CAB Conference Call May 26, 2022 12:00 ET Meeting Minutes

Participants:

Andrea Jacobi Medical Center

Anisa Harvard T.H. Chan School of Public Health
Claire Harvard T.H. Chan School of Public Health
Eduardo Harvard T.H. Chan School of Public Health
Exzavia Children's Diagnostic and Treatment Center

Falon University of Colorado, Denver

John FSTRF Westat

Kimbrae Texas Children's Hospital **Kylie** Texas Children's Hospital

Liz Harvard T.H. Chan School of Public Health Mandy Harvard T.H. Chan School of Public Health

Megan Westat

MelodyNew York University School of MedicineMonaUniversity of Alabama, BirminghamRosalvaUniversity of California, San Diego

Vanessa Harvard T.H. Chan School of Public Health

Veronica University of California, San Diego

• APPROVAL OF MINUTES

The minutes from the April call were approved with no changes.

SELF-CARE SPACE

Liz led the self-care space.

DEFRIEFING FROM THE SPRING 2022 VIRTUAL NETWORK MEETING

Megan talked about the Network Meeting.

Day 1 was focused on sleep and included the following sessions/topics:

- Plenary speaker **Nancy Redeker** talked about "Conceptualizing and Measuring Sleep in Community Populations: Design Considerations"
- The HECC presented an Interactive Community Session on Sleep
 - The session used polls and whiteboards
 - o Task Force and PUG members submitted quotes for the presentation about:
 - How much sleep they had the night before
 - Sleep quality
 - What affects their sleep

- After the two sessions on sleep, there were breakout sessions split into 3 groups: 1) Sleep in Adolescents and Young Adults; 2) Sleep in Pregnant Women; and 3) Sleep in Postpartum Women and Young Children.
 - o Each breakout session discussed the following questions:
 - What factors predict sleep in this age group, and how is PHACS positioned to address these?
 - What outcomes does sleep affect in this age group, and how is PHACS positioned to address these relationships?
 - How can PHACS incorporate community priorities and perspectives in addressing sleep?
 - Sleep in Adolescents and Young Adults
 - Claire mentioned that the discussion focused on Adolescents and Young Adults circadian rhythm. Circadian rhythm is like the body's natural clock. It helps tell us when it's time to sleep. Their rhythm sometimes does not match with their responsibilities (e.g. getting up early for school).
 - School and work could affect their sleep. There is lot of catch up sleep.
 - ART side effects could impact their sleep
 - Medications can cause insomnia.
 - Medications can change how they dream. For example, not dreaming in color.
 - Medications can make someone need to use the bathroom more than they normally would.
 - The group talked about making tips and an info sheet for better sleep
 - PHACS should be sensitive on how to disseminate this information.
 - People could feel stressed trying to follow the tips. Factors affecting their sleep could be out of their control.
 - Megan mentioned that feedback from community members is important to create an info sheet with tips for better sleep.
 - Sleep in Pregnant Women
 - Veronica mentioned that they discussed the possibility of using hair samples collected from SMARTT moms during pregnancy. A study could analyze medication concentrations in hair of pregnant women who have trouble sleeping.
 - Sleep in Postpartum Women and Young Children
 - **Kim** mentioned that they talked about the following:
 - Barriers to sleep.
 - Megan mentioned that new parents monitor their child's sleep which can in turn be affecting their own sleep.
 - Safe place to sleep. Healthy bedding.
 - Issues with using Fitbit on studies
 - Young participants feeling uncomfortable using the Fitbit when sleeping.
 - Megan said that it is important to consider the community perspective. Test the use of wearables like Fitbits with community members.

Day 2

- Status of PHACS/HOPE Research projects
 - SMARTT
 - o AMP Up/AMP Up lite
 - TERBO BRAIN
 - o HOPE
- New funding initiatives

<u>Day 3</u>

- Working Group and Task Force updates
- · Session on geocoding

Recommendations for future PHACS network meetings:

- **Veronica** suggested to have Spanish translation during the meeting for the benefit of Spanish -speaking community members and staff
- **Megan** encouraged the CAB members to fill out the post-meeting evaluation. The email with the link was sent on Monday, May 23.

PHACS CAB NEWSLETTER, JULY 2022 EDITION (ARTICLE BRAINSTORM FOR "MIGRATION" THEME)

Megan talked about the theme for the next CAB newsletter, "Migration". Topics around the theme could include:

- Migration of studies from older versions to new versions
- Personal migration either external or internal
 - External: moving to new places
 - Internal: parenting
- Migration of ARV medicines though the years

Ideas for articles:

- **Kim** suggested a question to site staff: What new medical discovery/progression had occurred on their site? Also, she suggested including drawings of people as a child and adult to show how they have changed; how their mindset had changed.
- Claire suggested several questions
 - o Migrations within a journey of living with HIV? Or disclosure?
 - o How someone has changed from when they were younger?
 - o Have they moved to a different part of the country or world?
- Self-care related to the topic.

• SITE CAB CHECK-IN

Megan asked about local CAB experiences:

- **Veronica** mentioned that families at her site want to participate in get together activities. Those activities can't be organized until COVID cases decline.
- **Kim** mentioned that they are organizing a small CAB activity. Anyone that wants to participate in-person needs to have their COVID vaccines. Those who are not vaccinated can participate virtually.

• HECC UPDATES

Mandy presented the TERBO BRAIN logo and received positive feedback from the CAB.

NOTE: The next CAB call will be June 23, 2022 at 12:00 PM ET.