

EIDBI Advisory Group
Department of Human Services
540 Cedar Ave., St. Paul, MN 55101
Jan. 19, 2018

Meeting minutes

Staff updates

- EIDBI clinical lead Sirad Shirdon informed the group that her last day would be March 1, 2018

Member updates

- In light of the departure of two parent members (Charles Ledonio and Fatima Molas), the EIDBI team is working to select two new parent members

Provider shortage

- The Minnesota Department of Health (MDH) has designated certain geographic regions of the state as health professional shortage areas (HPSAs)
- Health professionals considered in the HPSAs designation include dentists, primary care providers and mental health professionals
- Most counties in the state are designated HPSAs with the exception of the metro counties and Southeast Minnesota (e.g., Olmsted county)
- Dr. Esler reported that while on paper the metro counties are not considered an HPSA, the provider shortage affects the metro counties. Children are waiting a year on average to get an autism assessment.
- Nick asked if and how adults with autism can play a role in providing peer supports, given the provider shortage
- While adults with autism can be a great source of informal support for other adults with autism, qualifications (education and years of experience) may play a role in providing more formal supports

Updates

Community meetings

Minneapolis parent meeting (November 2017)

- Ayaan reported that the Minneapolis meeting went well overall, but expressed her concerns that many questions were not answered
- Mariam expressed her delight at the cultural diversity of the meeting attendees

Marshall parent/provider meeting

- Teri reported that the meeting was well attended with many county case workers and parents
- There was overall frustration about the lack of services

Parent/provider meetings in 2018

- Team is working to schedule more meetings

State plan amendment approval

- The federal Centers for Medicare & Medicaid Services approved Minnesota's [EIDBI state plan amendment](#) on Dec. 11, 2017
- The DHS commissioner has also approved the variances

People with autism and the criminal justice system

- Discussion was led by Officer Robert Zink, who has been with the St. Paul Police Department for 20 years
- Officer Zink is the father of two sons on the autism spectrum
- Developed the Cop Autism Response Education program, which trains officers and first responders about how to work with people on the autism spectrum
- Staff members with Vitals Aware Services shared information with attendees about the [VITALS app](#)

Roles of EIDBI advisory group members

Four people participated in the panel discussion: Dr. Sheri Stronach (assistant professor, Speech-Language-Hearing Sciences, University of Minnesota), Dr. Amy Esler (assistant professor, Division of Clinical Behavioral Neuroscience, University of Minnesota), Barb Dalbec (MDH) and Kara Tempel (Department of Education).

Questions

We asked the panelists three questions:

1. What is your role related to autism and/or related conditions?
2. What are some challenges evident in your work?
3. What recommendations do you have for DHS or others for improving the lives of people with autism and/or related conditions?

Responses

Question 1

- Dr. Stronach reported that her main duties at the University of Minnesota revolve around research, teaching and service

- Dr. Esler stated that her main duties revolve around completing autism assessments at the Autism Spectrum & Neurodevelopmental Disorder Clinic, completing clinical coordination and consultation and conducting research in collaboration with the Centers for Disease Control and Prevention and MDH
- Barb reported that in her role as director of the Children and Youth with Special Health Needs department at MDH, much of her time is spent seeking funding (80 percent of the work of MDH is grant-funded, while the state provides 20 percent of the MDH's budget).
- MDH looks closely at the data, identifies gaps in services and seeks solutions for improving the system overall
- Kara is the Part C coordinator for MDE (Part C services are outlined in the Individuals with Disabilities Education Act, and for children birth to 2). In addition to her work with MDE, Kara serves on the autism interagency workgroup, which aids collaboration between state agencies on issues related to autism.

Question 2

- Dr. Stronach expressed that her biggest challenge as an academic was the recruitment of culturally diverse students. Other challenges included:
 - A dearth of interdisciplinary work around autism
 - An abundance of studies that are not informed by actual needs
 - The disconnect between research and practice
 - Lack of graduate-level coursework on autism
- Dr. Esler said access to funding constrains her work. Dr. Esler requires grant funding to engage in her research. Increasingly, she faces challenges in accessing such funding. Clinical services at the Autism Spectrum & Neurodevelopmental Disorder Clinic are affected by the provider shortage. Dr. Esler expressed her worries about the impact on clinical services, with the upcoming departure of one of the clinic's only developmental pediatricians (there are very few developmental pediatricians in the state).
- Barb stated that her biggest challenge was coping with the slow pace of systems change, while trying to address the need for autism services.
- Kara stated that her biggest challenge is in educating people about the difference between education and medical services for children with autism. Some schools opt to diagnose children with a developmental delay instead of an autism diagnosis.

Question 3

- Dr. Stronach's recommendations for improving clinical research related to people with autism included:
 - Ensuring that diverse populations are represented in research studies
 - Improving communication and collaboration across different disciplines
 - Continuing to improve the public's understanding of the variety of intervention options for people with autism
 - Engaging students in discussions about the provider shortage (e.g., invite students as members to serve on the EIDBI advisory group)

- Dr. Esler applauded DHS for its work related to autism and recommended additional training for social workers about autism.
- Barb recommended that people who are knowledgeable about navigating autism services assist families of children who have been recently diagnosed. Families of children with ASD have a huge part to play in advocating for the needs of their children.
- Kara expressed her gratitude for DHS's efforts around autism and recommended continual engagement between the state agencies through the autism interagency workgroup.

[Next meeting](#)

10 a.m. Friday, March 16, at 444 Lafayette Road N., St. Paul, MN 55155