

EIDBI Advisory Group

Department of Human Services

Lafayette Building, 444 Lafayette Road N., St. Paul, MN

Nov. 3, 2017

Meeting minutes

Parent/ Provider meeting updates

Little Falls:

- About 30 people in attendance
- Main message was the lack of services in the area.
- Parents have to move into the metro area to access services.

Bemidji:

- 30-40 people in attendance
- Three or four providers interested in enrolling after attending the meeting
- Feedback from Bemidji meeting: Participants want a more parent-friendly, less clinical presentation

Lakeville:

- 15-20 people in attendance
- Parent panel focused on barriers to accessing services.
- Main message was the need for more transition-age youth services and supports.

Upcoming meetings:

- Marshall: 2 to 4 p.m. Dec. 4 at the Public Library
- Minneapolis: 10 a.m. to 12:30 p.m. Nov. 29
- Bemidji: 5:30 to 7:30 p.m. Nov. 20
- Dates, times and details will be added to the advisory group webpage

Roles of EIDBI Advisory Group members, their perspective on Autism services and supports and feedback on how state services could be improved to ease access

Nick, self-advocate:

- Abuse from other clients in the programs, including sheltered workshops he attended
- Sheltered workshops teach hands-on labor skills for adults with disabilities.
- Staff members were not always willing to listen and were not thorough when issues arose.
- Staff directions and orders were contradictory. This can be very frustrating for people trying to follow directions.
- Staff often did not listen to issues that clients raised and things escalated. Important to listen to all people involved and let them have a voice

- Difficult to obtain employment and overcome the stigma of the diagnosis
- People in the community don't understand the diagnosis and don't try to get to know the person or find his or her strengths.
- Need more training for community members and caregivers on person-centered planning.

Advocates Steven and Teri:

- Work on independent living skills.
- Work with employers to help them to understand people with different abilities and to focus on their strengths to find jobs.
- Use personal experiences to help expand services.
- Working with Disability Law Center, advocate for parents and families who face challenges to access services and supports.
- At the state level, DHS could do a better job of communicating with individual counties. Some counties do a great job and others are not as helpful.
- DHS could be better about bringing services to the people rather than expecting people to be their own advocates.
- DHS often allocates funds only to severe cases. Would be helpful to have more resources for people who need just some supports or short-term care. Those are often the people who fall through the cracks. IQ requirement on waiver policy is challenging.
- Lack of supports for people when they need it leads to crisis situations. And then there is a lack of supports to transition.

Counties and tribal representatives, Evan, Lori and Linda:

- Everyone is unique. The system is burdensome when people access services. DHS needs to simplify service access.
- Children with autism who score high on cognitive and adaptive scores don't qualify for case management, which sends families out on their own to try to navigate the system.
- Native American communities are under-represented in the data. There is not enough focus on the great need for supports. Families are often challenged to meet basic needs, let alone to access services and supports.
- Often services and supports don't coordinate or build relationships across programs. Need to become more welcoming as a community as a whole. Build awareness and understanding.
- Counties and tribes often spend too much time filling out paperwork rather than returning phone calls to families in need of answers. Need to find a better balance.
- The MnCHOICES Assessment and Support Plan take a lot of time to complete and may not be appropriate for children of different ages. The MnCHOICES applications also don't correct for culture.

Parent perspective on provider shortage

Kate and Kelly:

- Sometimes you have a full team. Other times a staff member quits or gets sick and then hours are low.

- Hard to find a personal care assistant. Many are going on to graduate programs and move on to research or internships.
- Difficult to find high-quality staff members who are attentive to the child and are trained in the necessary skills.
- Standards for PCAs are high and make it difficult to become a provider.
- In rural Minnesota, it is especially challenging to find accurate diagnosis, sufficient services and services that are appropriate with well-trained staff.
- Waiting lists are long. The longer it takes to get services, the more challenging it is.
- Not many families have the means to move homes, jobs and have family support to get services in metro areas.
- Resources have not come from teachers, doctors or case workers. All the resources came from other parents.

Provider shortage discussion with advisory group:

- What can we do to help providers to manage their workloads so they have time to complete paperwork for the Early Intensive Developmental and Behavioral Intervention Benefit (e.g., Comprehensive Multi-Disciplinary Evaluation)? How do we ensure that we are not adding additional paperwork time for professionals?
- The University of Minnesota soon will begin a board-certified behavioral analyst with specialization in special education degree program.
- Providers need more education about what resources are out there, so they can refer people to them when appropriate. Many providers do not understand that they have to make referrals.
- Important that we are focusing on other areas that have provider shortages, not just board-certified behavioral analysts. Let's think about ways to address provider shortage for other areas (social work, marriage and family therapists, etc.)
- Given the shortage of behavioral therapists, how can we make use of other professionals (speech therapists, occupational therapists, etc.) in the meantime, to ensure there isn't a huge lag in services while the child is waiting for behavioral intervention?