Bree Collaborative | Reproductive and Sexual Health Workgroup

May 6^{th} , 2020 | 2:00 – 3:30

Held Remotely Due to Covid-19

MEMBERS PRESENT

Charissa Fotinos, MD, (Chair) Deputy Chief Medical Officer, Washington State Health Care Authority

Leo Gaeta, Vice President of Programs, The Columbia Basin Health Association

Heather Maisen, MPH, MSW, Family Planning Program Manager, Seattle King County Public Health

Cynthia Harris, Family Planning Program
Manager, Washington Department of Health
Ivanova Smith, Patient Advocate, Self-Advocate
Faculty, University of Washington LEND
Program

Angela Chen, MD, Obstetrics and Gynecology, EvergreenHealth

Catherine West, JD, Staff Attorney, Legal Voice Giselle Zapata-Garcia, Co-Director, Latinos Promoting Good Health; Executive Committee Co-Chair, Latinx Health Board

Mandy Weeks-Green, Senior Health Policy Analyst, Officer of the Insurance Commissioner

Janet Cady, ARNP, Medical Director of School Based Program, Neighborcare

STAFF AND MEMBERS OF THE PUBLIC

Ginny Weir, MPH, Bree Collaborative
Alex Kushner, Bree Collaborative
Amy Etzel, Bree Collaborative
Cara Bilodeau, Public Policy Manager, Upstream

Trish Anderson, Senior Director, Safety and Quality, Washington State Hospital Association

CHAIR REPORT AND APPROVAL OF MINUTES

Charissa Fotinos, MD, Washington State Health Care Authority, and Ginny Weir, MPH, Bree Collaborative welcomed members to the workgroup and those present introduced themselves.

Motion: Approval of April 1st minutes *Outcome*: Approved unanimously

Ms. Weir told the group that the day's meeting would be focused on people with disabilities. She also shared relevant WHO guidelines, "Promoting sexual and reproductive health for persons with disabilities."

PRESENTATION: TRUE INCLUSION IN PARENTING BY IVANOVA SMITH

Ivanova Smith, Patient Advocate, Self-Advocate Faculty, University of Washington LEND Program, presented on her experience receiving reproductive health care and on her recommendations for the future.

- One of the focuses of the presentation was parenting rights for parents with intellectual disabilities.
- Education is vital. Children with intellectual and developmental disabilities (IDD) need the same education about sex and puberty as anyone else.
 - o Intellectual age theory is wrong; people with intellectual and developmental disabilities are not mentally stuck as children; they grow up and need appropriate education.
 - Many people in the IDD population are not receiving appropriate sexual education, and the media gives false/harmful information to this community.

- Support and encouragement for IDD persons seeking reproductive healthcare:
 - Support people with IDD in making informed, adult decisions and encourage safe actions—this is called Dignity of Risk.
 - People with IDD can have healthy relationships with people without IDD.
 - Ms. Smith was afraid of having children based on stories she had heard in the media about parents with IDD losing children.
- Person-centered planning was a highly useful tool for Ms. Smith during her pregnancy. The
 pregnancy was difficult, but also brought her a lot of joy.
 - She encountered health care providers who were supportive, and others who were not.
 - She brought her extended support network with her to the recovery room in order to feel safe.
- Ms. Smith emphasized the importance of not taking away children with IDD from their parents.

Action Item: Ms. Weir to send out link to video that Ms. Smith wanted to show with presentation.

- Ms. Smith discussed PAVE, a parent advocacy group that supports parents of children with IDD.
 They have also begun working with parents who have IDD themselves.
- Dr. Fotinos asked Ms. Smith how healthcare providers can behave respectfully towards patients with IDD. Ms. Smith said that she felt pressured by her providers to choose abortion.
- Ms. Weir asked about early education. Ms. Smith said that information needs to be more accessible to self-advocates who cannot read.
- Consent is also very important: persons with IDD have a history of being sexually assaulted, including within the medical community. Education about consent can also protect persons with IDD from learning incorrect notions of consent from media and other sources and potentially breaking the law.
- Dr. Fotinos asked how the hospital staff treated Ms. Smith when she presented in labor.
 - The doctor was great, but she had issues with nurses and other staff who were dismissive and laughed at her. These people were also confrontational when she offered suggestions for how to help her child eat after birth.

GENERAL DISCUSSION

- Ms. Weir asked the group if it was still satisfied with the four focus areas in the charter: access, patient-centeredness, appropriate care, and cultural sensitivity and being humble. The group agreed that these areas are still helpful.
 - Heather Maisen, MPH, MSW, Family Planning Program Manager, Seattle King County Public Health, said that the Access category could be more explicit about cognitive accessibility.
 - "Cognitive accessibility" was added to the draft in the "Access" row in Table 1.
 - In the Patient-centeredness row, Janet Cady ARNP, Medical Director of School Based Program, Neighborcare, suggested adding "involving family if desired by the person". This was added.
 - Catherine West, JD, Staff Attorney, Legal Voice, suggested changing the language of the bullet reading "disorders of the genital organs" in the Appropriate care row.
 - The group decided to add a bullet reading "Prevention, screening, treatment or referral for reproductive health conditions (e.g., USPSTF cancer screening, STIs)" to this row to cover cancer screening.
 - The group discussed how to rephrase "disorders of the genital organs" so that it would not stigmatize trans or intersex patients while still capturing medically

dangerous disorders and cancers. Agreed to continue working on this language between sessions.

- Added "free of coercion or provider bias" to the "Cultural sensitivity and being humble" row.
- Ms. Weir reviewed the different sections that the future report might be divided into. A
 member commented on the "primary care provider" section.
 - There are many trusted providers outside of primary care in the realm of reproductive and sexual health—the group should broaden that category. For example, family planning organizations such as planned parenthood and other non-profits. A large percentage of low income women go to these organizations, and are not receiving primary care there.
 - First bullet of "Patients and Family Members" changed to "find a health care provider".

Action Item: Ms. Weir to send out the draft document so that members can provide edits and changes between now and the next meeting.

- The final group for the workgroup to discuss is victims and survivors of violence. Ms. Weir asked for suggestions on how to approach this population.
 - Dr. Fotinos mentioned needing to include recommendations for victims and survivors of sexual trafficking and victims of abuse from people who they are close to.
- The group gave suggestions of people to contact to participate in the next discussion:
 - Sexual Violence Law Center
 - Washington State Coalition Against Domestic Violence; specifically Leigh Hofheimer
 - King County Coalition Ending Gender-Based Violence
 - Terry Stewart from Harborview Sexual Assault Center

Action Item: Trish Anderson Senior Director, Safety and Quality, Washington State Hospital Association, will connect with Ms. Weir to give recommendations; Ms. Cady will connect Ms. Weir to Terri Stewart.

- Dr. Fotinos asked about the increase of partner violence due to shelter in place. Ms. Cady to share resources on telehealth in this context.
 - Ms. Maisen spoke about the self-administered Depo-Provera work that the HCA is doing and will follow up with them.
 - Ms. Cady also added that mail order pharmacies being able to mail medication would be huge right now for those experiencing partner violence.

GOOD OF THE ORDER

Dr. Fotinos thanked all for attending and adjourned the meeting.