



Summary-COC-ES Meeting 03/11/20

- Welcome and Introductions
- Community Partner and Participant Updates
 - Amanda Mosley Communicable Disease Nurse from the Talbot County Health Department spoke about COVID-19. At this time, there are nine cases in Maryland and none on the Eastern Shore. Reminders about precautions- use of hand washing and hand sanitizer, staying away from those who are sick and focus on gathering information from official sites. She said the State lab is now open 7 days /week and it will take an average of 2 days for results. The LHD's also take a viral panel and can order CXR. Plans for the homeless population are being explored. Changes in programming could be affected as we move through this situation.
 - Wicomico Health Department- may fund a camp for respite with additional funding (unspent salary dollars).
 - Regional day camp for diabetes (Type I and 2) is scheduled from 7/20-7/23 at MEBA (St. Michaels Rd). Contact Wynn Aroom at 410-822-1000 for more information.
 - Discussion about "attraction camps" which focus on a specific diagnosis. The discussion was related to the Brainy Camps offered by CNMC for children/ youth ages 9-17 years of age, which are overnight camps, held at the Blue Ridge School in St. George, VA. They average 6 days and 5 nights

and are diagnosis specific- Autism, Celiac Disease, CP, Down syndrome, Epilepsy, Heart Conditions, Hydrocephalus, NF, SCD, Diabetes and TY. The camps are staffed with genetic counselors, MD's, OT's, PT's, Psychologists, SW's and Nurses. Campers learn about their condition, partner to manage care, connect in peer support groups, and develop friendships and gain confidence and self-esteem. If you have an interest, you can check out the CNMC website or call 202-476-5142.

- Megan Meck from the MCDD, Maryland Center for Developmental Disabilities, a branch of Kennedy Krieger Institute, shared information about the PPMD LEADers Program and the MCDD Summer Series. She also shared that the legal seminar that was scheduled with law students to execute legal documents has been rescheduled to the fall with a date to be shared at a later date. Additional discussion focused on a possible collaboration with Mid-Shore Pro Bono to provide something similar.
- Cheryl Coleman-Kent County Health Department-recently hired the fourth nurse. Talking about transitioning program with the Benedictine that would involve a 6- week training. The community is receptive to this opportunity.
- Linda Mann, Special Needs Coordinator for Johns Hopkins Healthcare shared that they are in a bit of a transition phase related to recent changes of management staff. She remains the only SNC for the ES with Johns Hopkins Healthcare.
- Dorri Gowe-Lambert, owner and Director of Building Bridges in Easton-shared that she is currently working on staffing to

keep up with PT, OT and SLT needs for the area. The Easton office also offers a feeding group for sensory- based picky eaters.

They now have a satellite office in Salisbury that has OT and SLT. The SLT at that location is full and they have a waiting list. They also offer a social skills group in Salisbury for the pre-teen group (12-15) once per week.

She spoke about the infrastructure needed for telehealth services and is looking into that option if needed as the COVID 19 concerns expand. Dorri also shared some groups that are being considered-fine motor boot camp, handwriting and nature based groups.

- The parent of a young adult with Prader-Willi Syndrome shared her ongoing search for at least two other adults with PWS. He is currently in a group home setting in the Baltimore area, as there are no homes on the ES. If she could find two other individuals on the ES there would be funding for a house on the ES.
- Dr. Katherine Jones from BACIL spoke briefly before she had to leave. She wanted us all to know about the therapeutic pool they have on site. It is an 88-94 degree therapeutic pool, open 6 days per week staffed by a recreational and aquatic trainer. They have 24 hours per week of open swim, exercise programs targeting specific disabilities, a locker room and showers, peer to peer to support and a pool ramp and aquatic lifts. A yearly membership is \$360 for a family of six. They have scholarships-remaining two for veterans, 8 for

women's health (breast cancer) and 15 from the Dana and Christopher Reeves Foundation.

- The mother of a child with Sickle Cell Disease joined the group for the first time today. She started by providing a definition of the disease and reviewed the primary treatment measures. She spoke about the difficulties encountered by individuals with SCD and especially by children and youth. She then went on to detail difficulties on the Eastern Shore in particular. She felt the lack of pediatric hematologists, general lack of knowledge by PCP's school nurses and ER staff was a great impediment to providing the care that her child and others require. She is hoping to be able to connect with others and explore ways to collect information to develop more resources for families and increase education. She mentioned Beth Mertz, part of JHH hematology and her exploration of a satellite on the ES. At this point, the Hole in the Wall Gang Camp in Conn. was mentioned as a resource. (Free to campers who qualify and started by Paul Newman).
- Wynn Aroom from SRHS hospital in Easton. Updated us about the current changes at the hospital related to COVID 19-NO VISITORS less than 18 years old. Suspended all volunteers in the hospital, which has had a ripple effect and has slowed some services down so the all patients and families are asked to be patient. Only one visitor at a time in any room. Entrance to the building is now only via the Emergency Room located on the side of the building.

Offering the Safe Sitter training program. Anyone interested should contact Wynn at 410-822-1000.

- Mary Wontrop, Executive Director of the Maryland Epilepsy Foundation shared two tentative activities (pending decision related to COVID 19)-3/22 a bowling event and May 2, a Wellness Fair in Cambridge, MD. She also shared about HB 675 or Brynleighs' Act, which would require that at least two school staff are trained in recognizing the signs and symptoms of a seizure, administration of first aid, assist in or administer seizure medication etc. She said it was moving along well and encouraged anyone who was interested in supporting the bill to write a letter to their state legislator, especially those on the Lower Shore to Mary Carozza.
- Mary Adkins from the Talbot County Judy Center- shared that TCPS is cancelling all out of state trips at this time, they are continuing with their play groups which are held at the Easton at the YMCA, twice a week on Monday and Thursday. She said they have 136 Infants and Toddlers who participate who are not in any other program. This is beneficial to the child and helps alleviate parent isolation.
- Sharon Ritter-Beall- invited those who have not had a chance, to visit Bitty and Beau's Coffee Shop at 124 Dock St, Annapolis, MD. It is one of several locations, the first in Wilmington, NC. It was started by Bitty and Beau's parents for people with ID/DD to have a place to work. Nationwide, 80 % of individuals with disabilities are unemployed. The original shop employed 19 employees all with ID/DD. Bitty and Beau have Down Syndrome. They currently employ over

80 individuals with disabilities at their various locations. You can get more details at www.bittyandbeauscoffee.com. Sharon also shared that there is currently a push to develop more of a legal structure for supported decision-making. Additionally, she mentioned the SECURE Act recently signed into law. It relates to beneficiaries of IRA's. If a beneficiary of an IRA is a person with a special need (and certified as such at the time of the IRA holders death) distributions would be paid out over the beneficiary's life (rather than within the 10 years per the new rules in the SECURE Act).

*Speaker- Paris Quillet-Empower Me Program see attached

Kenny Eck-Patient Sortal and Shantia Fitzgerald-Sickle Cell Association of America who were also scheduled to speak were unable to attend to meeting. Look for them to be re-scheduled for a future date.