

NC Stakeholder Engagement Group Meeting

October 24th, 2014

9:00 am – 3:00 pm

Hilton Garden Inn Raleigh Triangle Town Center

Present: Nessie Siler, Jonathan Ellis, Matt Potter, Sam Miller, Ron Reeve, Kurtis Taylor, Jean Anderson, Monica Foster, Mike Mayer, Anna Cunningham

Guests: Barbara Brent, Walt Caison, Deb Goda, Courtney Cantrell, Bridget Hassan, Erika Hagensen, Leah Smith, Beth Stalvey

Staff: Chris Egan, Steve Strom, Kelly Friedlander

1. Introduction and Review of Agenda

SEG members, staff, and guests were welcomed by Kelly Friedlander, Barbara Brent, Mike Mayer, and Ron Reeve. Ms. Brent discussed how the SEG initiative was garnering national attention, as other states are looking for ways to meaningfully inform and engage consumer and family members. It was also pointed out that, given this unique time of change, the NC SEG can work together to have real influence on the system. Introductions were made around the room, with everyone in attendance sharing why they are participating in the NC SEG. Ms. Friedlander reviewed the agenda for the meeting.

2. Feedback Request from the Division: Monitoring Tools for LME-MCOs

Chris Egan, Executive Director of NC Council on Developmental Disabilities, presented information about the Division's Provider Monitoring Collaboration Workgroup that is meeting to redesign how LME-MCOs monitor providers. Mr. Egan is a part of the Advanced Standing Focus Group within the Workgroup; they are exploring how monitoring is happening now, what should be kept, and what should be added. The group will then discuss the details about how to reach these visions.

Mr. Egan shared the NC SEG report with the focus group and plans to continue to share it to make sure the report is kept in mind during monitoring tool discussions. He talked about a gold standard tool that Cardinal Innovations has promoted, which rewards certain high performing providers who demonstrate excellence in service. As an incentive for their hard work, these providers of excellence do not have to be monitored as frequently as other providers. Mr. Egan also spoke of quality measures compared to process measures, and mentioned National Core Indicators and the Council on Quality and Leadership's 21 Personal Outcome Measures.

Mr. Egan will continue to share updates from the focus group with the NC SEG and seek feedback.

3. Update from the Division of MHDDSAS

Courtney Cantrell, PhD, Director of the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MHDDSAS) provided members an update on the Division. Dr. Cantrell highlighted some of the many recent changes within the Division, including:

- The Crisis Solutions Initiative has funded 10 initiatives in the last cycle;
- Three different stakeholder initiatives are currently being held;
- 13 I/DD listening tour sessions with Dave Richard are being conducted across the state;
- Medicaid reform discussions are currently happening through a legislative oversight committee and the topic will be a large focus of the house and senate when they convene for the long session in January; and,
- The Division is exploring the opportunity to draft a new waiver for individuals with Traumatic Brain Injury (TBI).

Dr. Cantrell emphasized that she welcomes feedback and ideas from stakeholders. She is happy to have meetings and can be reached by email or phone. SEG members had a chance to ask Dr. Cantrell questions at the meeting, and she provided feedback. Some topics discussed include:

- The Department is interested in focusing more on employment and is trying to hire another staff member in the I/DD section to focus on employment.
- Dr. Cantrell is interested in educating individuals receiving services and agencies about Health Coverage for Workers with Disabilities (HCWD) and how people with disabilities can work and keep their benefits.

4. National Perspective: Changes & Opportunities

Barbara Brent, Director of State Policy at the National Association of State Directors of Developmental Disabilities Services (NASDDDS), led the group in discussing the Home and Community-Based Services (HCBS) regulations and what the process will look like in North Carolina. The federal regulations were out as a draft for a couple of years. They were sent out, commented on, rewritten, and have been finalized by the Center for Medicaid & Medicare Services (CMS). CMS will be releasing additional guidance soon.

All states will have to create plans based on the new regulations and present their plans to CMS for approval. CMS is paying particular attention to the stakeholder input requirements when reviewing plans for approval. Because of this, the NC SEG is poised to have to be able to engage meaningfully in systems change processes.

North Carolina will have to look at policy, licensing, and elements of community in the discussions about HCBS. Community will need to be defined: What is the meaning of community? What are the characteristics of community? What is not community? The state will have to think about which current programs and services may or may not fit in its definition of HCBS. The definition of person centered planning might need to be more consistently defined.

NC SEG wants to be an authentic voice partnering with the Department and the Division. The NC SEG outcomes can be used to positively improve the system.

5. Refining Outcome Tools

Using notes from the NC SEG September 18 meeting, the group worked on a one-pager on the outcome of competitive and integrated employment. The one-pager included facts, the SEG's position, and ways to support SEG's position. SEG members discussed a variety of ways to amplify the impact of the SEG, including writing to legislators, talking to civic groups, celebrating good employer success stories, organizing "take your legislator to work" days, and writing newsletter articles.

6. Advocacy in 2014: What Makes a Difference

Erika Hagensen, Director for Policy at the Arc of North Carolina, recognized the expertise in the room, acknowledging that it was funny to give a presentation about advocacy to a room full of advocates. She honored the rich history of disability advocacy work, sometimes referred to as a "kitchen table movement", since it was started by people sitting around kitchen tables wanting change. She encouraged the group to engage others to advocate for the NC SEG outcomes and expectations because more people are needed at the table.

Ms. Hagensen informed the group that a good amount of the members of the NC General Assembly have been there for 4 years or less, and that if they didn't know about disability issues before, they are now making lots of decisions which affect people with disabilities. Many representatives who have championed disability issues at the state and federal levels are retiring now, which means that advocacy groups need to build relationships with and educate new representatives.

In connecting with elected officials, it is important to remember that every citizen has one thing officials need to do their jobs: one vote. When you contact officials, they can look you up, and your voice means more to them if you live in their district, and even more if you actively vote in their district. It is also important for advocacy groups not to close any doors with officials that currently don't support the issues. Officials might later have children or grandchildren with disabilities, and if groups closed the door

earlier, officials might remember that and not want to engage with those groups. If an advocacy group gives good information and leaves the door open, officials might remember that and call that group first.

7. Advocacy & Outreach Brainstorming

The group explored tools that could help NC SEG impact two real pressure points for state-level change: HCBS rule changes and Medicaid reform. Advocacy work can be looked at as a two-pronged approach, with systems work in Raleigh and grassroots work in communities.

Further brainstorming of advocacy actions created further ideas:

- Seek support for NC SEG from other advocacy organizations through endorsing or signing on to their Outcome & Expectations Report.
- Build relationships with community college and business communities to advance competitive employment.
- Making sure to constantly be in “network mode”: business cards, have an elevator pitch prepared, and constantly look to educate others.

Ms. Friedlander emphasized that she is here to assist SEG members with brainstorming action ideas and making appointments with legislators.

8. Next Steps

The meeting concluded with discussions about next steps for NC SEG. Ms. Friedlander said the long legislative session starts in January and that the group will start meeting once a month. Members expressed in meetings and/or connecting with one another before January. Communication will be sent out about the next meeting, whether it will be held in person or virtually. Members were asked to complete an event feedback form before leaving.