

Rare Disease Council Quarterly Meeting: Wednesday, February 15, 2023, 10:00 AM – 2:00 PM
Meeting Location: All-Virtual Meeting (Zoom)

Council Members Present (*ex officio members italicized*): Dr. Lisa Kaplowitz (Chair), Jana Monaco (Vice-Chair), Ijeoma Azubuko, Wes Fisher, Dr. Michael Friedlander, Dr. Stephen Green, Dr. Peter Kasson, Susan Klees, Dr. Richard Nicholas, Megan O'Boyle, Sarah Paciulli, Elissa Pierson, Dr. Stephen Rich, Elisabeth Scott, Dr. Tiffany Kimbrough, Dr. Samantha Vergano, *Dr. Samantha Hollins, Jennifer Macdonald*
Council Members Absent: Gregory Josephs, *Dr. John Morgan*
Virginia Department of Health (VDH) Staff Present: Lauren Staley

Meeting Minutes

Council Business: The Chair called the meeting to order, VDH staff conducted the roll call, and the Chair confirmed the Council met the requirements for a quorum. The Chair reviewed the agenda, and the Council approved the 11/29/2022 draft meeting minutes with no objections. The Chair shared that since today's Council meeting was all-virtual, the next meeting would be an in-person meeting and would require an in-person quorum for the Council to conduct business and asked Council members to make every effort to attend the meeting in person. Council members discussed challenges with meeting an in-person quorum, and the Chair and Vice-Chair offered to approach Delegate Murphy on the Council's behalf to see if changes might be possible for in-person quorum requirements for the Council. The Council reviewed the updated draft of the Electronic Meetings Policy for in-person and all-virtual meetings and voted to not adopt the updated draft policy at this time; 11 voting members voted to not approve, 1 voting member voted to approve, and 4 voting members abstained from voting.

Discussion on Medicaid Waivers: Ann Bevan started the discussion on Medicaid Waivers, sharing that she works for the Virginia Department of Medical Assistance Services (DMAS) in the Division of High Needs Support, which includes waiver services. She provided a summary of the way waivers have changed over time, including accounting for individuals accessing services in different ways and more consistency with waiver redesign, moving to a community-focused system that is person-centered, needs based, and includes data for accountability, assessments, and prioritizations. Ms. Bevan provided Council members with a definition of a waiver, describing that waivers waive standard Medicaid eligibility requirements and are outside of the general state Medicaid plan. Waivers are special programs designed to address particular needs and may waive some financial eligibility criteria (example, for dependent children) that would normally apply for the general Medicaid program. Ms. Bevan then shared information about four specific waivers in Virginia: three Developmental Disability (DD) Waivers and the CCC+ Waiver. She shared that there are about 15,000-16,000 individuals in DD Waivers currently, and about 35,000 in the CCC+ Waiver.

The *Building Independence Waiver* is a DD Waiver for individuals age 18 and over living independently in the community that need some supports to help them live in their own homes. Services might include matching with rental subsidies, promoting independence and skill-building, assistive technologies, or environmental modifications. The *Family and Individual Supports Waiver* is a DD Waiver for children and adults living with families, friends, or in their own home, who need a bit more support than the prior waiver. Services can include medical or behavioral needs, as well as in-home supports such as personal care, respite, and assistive technologies. The *Community Living Waiver* is a DD Waiver that includes 24/7 care, though not everyone receives 24/7 care. Services include residential supports, non-medical supports such as personal care, and complex medical and behavioral support needs. Most services are certified or licensed, though there may be options for some consumer-directed services not hired through an agency. The *CCC+ Waiver* is a more medically focused model for

individuals that need a nursing facility level of care, whereas the three DD Waivers meet an ICF (Intermediate Care Facilities) level of care.

Ms. Bevan next spoke about eligibility factors for DD Waivers. An individual must meet diagnostic eligibility by having a diagnosis of a developmental disability. An individual must also meet functional eligibility as defined by the VIDES (Virginia Individual Developmental Disability Eligibility Survey). Additionally, an individual must meet Medicaid financial eligibility criteria, and must be willing and able to accept services within 30 days if offered a slot in a specific waiver. Ms. Bevan shared that waivers share one waiting list, prioritized into three needs-based categories, and that about 14,000 – 16,000 individuals are currently on the waiting list. To access DD Waivers, Ms. Bevan shared that individuals would typically go through a Community Services Board (CSB), which would do intakes, determine eligibility, and send information to the Virginia Department of Behavioral Health and Developmental Services (DBHDS) to be added to the waiting list.

Heather Norton, from DBHDS, joined the discussion, and shared that her organization is working with individual and family support programs, developmental pediatricians, and other stakeholders, to identify ways to help connect families to the system and to refer them to CSBs for a CCC+ Waiver. Ms. Norton welcomed additional stakeholder ideas from Council members, and mentioned the My Life, My Community Virginia website as a resource for information. Ms. Bevan also mentioned that families look to advocacy organizations like The Arc and other families as sources of information. Ms. Norton and Ms. Bevan continued the discussion by speaking about CSBs re-assessing individuals on the waiting list and in the waivers annually, or more often, if needed. A supports intensity scale helps to identify areas where a person might need certain services, and what types of services might best support them. These scales help to translate into reimbursements for providers, based on each individual's need. Council members shared individual experiences with waivers and challenges when children age out of supports provided by the educational system, as well as challenges with different systems not working together. Ms. Norton shared that DBHDS is working on a project geared towards transitioning of records from education to adult services to improve information that reaches the Department for Aging and Rehabilitative Services to help make the transition from pediatric to adult services smoother.

Rare Disease Day 2023 Presentation: The Vice-Chair next introduced Annissa Reed, State Policy Manager for the Eastern Region of the National Organization for Rare Disorders (NORD). Ms. Reed shared that NORD was established in 1983, was instrumental in the Orphan Drug Act, and supports over 300 patient organizations to address the needs of the rare disease community through education, information, and policy initiatives. One of NORD's resources is a Rare Disease Database that provides continually updated information about specific rare diseases for patients and providers in non-technical language. NORD also created Patient Assistance Programs in 1987 to provide services and support to patients and families with rare diseases, including help with obtaining medication, financial assistance with premiums and copays, diagnostic testing assistance, and travel assistance for clinical trials or specialist consultations. A Patient Services and Information Services Team is available to assist patients and families throughout the week. Ms. Reed next reviewed NORD's efforts to establish Rare Disease Advisory Councils in each state, as well as NORD's 8th annual state report card, which includes a report card for Virginia based on data as of November 2022, which she indicated could serve as a potential resource for the Council.

Ms. Reed then spoke about Rare Disease Day, which is on the last day of February each year and is a patient-led international awareness campaign that highlights the challenges of over 300 million people impacted globally by rare diseases. Rare Disease Day started in 2008, and this year's theme is health equity. NORD is the official US sponsor, as a partner with EURODIS: Rare Diseases Europe and other national alliances and health equity advocates. Ms. Reed shared some of the events that have helped to draw attention to rare diseases over time, including the #ShowYourStripes campaign and Light

Up for Rare. The Vice-Chair also shared that she is the state ambassador for the RareAction Network for Virginia, which is another resource for individuals to become involved with rare disease events.

Public Comment Period: No one provided comment during the public comment period.

Breakout Sessions, Group Discussion, and Action Plans: After a lunch break, Council members each chose to participate in one of the following breakout sessions: *Resources/Education*, *Data Collection*, or *Strategic Planning*. Council members then reconvened after the breakout sessions to share findings with the full Council. Members in the *Resources/Education* group shared that the Council could be a resource for patients, families, and providers to find information, including where to go for a rare disease, how to get information needed for care and treatment, as well as the importance of educating providers and coordinating resources for families and patients to help reduce barriers. Members also suggested the Council could help to identify gaps or areas needing improvement across the lifespan and across Virginia, including through resources such as academic health centers. Members also mentioned the Council could work to connect patients with trials and organizations that provide families with financial or transportation assistance, as many may not know about these resources otherwise. They would like to see the Council become an everyday resource for the medical field and families in Virginia.

Members in the *Data Collection* group shared that they primarily discussed the option of a survey, including the need to identify survey goals, who to survey and how to reach them, survey content, and survey length. Members mentioned some potential goals of the survey could be to identify the needs of the rare disease community in Virginia, areas for improvement, and how the Council can best serve as a resource. Members shared that the target audience for the survey could include patients, families, caregivers, or medical professionals, and could address potential issues such as lack of providers, traveling to see providers, access to care, and lack of knowledge about specific disease states and symptoms. Members expressed interest in reviewing surveys from Rare Disease Advisory Councils in other states to serve as a reference point.

Members in the *Strategic Planning* group shared that they primarily focused on addressing policy issues. Initial goals would be to gather information from the community first to set priorities, perhaps through a survey or evaluation, engaging the rare disease community through patient organizations and advocacy groups, integrating attendance at hearings or meetings, and creating partnerships with institutions looking at rare diseases. Members also spoke about raising awareness for the Council, Rare Disease Day and health equity, and identifying potential sources of funding.

Council Business: The Chair invited Council members to provide updates, and the Vice-Chair shared information about a bill in the General Assembly about the Interstate Medical Licensure Compact and that Medicaid service providers can no longer provide clients with virtual visit options. Council members discussed if either topic might be a future potential policy issue for the Council to explore. The Chair then invited Council members to propose agenda items for the next meeting. Members suggested presenters to talk about comprehensive care centers and national initiatives for rare diseases and offered to reach out to specific contacts. Members also expressed positive feedback about the use of meeting time for breakout sessions. VDH staff then invited Council members to provide recommendations for content to include in the Council's annual report before the next meeting so the Council can review a draft of the report at that time. After the Council concluded its discussion, the Chair adjourned the meeting.