FOUNDATION FOR Health Care Quality
Washington
PATIENT SAFETY COALITION

Addressing Stigma & Bias Workgroup Meeting
Thursday, February 18, 2020, 4 PM PT
Meeting Minutes

PRESENT

Steve Levy, Anita Sulaiman (Chair), Dr LuAnn Chen, Amy Etzel, Jessica Martinson, Nicholas Locke

MATERIALS

AGENDA

January Minutes
Approved

Updates

- Website/web page revamp:
  - AS: Took a quick look at the mock-up/alpha version. Vastly better now. There are areas for potential improvement, but it is nice to see all the materials on there vs not even having a landing page. SL & NL did a fantastic job, esp. with the meeting minutes & Year-End Summary. YE Summary: v important; can see what the workgroup is about at a glance.
  - AS to properly review with NL & SL on 2/24, at 4 p.m.

- 1/28 Safe Table event & evaluation results:
  Workgroup comments:
  - SL: 24 attendees. AS did a fantastic job facilitating. Good participation.
  - JM: Demonstration of success – everyone was putting their email in the chat, hoping to connect again. In a short time, the group bonded in a way we do not typically see. A lot of new faces; good representation from different organizations. Is there more we can do with that group e.g. think tank, sounding board? How to use them? Learned a lot from it.
  - SL: We should leverage that. It showed there is a "split" when it comes to stigma & bias between racism & disabilities. Followed up with the disability orgs. Will do a podcast with them, possibly webinars too.
  - Discussed vaccination rollout & disability community.
  - SL: They reached out to thank us. Observed difference between disability as an issue & other stigma & bias themes like racism. Disability issue is across all other biases. This one is really important because often disabilities were created by a problem in healthcare; it is like adding salt to the wound. (AS, SL & NL had met with them on 2/10, as a follow-up to the Safe Table, to discuss the possibility of a podcast.)
  - AS: Supposed to meet with the disability orgs again. Proposed spending ½ the time at the 2/24 meeting discussing this (apart from website revamp).
  - JM: Will share recent research on Physician perception of people with disabilities. Findings were startling, very sobering.
  - AS: Shared link: Letter written to the Gov., sent by the ED of the Washington State Developmental Disabilities Council. This came up the day before at the 2nd meeting for the

Vaccine Implementation Collaborative around the state. There was a lot of conversation around how people with disabilities & with disabilities as well as co-morbidities were disproportionately impacted. Might be of interest to people. https://ddc.wa.gov/wp-content/uploads/2021/02/Developmental-Disabiltiies-COVID-Vaccine-Letter-2.5.2021.pdf

- SL: One of the issues that came up in the f/u discussion with Kim Conner (WASILC): Folks with disabilities are often unable to get to vaccination sites. There is limited or no outreach. She mentioned FEMA grants are available. If, as a community, we can organize an outreach program, they will fund it.
- SL: Wrote to Darcy at WSHA to ask if the WSHA is doing anything in that realm. Will forward to JM. WSMA needs to be involved; the Nursing Association as well if we do something.
- JM: That is well underway. Have been promoting that to their physicians – some sort of repository for clinicians to volunteer at the state level, in addition to opportunities at the system level.
- SL: If this moves forward, will invite JM. Think WSMA, WSHA & the disabilities group can have a brainstorming/vetting session to gauge interest. They are not an agency of the government, but they are a Council under the state, DOH.
- AS: Asked if SL was referring to the Developmental Disabilities Council. That was the link sent earlier i.e. the letter they sent to the Gov. & new Secretary of Health expressing concerns a few groups had that they had not seen being addressed yet.
- JM: Shared the vaccine equity dashboard off WSMA's site. Wanted to see if could drill down statistics by disability. King is showing 8%. Snohomish: 18%.
- AS Qs: 18% of the county has disabilities: Is that what we are reading? JM: Good qs… AS: One of the issues raised in yesterday's meeting was that a lot of people with disabilities are not eligible, because they have been looking at primarily age, then you go down the line with the other criteria for organizing priority.
- JM: Also shared WSMA's Strategies for equity in COVID-19 vaccine distribution. AS: Can we share this? Is it members only? JM: Yes. Links in chat. Also shared the article: Physicians' Perceptions of People with Disability & Their Healthcare. https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2020.01452
- AS: Another issue that was highlighted - people with certain disabilities are at risk of much more serious consequences with COVID.
- JM: Oregon just passed a law (anti-discrimination bill) this summer in response to people with disabilities not being treated, in the way they wanted to be treated for COVID; saying you could not withhold care based on disability status.

- **SL presented survey results:**
  - AS: Went v well. Looks like there is appetite for more discussions around the topic.
  - Received 5 responses out of 24 attendees. (20.8%; good response rate.)
  - 1 Satisfied, 4 Very satisfied.
  - All were comfortable participating.
  - Was there information shared that you could take back to your org &/or use in your work? 4 Yes, 1 No. 2 provided comments.
  - All interested in attending more S&B Safe Tables conversations. 3 monthly, 2 quarterly.
  - Is there anything we could have done to make the ST event better? Comments/suggestions?
  - Attendee: *I would love to hear from people in specific positions who are implementing programs for patient safety that address stigma and bias. + 2 other comments.*
  - JM: Do not have to be so formal. It is taking shape as a learning collaborative.
  - AS: People were v candid, much more than was usual. Maybe the pandemic is changing how people interact, perhaps because of the urgency of finding a fix to these problems.
  - JM: Think we have hit a tipping point. This used to be a niche topic. AS: Now, everybody wants to talk about it.

- **Podcast:**
  - SL: In progress. Plan: Kim Conner, Executive Director, Washington State Independent Living Council to do a podcast on a disability related theme. She feels her constituents cannot get to a vaccination site; wants a mobile program that goes to those in need to offer inoculation. AS, NL & SL will meet to discuss further.

- **SC Meeting:** MAPS-MCRC Clinic Director, Nehath Sheriff as guest speaker.

AS confirmed Nehath Sheriff will speak at Steering Committee meeting on March 19. SL confirmed speakers are not asked to submit presentations ahead of time.

Review of ASBW Planning Document

- **Mission**
  - Discussed Proposed New Mission Statement.
  - AS: At last meeting, there were certain elements we wanted to take out & others we wanted to add to the verbiage. → Wordsmithed it.
  - Proposed new mission: To *build recognition of issues* within the healthcare system that contribute to stigma and bias faced by certain segments of the population in Washington state. Partnering with our sister program, the BREE Collaborative, the Addressing Stigma and Bias (ASB) Workgroup will identify and address barriers to *meaningful access to quality care*, with a view to initiating a culture shift at the system level centered on improving patient safety and *health outcomes*, and reducing health disparities.
  - AS: Switched from "raise awareness" to "build recognition". Consensus was we already raised awareness. This is the next step. We also took out "access" & "health insurance coverage". It is cleaner now. Next bit: "meaningful access to quality care" key words added in. When I headed the Linguistic Services Dept at Swedish Medical Center, my job was to ensure culturally & linguistically appropriate services. The language was always "meaningful access" to services. Love this term because it means "meaningful" - to the patient + talked about the quality of the care. We liked the "culture shift"; added "health outcomes".
  - JM: Would change "Mission" to "Purpose" or replace it with something else, like "Aim Statement". Typically, it is an organization that has a mission, not a workgroup.
  - AS: Valid point. Original word was "Purpose". I changed it to "Mission" when preparing for the YE Summary. What I inherited was "Purpose" & then "Goals". Yes, a mission is generally associated with a bigger organization, but you can have a mission for a sub-organization as well. For me, it goes with your goals, which are based on your stated mission. Asked if there was any other input on this. JM: No strong feelings on this.
  - JM: Brought up Dr Danielson's comment on disparities because of race vs racism.
  - AS: That is fundamental. We use these words, but we do not give them the level of thought that somebody like him with his experiences with racism does. He pointed out that disparities/inequities are not caused by race, they are caused by racism.
  - JM: Right. That might be too narrow (a focus). Wanted to make sure we include active verbs, about how systems are creating disparities.
  - AS: How do you propose we do that?
  - JM: At the end – "reducing disparities from discrimination"?
  - AE: Yes. Or bias. Bias is all-encompassing, beyond racism.
  - AS: That is a good point. "Stigma & bias" is all-encompassing, so even though we have focus areas – these are things we will focus on - it does not mean we will not look at areas outside of that.

- JM: Clarified that she is not suggesting to put "racism" in there, rather put in the active verbs acknowledging that discrimination does not just happen i.e. call out the fact that health systems are creating disparities.
- AS: Will make a note of that. Thank you.
- JM: Not sure what word to use, but put in the active voice e.g. there are not slaves, there were people who were enslaved.
- AS: Good point – same thing we are trying to do with language. That is why we are using the correct pronouns & when we speak to people, we talk about the conditions vs calling them addicts or alcoholics.
- SL: We could say "reducing health-created disparities"?
- AE: Or say, "reducing disparities created by x, y, z".
- — LAC joined the discussion (from another meeting). New Board member. She commented on significance of racism in healthcare delivery & link to poor outcomes.
- LAC: Noted that equity issues are the way things are & should be fixed. Disparities are when there are equity issues created by structures that are imposed by people. Disparities, by definition, are inequities that are created by policies & things that we do.
- JM: This came up at the Safe Table when Dr Danielson noted that there are disparities caused by racism.
- LAC: Disparities are more intentional; they are created by policies societies have made & that is what is locking people into these inequities. Got this from Dr Danielson.
- JM: It was a complex conversation. Filled LuAnn in: the heart of the conversation is we are deciding if we should add anything to the last word of the text in green (proposed new mission).
- AS: We are talking nuance now. In trying to wordsmith this, I considered what LAC just said, which was specifying that these are caused by policies & practices, but, like you said, it is inherent in "health disparities"; at least when it is spoken of, that is what people will talk about, that is where people's minds will go. It is policies & practices that create those health disparities.
- LAC: Right.
- AS: It is tricky because we want the balance of having all these important points put in, but also, we do not want it to get too wordy.
- LAC: Agree.
- AS: The wordier this is, the more the message is lost & people will not look at the statement. Even us. It is going to be "that big blob of words".
- LAC: Right. I think that is good. The goal is to illuminate health disparities.
- AS: This is why we changed the language to "build recognition", because it is a step up from just raising awareness. If you are aware of it, do you recognize it is an issue. And then what?
- LAC: Yes. I like that. Building recognition is very good.
- AS: Asked for group to send in chat or email if they have anything else to add. We will take that into consideration when preparing for the next meeting.
- LAC passed out event information. Naming Racism in Real-time: Can You Handle the Truth? https://kcmsociety.org/

- **Focus Areas:**
  LGBTQIA+ Healthcare: Taking another look

- AS: Take another look at this wording. Not convinced that everybody really confidently understands what LGBTQIA+ stands for. I would like for us, as a group, if we are to lead this work, to really understand what we mean by this. Had mentioned before that a lot of people do not know what the "I" or "A" or "+" stand for. In looking up the definitions, I realized "A" could mean Asexual or Allosexual; or Allies. What do we mean by this? My take is we do not need the Allies part, because they are not the ones who need the focus from us, from a stigma & bias standpoint. So, I am thinking "A" is for Asexual. Allosexual is not a sexual identity. Am I making sense?
- AE: Yes.

- AS: The definitions are important. If nothing else, we can help make this acronym more mainstream, so people understand the minute you say, "LGBTQIA", what we mean. Biggest qs is: What is the "+".
- AE: Always thought that the "A" was Asexual & the "+" was the Ally community.
- AS: Same. Some people say that, but there are differences in understanding. If we are going to say that this is our focus area, then we need to blast that LGBTQIA+ means ___.
- JM: Pushed back. Do not think it is up to this group to decide what the acronym stands for. The LGBTQIA community has a lot of opinions about it. What I see as the conversation that is important for us to have is: when we are talking specifically about healthcare, the conversation about whether "A" stands for Allies or Asexual is important because it could impact healthcare. Beyond that, I do not think it is our place to declare even what we think it means.
- AS: Ok. Showed a link to ok2bme.ca web site: "WHAT DOES LGBTQ+ MEAN?" Asked the group what they thought. Think this is one of the best resources available on LGBTQ. https://ok2bme.ca/resources/kids-teens/what-does-lgbtq-mean/
- LAC: We should use what is accepted in the community. Think that there are so many letters because they are being inclusive. It is a matter of inclusion. If the community thinks that this should be the letters that represent them, then that is what we should do. We should not say we do not want the "I" or the "A" i.e. say we do not want to be inclusive.
- AS: Let me address that. If you look at the link, the reason I like it is this is the first time I am seeing what all the "+s" can stand for. Actually, this one says it should be LGBTTQIAA, then there are 6 +s. It opened my eyes. **Propose:** We collect these definitions & put in our Resources what they can stand for – everything they can potentially stand for; to your point. My point with the focus area – for our definition, in our planning document only – is that: Allies will not be our focus, when we are talking about discrimination. If you disagree, if you have a really good reason, please tell me; this is an important discussion. The focus is on the actual members of the LGBTQIA+ community. Allies are important, but not the focus of our work in talking about stigma & bias.
- LAC: V impressed with how big this umbrella is. There is probably room for everybody under the umbrella; good because most of us are stuck in this puritanical image which does not really fit anybody. This is great.
- AS: Let's vote. Do we want to keep it LGBTQIA+ or LGBTQIA?
- JM: Vote for exactly as you have it, with the "+".
- LAC: Like that too.
- AS: Ok, we are keeping this. Thank you.
- LAC: Think it is more generous & it is what the community is using.
- AS: Actually, the original document only had LGBTQ. Suggested we add the "I", "A" & "+". It was embarrassing for me that I did not know what these other letters stood for. Had to look it up.
- LAC: It is good that you looked it up.
- Group decided to keep focus area #1 as LGBTQIA+.

Including Mental health as a proposed new focus area

- AS: Mental health: potential 2nd pandemic. Coming across never-seen-before posts on social media of people sharing their sense of hopelessness, overwhelm & feeling like they cannot go on with life, on hiking groups etc. Shared that people around me breaking down, worried about testing positive for COVID, going through depression. In the blog I wrote last August: the numbers are staggering.
- AS: Suicide is a sub of that. We pulled it out in recognition of its significance & the rise in cases. With recent developments, propose we add/include mental health as a priority.
- AE: Propose using behavioral health, or behavioral health & mental health. Mental health is more specific – it is the psychological aspect. Behavioral health broader – includes substance abuse disorder & other BH issues. Be specific? Or broaden the language?
- Anita reviewed history from 2020. Group started out with behavioral health as a focus. We felt that behavioral health is a broad topic. (This may be in the meeting minutes?) Qs came up: What exactly

under BH do we want to focus on? We pulled out mental health as a specific sub-topic & then parsed it out some more & decided to address suicide prevention.

- AE: Thought we were thinking about the stigma around opioid use disorder. When Ginny & I brought this as a topic way back when, we were thinking specifically around stigma of addiction & dependence.
- AS: I remember that. The discussion that ensued was that this was too broad a topic for us to be able to focus on. Look at what we did last year. We had LGBTQIA+ Health & Suicide & we ended up focusing on LGBTQIA – we did a decent job – but we barely touched suicide. I would caution against going back to too broad of a focus area.
- AE: Wonder if mental health & suicide are too similar.
- AS: Valid point. Asked if anyone can remember why we pulled out suicide.
- AE: Because the suicide rates are skyrocketing. Do we need mental health AND suicide prevention? Or do we want to change it to suicide prevention & something specific within BH related to addiction & dependence?
- JM: What is the stigma & bias aspect of suicide that we are trying to address?
- LAC: Think it is more a stigma of mental health, because if people are depressed, they do not feel safe to bring that up to their providers; they will be judged. Suicide is a stigma for survivors. They do not get the compassion others get for other reasons. Suggestion: Mental health/suicide? Add substance abuse disorder as another focus area.
- AS: Shared perspective of faith. In her community, it is a total taboo topic – more for suicide, but also mental health. Hardest thing about broaching this topic is people correlate mental health issues with a weak faith i.e. you need to pray. Attempting/committing suicide is a big sin. Some will not attend the burial of a person who committed suicide. Such is the stigma. In Christianity, there are people who share those beliefs. They are branches of the same tree.
- JM: See it as addressing stigma & bias in mental health to prevent/reduce suicide.
- AS: Not just to prevent suicide.
- JM: What are we as an organization trying to do, if we are addressing stigma related to suicide? The word is "suicide prevention". Are we trying to prevent suicide? Or are we trying to address stigma associated with attempts & death by suicide?
- AS: Good question. [Almost out of time.] This is an important topic. We can continue at the next meeting. Please think about this between now & then.
- LAC: Reiterated adding substance use disorder, because there is huge stigma & bias associated with that. The assumption is that it is people's fault. Why can you not just stop?
- AE: People need to recognize that opioid abuse disorder is a brain disease. It is a disease, like diabetes or cancer.
- AS: Agree.
- LAC: Whether we get to it or not, at least it is on the list as something that needs to be addressed. SUD-related stigma can negatively impact mental health, contribute to suicide, etc.
- Anita reminded group we have limited bandwidth. Last year, we had 2 focus areas: LGBTQIA+ Healthcare & Suicide Prevention. Now, we are talking about mental health, substance abuse & disability. If we start parsing & pulling stuff out, then there is racism… Each of these is important, but we cannot make all of them focus areas, if we are to be effective. We are a group of really 3 people; Steve & Nick wear many hats. Keep in mind we are a small group.

Next Steps & Other Items

- AS will list potential focus areas (per today's discussion) & ask group to vote on 2, max. 3. SL to send email out. Voting to be done between meetings. Group to confirm final selection at March meeting.
- LAC: Mentioned program on racism in medicine at the King County Medical Society: kcmsociety.org on Feb. 23 – Naming Racism in Real Time: Can You Handle The Truth? SL will share info.

- SL: What criteria are we using to determine what we are listing as our focus? One of the criteria we really need to consider is ability to get something done. It is great to list intentions, but it is another to list things we can accomplish.
  - AS: Good point.
- SL: We do not have to feel like we are neglecting something if we do not list it. We are just not putting it in our shopping cart right now.

Next Meeting: March 18, 2021

Meeting minutes prepared by:
Steve Levy
Anita Sulaiman