



Health Care Providers Subcommittee Meeting Minutes

Tuesday, July 15, 2025

12:00 p.m. EST

Virtual

Welcome/Introductions:

The Chair, Anita Davis welcomed members to the meeting with opening remarks of working to achieve the business of the council. Meeting began at 12:03 p.m. EST.

The following members or designees were in attendance: Quorum not met

Anita Davis, PT, DPT, Brooks Rehabilitation (Chair)

India Holroyd, JD, MBA, Department of Agriculture

Colleen Barrett, DNP, BayCare

Guests and Staff:

Aleskia Fernandez, Radiology Physician Coordinator, Advent Health

Jon Conley, Strategic Initiatives Manager, Department of Health

Yolanda Bonds, Council Coordinator, Department of Health

Kristin Craze, Contractor, Department of Health

1. Discussion Topics:

a. Define the relevance of the subcommittee

Chair discussed the importance of the annual report and highlighted how the work of the subcommittees can drive the forward activities related to the council's annual report and the recommendations captured in that report. The members were asked to consider the report as the framework that can be used to plan a path in 2026.

b. Identify specific items from the 2025 Annual Report

The subcommittee members reviewed the recommendations from the 2024 Rare Disease Advisory Council Annual Report, relevant to the Health Care Providers subcommittee. They focused on the recommendations that they could focus on to try to accomplish in the year to come. The members present highlighted recommendation 3 – Encourage Enhanced Health Care Services for Individuals Living with a Rare Disease. It was suggested that a potential opportunity might include networking with state agencies to encourage sharing data, creating needs assessments and staff trainings. The Chair mentioned how Department of Education might assist with developing requirements for education as it relates to education on rare disease. Specifically, towards the goals of recommendation 5 - Promote Provider Education and Awareness for Rare Diseases and recommendation 6 - Encourage Streamlined Rare Disease Diagnosis.

c. Resources for the website – i.e. links, data

The Chair said she would like to see a website with relevant resources for the public, that would be easy to access and easy to share. Colleen Barrett, DNP, BayCare asked if the subcommittee was trying to create a resource for providers in the State of Florida for all individuals living with a rare disease, or for specific rare diseases?

Chair replied that mentioning rare diseases individually would create work the staff nor the council has resources to monitor. Chair suggested housing a digital or electronic resource from information that has

already been established such as organization websites. Colleen Barrett, DNP, BayCare also suggested narrowing the rare diseases to adult specific. Chair agreed that it would help by reducing the over 7000 rare diseases which is outside of the scope for the subcommittee. She talked about determining a starting point much like using the top 50 ICD 10 codes that was identified in a previous full staff meeting. Another good way is to research other State RDACs that previously presented to gather thoughts on resources and implementation of their websites. Chair will reach out to the other RDACs for more information that can assist with gathering reputable, vetted resources. Colleen Barrett, DNP, BayCare agreed to research organizations that can be linked on the website as a reputable source.

Staff, highlighted the benefit of developing a website and the possibility of being able to catalog information for patients, care givers and care providers all in one place. He mentioned the importance of working with the council members and their respective stakeholders to identify resources for the website.

Chair asked if they could move forward on gathering resources to move the process along and have ideas should there be an opportunity to develop a comprehensive resource online.

d. Operational update

The subcommittee discussed the challenges that it has had with meeting quorum and ways that they might adjust the schedule, cadence and timing of the meetings to accommodate more members schedules. All the members who were present agreed that the current time slot worked, and agreed to allow staff to consider September 15, 2026, as the next meeting, pending the availability of other members. There was a desire to establish the dates a head of time and let the members know of the dates as far in advance as possible.

e. Suggestions on future topics

No items were discussed.

2. Public Comments/Open Discussion:

No public comments were received.

3. Adjournment:

Meeting adjourned at 12:33 pm EST