DBHDD

Autism Services Initiative for Adults
Autism Advisory Committee
Meeting Minutes

February 26, 2016
10:00 a.m.
24th floor Board Room, 2 Peachtree Street, NW, Atlanta, Georgia 30303

Facilitators:	Scott Bales (co-chair) and Stacey Ramirez (volunteer co-chair substituting for April Umstead)
Minutes Secretary:	Katherine Roeder
Advisory Committee Attendees:	Deborah Conway, Rena Harris, Theresa Heard, Ray Johnson, Kim Lucker-Greene, Eren Kyle Niederhoffer, Greta O'Dell, Julie Prescott, Michelle Schwartz, Pauline Shaw
Absent:	Jennifer Briggs, Tim Cartledge, Stacey Lane, Laura Owen, April Umstead
DBHDD Staff:	Darlene Meador
Emory Staff:	Joseph Cubells, Silke von Esenwein, Katherine Roeder, Danielle Belva, Nassira Bougrab, Emily Deubler
Visitors:	Dan Crimmins (Georgia State University)

Agenda

Call to Order
- Scott Bales called the meeting to order at 10:10 a.m.

- Stacey Ramirez invited each group member present to introduce him- or herself. The group welcomed new member Theresa Heard.

Approval/Discussion of Minutes of August Meeting
- Stacey Ramirez invited the group to review the minutes from the December 11, 2015, meeting, which had been previously distributed. She then asked for a motion to approve.

Motion: Dan Crimmins
Second: Joseph Cubells

The group voted unanimously to approve the meeting minutes from December 11, 2015.

Topic: Overview of Data Analysis Plan

Emily Deubler informed the group that the Emory team has obtained almost all the data sources from DBHDD that will be necessary to undertake the data analysis:

- Case Management Information System: application for service use
- Health Risk Screening Tool: health characteristics of adults with autism spectrum disorder (ASD)
- Waiver Information System: waiver services authorized versus waiver services used
- Support Intensity Scale (SIS) needs of population: support needs of adults with ASD
- National Core Indicators (NCI): adult survey information on NCI indicators for those who self-identified as having a diagnosis of ASD

Crisis system data is pending receipt but is expected within the next few weeks.

The Emory team has created an analytic data set describing demographic aspects of the cohort under study. A handout entitled "Demographic Characteristics for a Cohort of Adults with Autism Spectrum Disorder," which describes demographic characteristics of the Autism Cohort by status group (short-term planning list, long-term planning list, waiver, and state-funded), was distributed.

Future analyses include looking at characteristics by region, service provider information, and NCI data for people with autism compared to those without.

After studying the cohort data, the group started a discussion.

Group Discussion Highlights

- DBHDD currently administers a short-term planning list and a long-term planning list, but the process for administering the planning list will be changed in the near future. The short-term list is comprised of individuals who need services within six months, and reflects immediacy of need. People move from the long- to the short-term list as needs become more urgent.
- State-funded services are provided with 100% state money.
- The waiver program is divided into the New Options Waiver (NOW) and the Comprehensive Supports Waiver (COMP); both are paid with a federal match by Medicaid.
- While the ASD recipients are a small percentage of state and waiver services at present, the population is growing, and being able to respond to this need is one of the reasons for our project.

- It is not possible to tell which services clients are receiving from the Case Management Information System (CIS).
- Family support funding is not being reviewed in this study since data identifying all adults with ASD receiving family support is unavailable. Data collection on the demographics of those receiving family support for developmental disabilities is in the process of being improved.
- It would be useful to have improvements in available data about adults with ASD. The committee should review the types of data required for effective planning/service delivery and make recommendations on improvement in data collection.

Topic: Focus Group Update and Overview of Training Strategies & Priorities

Silke von Esenwein reported that the Emory team has conducted individual focus group meetings with parents, administrators, and a DBHDD psychologist. The team has completed three focus groups, each with six-to-eight parents of individuals with ASD. The participants were invited to talk about topics such as their experience taking care of their family member, the role that DBHDD services played in the individual's care, provider competency/availability, and suggestions for provider training. The first round of focus groups yielded good information, and certain trends appear to be emerging from the information. The following broad trends about training emerged from the focus group sessions:

- Direct care staff does not have the autism-specific training to deal with individuals with ASD.
- Help with behavior modification is a real need. Parents request expertise here.
- In most cases, the parents are the experts at dealing with their kids.
- Parents/families need training on how to deal with the system; peer-to-peer networking is suggested.
- Try tapping into families to provide training. It will help with sustainability.
- There should be co-learning between service provider and the parent, working together to create a good environment and making them a "unit."

The next step for the focus group effort is to strive for more diversity in the participant base and go into the outlying regions of the state. The group was then invited to discuss trends, and to talk about training strategies and priorities.

Group Discussion Highlights

- Make use of videos as training tools.
- Consider cultural diversity difference, as well as the immigrant population, in planning. The goal should be access to educational and community supports as soon as the diagnosis of ASD is made.
- Families want to network. It should not be the government that provides all training. We have pockets of knowledge...and then the opposite...lots of uninformed families.

- Pauline Shaw shared her experience with founding and running a support group in the Savannah area. It is a 501(c)(3) organization from which parents obtain tremendous benefit.
- Claire Dees in Gwinnett started Spectrum, a successful ASD support group that offers programs. Eren Neiderhoffer volunteered to connect the group with self-advocates he knows in Gwinnett County who are working with parents and not with government.
- A common problem is siblings who want to help but don't know what to do.
- While this type of support may not be government-provided, the government needs to know about it, in terms of staying informed about what is going on in the community, and being able to refer parents to them. Models from other states would be welcome.
- Kim Lucker-Green asked if it is possible for the government to set up an online resource guide listing providers by location/area. She mentioned a similar effort in Florida that is being modeled after a Michigan example.

Breakout into Working Groups

Three breakout groups were organized to discuss, develop, and present suggestions for training strategies and priorities.

Group 1: Theresa, Eren, Julie, Kim and Pauline
Group 2: Scott, Dan, Ray and Stacey
Group 3: Debbie, Joe, Danielle, Rene, Greta

Group Reporting – Suggestions for Training Strategies & Priorities

Group 1:

- Website
  - Quality control is key
  - Link to individual providers/resources by regions
  - Links to trainings
  - Calendars for each region

- Family supports can help fund behavior consultations and supports which in turn can work closely with direct care staff.

- Require providers to have direct care staff obtain the credential of registered behavioral technician (RBT). Require parents to actively participate in order to improve their understanding of the functions of the behaviors and how to replace the behaviors.

Group 2:

- Design training around specific target audiences: professionals, parents/siblings/ friends, self-advocates, non-professionals, private providers, policy makers

- Develop a network of existing support groups that offers technical assistance to form and operate new support groups. It should include self-advocates who share key information on forming and operating support groups.
- Centralize the resource database, and update it regularly; provide for geo-linking and user ratings. (See models like YELP, and also include resources such as autism friendly restaurants, etc.)

Group 3:

- Simplify DBHDD website to make it easier to find information on how to access services.
- DBHDD to offer basic/general autism training followed by parents providing 1:1 person-centered care.
- Coordinated sharing (looks like NAMI, SAMHSA, AA) that builds on parent-to-parent, GCDD Real Communities, SPADD, and the Sibling Support Project.

Update on Contract Status

Darlene Meador and Joe Cubells informed the group that a request has been made to extend the contract for the Autism Services Initiative for Adults (ASIA) project between Emory and DBHDD by six months, to end September 30, 2016. Due to the scope of the initiative, the deliverable requirements will take more time to complete. During the extension period, a proposal will be developed for Year 2 of the ASIA project. Year 1 work is yielding good information and ideas about sustainable efforts to improve service delivery. This will serve to inform the proposal development process for Year 2.

Next Steps

The next meeting will take place on April 29, 2016. The Emory data team will be presenting its findings to the group for review, discussion, and input.

Adjournment

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