung health. Advanced age is the strongest predictor for poor outcomes. Other factors such as developmental disability were not relevant to the predictors and would not be used.

The issue of the use of the word “cognition” was raised by Kathy. She observed that it isn’t really relevant and when she saw that language in the worksheet, she wasn’t sure why the word was included. Perhaps it was intended for elderly patients, but it needs to be reconsidered. They are asking that question now of the committees.

Paj emphasized that the standards exist to address the concerns of oppressed communities and he understands how a certain distrust develops. He observed this is impacted by how information is disseminated. He wants to ensure that they address the issues raised today.

Would also like to ensure new language is consistent with the guidance recently given by the federal government in its March 28, 2020 Bulletin: Civil Rights, HIPAA and the Coronavirus Disease 2019 (COVID-19).

Key Take Aways:

Disability advocates expressed desire and ability to collaborate with health care agencies and professionals to issue guidance which is responsive to current and future concerns, including both inadvertently perpetuating disparate impacts and omitting disability advocates out of conversations generally. DOH was open to continued collaboration.

DOH indicated that they are currently refining and updating protocols with our concerns in mind. DOH committed to letting us know what the next version looks like before it is official. Paj offered to loop us in once he has had the chance to review it.

DD advocates remain concerned about the inconsistent application of guidelines from hospital to hospital. Enforcement mechanisms remain unclear.

DD advocates offered to be a continued resource for DOH and other agencies, and look forward to continuing this important conversation.

Next Steps:

- 1) DOH will be in contact with disability advocates for additional input on the next iteration of the Scarce Resource Management document - meetings are happening now. Maybe in two weeks DOH can have something to disability advocates.
- 2) Disability advocates asked if our state can produce a "values statement" or clarification similar to California from our Washington DOH (and perhaps HCA)? DOH will take a look at it. Amber Leaders forwarded the California document to the group.