

Maryland Respite Care Coalition

Meeting Notes: October 16, 2018

Members in attendance: Mary Chaput, Hailey Davis, Naomi Duffort, Betty Jones, Cheryl May, Shayla Mitchell, Mary O'Brien, Linda Ramsey, Dee Scharff, Leah Schryer, Chris Stewart, and Melissa Wright Powell.

Guest: Paulette Roseboro

I. Welcome and Introductions

II. Old Business:

- ❖ Minutes from July 17, 2018 were reviewed. Mary moved to approve/seconded by Betty. Minutes were approved.
- ❖ Membership: Linda stressed the need for more contributing members who will actively participate on a regular basis; this is the only way MRCC will be able to achieve its goals. General members are those who may not be able to participate in meetings regularly; but are committed to the mission and goals of MRCC providing resources, support, and expertise as needed. Members discussed having other State agencies join MRCC such as Office of Genetics (Monica Bacardi), and Maryland Department of Disabilities.
- ❖ MRCC Secretary position is still vacant; Linda asked members to consider taking on this role. While the duties of the position may grow over time, the primary role is to take notes and review with the Chair and/or Vice Chair for distribution to membership.

III. Update on Emergency Respite Care in Maryland

Naomi shared news about the Emergency Respite Care program which provides an annual grant of \$225 for emergency assistance for individuals with special needs, living in community across the age and disability spectrum, in or out of their homes, by qualified care workers in order to provide relief for their families or informal caregivers. The program is administered by the Elizabeth Cooney Agency (Elizabeth Weglein), a home health-care agency. Families can pre-register for the grant so that the paperwork is on file ahead of time when and if they need to seek assistance. As of July 30, 2018: 50 families have received services; 50 families have pre-registered. They are looking at revamping outreach activities to ensure greater participation. Chris suggested connecting with AAA (Area Agency on Aging) conferences.

Discussion concerning the difficulty families are facing when caring for family members, particularly when dealing with state regulations and understanding how to work within the system. For example, currently there is an 8-year waiting list for families who need a waiver for assisted living/Medicare services. Definition of respite services depends on field or area of professional services, i.e. mental health field uses a different definition or criteria which impact a family's ability to access support.

IV. Funding/Building the MRCC Budget

Linda opened the discussion emphasizing the need for MRCC to begin looking at funding to support its efforts. For the past year, MRCC activities are supported through in-kind resources

from several agencies, particularly Maryland Family Network (Linda), Maryland Center for Developmental Disabilities (Christine), and Anne Arundel County/Aging (Mary). During the first year, DHS provided support through a student intern. Group discussed possible options for soliciting financial support; however there was consensus that MRCC must first establish objectives with specific projects to be accomplished in order to solicit funding for support. It's important to define what MRCC plans to do with resources before making funding requests. Suggestions included Office of Genetics (interested in respite services), Christopher Reeves Foundation, etc.

Linda suggested planning for a retreat using the World Café model as a strategy for determining MRCC's projects and funding opportunities.

- V. **Special Presentation: Prince George's County Community of Practice – Supporting All Families.** Paulette Roseboro shared her family background with the group, particularly her advocacy role as a mom working to secure services for her daughter, Brianna. Paulette's career spans from government to the private sector giving her a wealth of information about systems and processes for securing services. She shared struggles and challenges faced by many families who do not have the information to successfully secure needed services for themselves and their family members. Families must be empowered with information. The Prince George's Community of Practice includes self-advocates, family members, public and private stakeholders committed to building capacity across and within the County to create policies and practices to enhance the lives of individuals with intellectual and developmental disabilities (I/DD) and their families. Local communities of practice are guided by local leadership (in this case, Paulette), who remain connected and typically meet by-monthly to identify areas of priority, develop strategies for next steps, collaborate and inspire each in ways that lead to changes in policy and practices that better support families across the lifespan. Paulette stressed the importance of getting faith-based organizations, businesses, entertainment, and other fields involved in the effort.

VI. **Announcements:**

- ❖ Check out **The Gathering Place** to be launched on Sunday, November 4th, a program specifically designed for Adults with Special Needs. The group will meet every Sunday afternoon at Cresthill Church, 6510 Laurel Bowie Road. Website: thegatheringplacemd.org Please contact Pastor Tommy at 301.807.5947
- ❖ **Kinship Navigation Program** meeting to be held at Spring Grove Hospital (Mitchell Building – 1st Floor Conference Room) on Monday, October 22, 2018 at 9:30 – 11:30 AM.
- ❖ **ARCH** is seeking exemplary and innovative respite care services from across the nation. ARCH is also seeking respite services that use outstanding or innovative person and family-centered approaches to respite or work to improve quality of services. If you know of a respite service that is exemplary or innovative, please contact www.archrespite.org
- ❖ **2019 National Lifespan Respite Conference, entitled Illuminate Respite** will be held April 30 – May 2, 2019 in Buffalo, New York.