

Notes from the Long-Term Care Taskforce Access to Care Committee Meeting Tuesday, March 11, 2014 • 3:00 p.m.-5:00 p.m.

Meeting Attendees

Present: Jeannette Andrews (guest), Stephanie Blunt (co-chair), Anna Maria Darwin, Joyce Davis, Brenda Hyleman, Stephanie Kemp, Norma Jean Mobley, Lee Pearson, Anna Scheyett (co-chair), Eleanor Stein, Kimberly Tissot, Sam Wiley

Absent: Kaye Gooch, Pete Liggett

Meeting Minutes/Discussion Points

The Access to Care committee co-chairs, Stephanie Blunt and Anna Scheyett, thanked the members for their willingness to participate and then opened the floor for introductions.

Taskforce Overview and IMPH's Role

Following introductions, Lee provided brief remarks regarding the history of the South Carolina Institute of Medicine and Public Health (IMPH) and the development of the Long-Term Care (LTC) Taskforce. He explained that the role of IMPH is to serve as the neutral convener of the taskforce so that experts and stakeholders from throughout the LTC system can come together to collaboratively develop actionable recommendations to improve the system. The target date for releasing the recommendations is January 2015. Lee emphasized that the IMPH Board is committed to bringing high-level attention to the work of the taskforce, though it cannot advocate for specific recommendations. The taskforce steering committee and members will play a critical role in championing the recommendations once they have been released. (Lee referred the group to the handout entitled "Long-Term Care Taskforce Overview" for additional details.)

Identifying "Access to Care" Issues

Anna then introduced a discussion to identify specific issues related to accessing long-term services and supports (LTSS). She noted that the taskforce has four committees and many issues will overlap among them. In order to carve out a focus for the Access to Care committee, she suggested that the members focus on how people who need LTSS get to and transfer between those services and supports—both in terms of knowledge about and referral to those services and also in terms of how they physically access services (e.g., whether they have transportation, whether the services exist in their counties). She explained that the Service Delivery committee will likely focus on what the services and supports are like once people get to them. Discussion about a broad range of access-related issues followed, including:

- Lack of patient-centeredness in the system of services and supports
- Social determinants' impact on people's abilities to access what they need
- Fragmentation in the system and lack of coordination among services
- Importance of accessing opportunities for meaningful activity
- Insurance barriers in accessing appropriate medical services

- Providers and professional of all types (including health care teams, hospitals, doctors, lawyers, first responders, etc.) are not equipped to serve people with disabilities (for example, they lack accessible scales) or those with dementia
- Lack of accessible housing
- Various service providers and resources do not know how to communicate with consumers and do not communicate well with each other
- Lack of geriatric training for providers
- The need for more planning prior to a crisis situation
- The importance of self-advocacy and peer-on-peer support
- The need to help caregivers access training and respite
- The need for more care and services to be provided in consumers' homes as well as the need for more local services so consumers do not always have to travel
- The need for an inventory of services that is up-to-date, accessible and widely used
- The challenges in helping people find small, community-based services that are crucial services but not always included in the broader information and referral networks
- The impact that better transition planning could have on accessing needed services and supports
- The role technology might play in helping consumers access services

Anna noted that the issues seemed to be coalescing around three major themes:

- Professionals of all kinds are often not educated about, experienced in or sensitive to issues relating to working with older adults and/or people with disabilities.
- The system of services and supports ought to be more person-centered; the focus should be on the people and families involved. (Services and supports should emanate from the needs and preferences of the individuals, rather than individuals having to make their lives fit the services and supports that exist.)
- The information system is not synthesized; it is fragmented and uncoordinated.

Anna Maria emphasized that the entire system of services and supports is fragmented. Kimberly stressed that people do not listen to consumers. Following these two comments, Anna noted that the brainstorming session made it clear that the problems are more fundamental than just adding services. She said that, for example, “we could have a fleet of a million buses [to try to augment transportation services], but [the system] is not going to change if” it stays fragmented.

Anna noted that, so far, the group had discussed access-related issues by focusing primarily on the commonalities between the two broad “target populations” (older adults who use LTSS and people with disabilities who use LTSS). She asked the group to take a moment to consider the differences between these two groups as well to see what other issues surfaced. The following issues were identified:

- The two “target populations” have different eligibility requirements.
- People with disabilities sometimes end up in skilled nursing facilities when they really could live in the community.
- There are not adequate and appropriate facilities specific to the needs of people with brain injuries.

Anna and Stephanie said that they will use the brainstorming list to create a survey for the group to aid in prioritizing the issues and deciding how to focus moving forward. They requested that committee members send any additional thoughts about items that ought to be included in this process via email.

Data/needs assessments

Stephanie introduced a discussion about what kinds of data and needs assessments the committee might need to complete its work effectively. Kimberly offered to provide information from needs assessments that Able South Carolina has completed. Anna Maria offered to follow up with the information and referral team at Protection and Advocacy for People with Disabilities for useful reports as well. Committee members were asked to think further about needed data and research and how to access it.

Guiding principles and operating procedures

Anna and Stephanie then directed the group's attention to the handout entitled "Purpose, Structure, Guiding Principles and Operating Procedures DRAFT." Lee explained that this document was created to help ensure effective collaboration and help the group function as smoothly as possible. This final draft is currently under review by the LTC Taskforce steering committee. It is intended as a common document among all four committees. It is also meant as a "living document" so committee members are encouraged to share their thoughts on what is included and whether anything is missing.

Wrap-up and Adjournment

The group was asked to consider what perspectives might be missing from the committee and who else should be invited. The group decided to invite additional members as follows: a transportation representative and a Veteran's Affairs representative. Jeannette Andrews, who is serving on the Providers and Workforce committee of the taskforce, offered to reach out to another USC College of Nursing faculty member to participate on this committee. Lee also noted that we could gather additional input by inviting "subject matter experts" as needed.

Members agreed to a routine monthly meeting time of the fourth Tuesday of each month from 10:00 a.m. to noon (from April through early fall). The next meeting is April 22nd (exact location is TBD).

Additional items

- IMPH is considering conducting focus groups in both urban and rural areas across the state to solicit additional input from caregivers. Focus group questions could be informed by the work of all four committees. IMPH will reach out to committee members for help in finding participants for these focus groups.
- IMPH staff can share articles of interest to the group via email and on its website, which will have a webpage dedicated to each of the taskforce committees.
- Please let Eleanor know of any needed revisions to the contact list that was provided.

Action Items

- Invite additional members to join the committee (March 21). *Eleanor*
- Send additional thoughts regarding needs or barriers that should be included in the priority-setting survey that the co-chairs are preparing (March 21). *All*
- Submit needs assessments and reports that might inform the committee's discussion (March 21). *All*
- Create priority-setting survey for committee members to take prior to the April meeting (April 11). *Co-chairs*