DBHDD

Autism Services Initiative for Adults
Autism Advisory Committee
Meeting Minutes

December 11, 2015
10:00 a.m.
24th floor Board Room, 2 Peachtree Street, NW

Facilitators: April Umstead and Scott Bales (Co-Chairs)

Minutes Secretary: Katherine Roeder

Advisory Committee Attendees: Jennifer Briggs, Tim Cartledge, Deborah Conway, Stacey Lane, Kim Lucker-Greene (via teleconference), Erin Niederhoffer, Greta O'Dell, Julie Prescott, Stacey Ramirez

Absent: Reena Harris, Ray Johnson, Laura Owen, Michelle Schwarz, Pauline Shaw, Rita Young

DBHDD Staff: Darlene Meador

Emory Staff: Joseph Cubells, Silke von Esenwein, Katherine Roeder, Danielle Belva, Emily Deubler

Visitors: Dan Crimmins (Georgia State University), Emily Myers (Briggs & Associates)

Agenda

Call to Order

The meeting began at 10:00 a.m.

Co-Chair April Umstead invited each group member to introduce him/herself for the benefit of the others present.

Approval/Discussion of Minutes of October Meeting

Co-chair April Umstead asked for a discussion of the minutes. Deborah Conway indicated that she was marked as present on the meeting minutes from October 3o, 2015, but she was actually absent. The correction was noted, and Umstead asked for a motion to approve the minutes from the October 30, 2015, meeting.

Motion: Joseph Cubells
Second: Silke von Esenwein

The minutes from the October 30, 2015, meeting were unanimously approved.

Topic: Advisory Board Service

- Umstead asked that the recently approved mission statement for the group be read out loud to preface her comments about the scope of topics for group discussion. Stacey Lane read the statement and turned the discussion back to Umstead, who advised the group to periodically review its focus, keep discussion on topic and be patient with the changes and reorganization in progress at DBHDD. She cautioned that in future discussions, issues that are not relevant to the group's mission would be placed in a "parking lot," so that the group can stay on track. Concerns or ideas may also be sent to her in writing. The group agreed with this strategy to save time and stay focused.

- Umstead proposed that the committee establish a process for assigning replacement members and alternates, should a committee member resign or miss a meeting. Individuals recommended by committee members as replacements or alternates would submit a form, along with a letter of interest and curriculum vitae, to the Emory and DBHDD staff, who will review and decide whether to accept the recommendation. Candidates are required to submit all necessary documentation for review *at least 30 days before* the next meeting. However, members who will be represented by an alternate *should* notify the committee at the time the meeting invitation is sent, or as soon after as possible. No additions to the absolute number of group members are anticipated.

- Umstead asked for a volunteer to chair the next meeting (February 26) as she will be out on maternity leave. Stacey Ramirez volunteered, and the group agreed with Ramirez chairing the meeting.

- Emory and DBHDD staff will determine whether to hold future meetings in Decatur or at DBHDD's central office in Atlanta. The group expressed no preference.

Topic: Revisit Outcomes Measures

- Silke von Esenwein circulated a handout entitled, "Eligible adults with ASD receiving DD services in the DBHDD system and those on the planning list," which details outcome measures (see "sub domains"):
    - <u>Access</u>: Approved services, availability of providers in a given geographic area, and available transportation options.
    - <u>Services</u>: Use of available services, and emergency services (if applicable).

  - Quality: Credentialing and training of providers, family satisfaction, and services delivered, measured against the standard of care. Examples of useful measures include evaluating family satisfaction with services delivered and whether or not the individual is improving and benefiting from the care. The Emory team is researching standard of care measures.

Group Discussion Highlights

- Positive outcomes for individuals with ASD include experiencing joy, growth, and overcoming challenges, which are tough to measure objectively.

- Other possible outcomes are cessation of problem behaviors, gaining access to community, doing things for themselves at home, learning skills and using them.

- As the level of services goes down, access to community, independence, and reduced need for support staff due to skills gained should be visible.

- Self-advocates need to know that they *can* do things. Hope and learning can transform a self-advocate's life. Hope can be more important than method.

- It is valuable to the self-advocate to know that someone is listening; it is valuable to DBHDD to receive input from self-advocates.

- It is one thing to look at data, but we have to remember that there is a story behind all of the data. We have to look at both. We can see things in data we may not be able to understand; we need input/help with interpretation.

- Currently, DBHDD is recruiting more providers to increase access to services. Given that, how will things look in six months? The group agreed that doing this planning at the same time the department is increasing provider capacity is fine, as it will just put us that much further ahead.

- Data in our system are being pulled on individuals with either a primary or secondary diagnosis of autism. We will look to see where these people are, how long they have been in services, and whether they have co-occurring intellectual disabilities.

- Individuals with ASD access the crisis system and obtain exceptional rates more often than the rest of the IDD population.

- Data may show an approval for services, but then no use. This may be because there is no provider in the vicinity.

- Sometimes, services are offered, but the family chooses not to use them for various reasons.

- Include the use of both of these sub-domains: a) a choice of services; and b) a mechanism to gather feedback from the person being served.

- ASD is complex, and not necessarily fixable. A person can be brilliant in one area and have zero capabilities in another. Life changes can undermine progress. Unexpected regressions and meltdowns can and do happen.

- Providers are generally not prepared for the unexpected.

- Families are concerned with having the individual, personal needs of their family member with ASD met.

- We might have to find different ways of delivering services in a positive way. The existing system of service delivery is not working for this population.

- Remember that individuals with ASD may exhibit an intense interest in certain things.

Breakout into Working Groups

The committee broke out into three groups to discuss priority areas for outcome measures. The groups and facilitators were:

- Access: Jennifer Briggs

- Services: Danielle Belva

- Quality: Stacey Lane

Priority Outcomes Measures

After discussion, the groups prioritized outcome measures for their areas:

Access:

- Frequency of visits and quality of provider: it is worth it to travel to see a good provider.

- Does the provider come to the home or not?

- Does the approved service meet the needs of the individual? Is it enough?

- Issue of Availability

Services:

- Choice is important, as not all providers have expertise in every area. Families might switch provider options to get exactly what they need.

- Flexibility is key. Providers get feedback from parents and individuals to gauge what is effective and what is not. Cookie-cutter programming does not work with this population. Delivery should be tailored.

- Teamwork: One or two individual views is not sufficient. Five perspectives would be better. Service provider, doctor, individual, buddy, neuro-typical mentor, etc., should all work together to provide feedback (holistic approach).

- See the life of the person in its entirety, considering multiple viewpoints.

Quality:

- Collection of family and individual satisfaction data will tell us if there is satisfaction with the services, and that is the goal.

- There needs to be evaluation and monitoring of homes, supported employment, and all other services.

- There have to be preventative measures in place with each provider that will indicate a problem before a crisis point is reached.

- Training in autism disability doesn’t fit into a checklist; it must be individualized.

- Individuals need to be in the community, have independence, work, and act as self-advocates. Training families to get the individual to this point is a good idea. Parents can impart skills if they know how to do it.

- Natural support training is available, and agencies can call upon it.

- Parents training other parents is another cost-effective approach.

Data Presentation

Emily Deubler provided the handout, “Table 1: Demographic Characteristics for Adults with Autism Spectrum Disorder,” to the group. This table reflects demographic data from state sources and includes demographic information on 1,505 individuals who will be the subject population for the gap analysis. The data include descriptions of the subject population. Various demographics were highlighted at the meeting. The Emory and DBHDD teams plan to meet to identify variables that will be of interest from numerous sources (WIS, CIS, SIS, HRST), and variable extraction has begun. The team will use this study cohort and the variables provided by DBHDD to identify information regarding service use.

Next Steps

The next meeting will take place on February 26, 2016. The topics for this meeting are data, focus groups, and final report status.

Adjournment

The meeting was adjourned at 1:00 p.m.