

EIDBI advisory group

Meeting minutes

July 13, 2018

MN-Autism Developmental Disabilities Monitoring Network (MN-ADDM) data release

Jennifer Hall-Lande and Amy Esler presented information on the prevalence of ASD in Minnesota:

- [MN ADDM data](#) is for Hennepin and Ramsey counties
- Would like to expand data-collection locations in the future with additional funding
- CDC requires that the counties added need to be contiguous to the current data-collection locations.
- National average is 1 in 59 children with ASD.
- MN rate is 1 in 42. This was expected since a highly populated area was evaluated where services are available.
- Average age of diagnosis is 4 years 9 months.
- More white children were still found to be identified with ASD than black or Hispanic children. Black children were found to be identified at a higher rate than Hispanic children. However, there was no statistically significant differences in prevalence across race.
- Still have many goals for future research.
 - What causes ASD?
 - Somali families study their risks
 - Adult prevalence
 - Vaccines and how they relate to ASD
- 2.4 percent of children with ASD need services and supports right now
- Lower age of first diagnosis
- Build provider capacity

Questions:

- What are the U of M and ADDM doing to increase research for girls?
 - There is a biological vulnerability identified in males.
 - Still a great need to look at why girls are being missed. If concerns are identified, why aren't referrals being made or followed up on? Research focused on if symptoms are different in girls.
- Many children are identified as developmentally delayed and what is being done to address this?
 - Services are not as intensive for DD as for ASD services. However, many clinicians or schools may still give this diagnosis because they are hesitant to deliver the ASD diagnosis.
 - Autism Navigator is helping to educate others on this.
- How to respond to people who oppose the 1 in 59 prevalence estimate
 - Some would say that we are not seeing an increase but we are identifying what has always been but more accurately.
- How to engage more school districts such as Roseville
 - Continuing to work to add more districts
- When do you estimate that counties can be added beyond Ramsey and Hennepin?
 - Funding is through the CDC.
 - Talk to your legislators who can help direct funding.
- Is the DNA of biological parent of child being collected?
 - No

Telehealth services for EIDBI

Adele Dimian and Jessica Simacek shared info and sought feedback on survey design:

- Not enough providers to serve the number of children identified with ASD
- Causes long waiting lists and delays to diagnosis and starting intensive services
- Board Certified Behavior Analysts (BCBAs) are not often found outside of the metro area, which makes it challenging to supervise programs for EIDBI.
- For Children's Therapeutic Services and Supports services before EIDBI, children received about 19 hours per week and it took about 9 months to start services. This is considered a baseline level.
- Generally the placement that a child received early on in schools is where he or she typically stayed.
- Wait lists showed that children in the metro area were also found to wait 9-13 months for treatment even with a higher number of providers.
- Tele-health is one solution to help address wait lists and provider shortage, especially to reach children in greater Minnesota.
- Tele-health is helpful because:
 - A trained person does not need to be in the same place as the child.
 - It works to address pivotal behaviors.
 - It tries to fill in the gaps and get services started while waiting for intensive in-home services.
 - Families are feeling empowered by having to do therapy themselves.
- Research has shown that children were able to make progress on learning communication skills, challenging behaviors, play skills, etc. through tele-health services.
 - Future research focused on therapy in more naturalistic settings (e.g., school, community) and joint attention skills.
 - Research has shown that there is a cost saving for providers
- Limitations may be:
 - If a child has severe self-injurious behavior or challenging behaviors
 - Privacy
 - Internet connection
 - Elopement behaviors
 - Funding available but not widely adopted
- A parent asked if they are working with schools, speech, OT, etc.
 - Preparing grant for funding to do research with school districts
 - If you have districts with letters of support from parents
- Provider noted that recent services have been provided via tele-health.

Medical marijuana for people with ASD

Michelle Larson provided an update on change in Minnesota statute:

- Minnesota is the 22nd state to approve medical use of cannabis.
- Minnesota has a more conservative medical marijuana program
- No national standard
- Recreation use states very different
- Only allow for liquids, oils, tincture or vapor form in Minnesota
- Limited group of medical conditions that qualify
- Must be approved by certified health care practitioner
- ASD was added July 1.
- On MDH website, public may petition to add other conditions from June 1-July 30. Petition for ASD submitted last year. An advisory panel, literature review and public testimony recommended that ASD be added. Commissioner does not have authority to remove condition unless Legislature removes.
- Only one person has been certified so far for ASD. PTSD rolled out last year and was slow, but is now the second most prevalent condition.

- More than 10,000 people in Minnesota are receiving cannabis.
- Caregivers must be approved as well.
- Expensive, but reduced for people on Medical Assistance.
- Patients asked about other medications and quality of life.
- Patients report positive results.
- How do qualifying conditions get added?
 - Literature review and advisory panel. Made up of health-care professionals.
 - ASD was put in twice and was approved this year.
- What about nasal sprays?
 - Petition for different ways to be used and that is one being reviewed right now.
- Is there an age limit?
 - No age limit. Small pediatric population.

Equivalent graduate course work

Nicole Berning presented on proposed language to be added to the EIDBI policy manual:

- Equivalent graduate coursework is defined as a combination of experience and/or training hours and hours spent completing coursework.
- Coursework must be documented in one or more of the following areas: Autism spectrum disorder (ASD) or a related condition diagnostics, ASD or a related condition treatment strategies, or child development. Examples of related conditions include, but are not limited to:
 - Asperger's syndrome
 - Fetal alcohol spectrum disorders
 - Pervasive developmental disorder, not otherwise specified (PDD-NOS)
 - Rett syndrome
- Submit a transcript to demonstrate proof of completed coursework. One credit of completed coursework is equivalent to 45 hours of time. Coursework must be completed at a bachelor's or master's degree level at an accredited university or college.
- Experience and/or training includes the examination and/or treatment of people with ASD or a related condition. Experience may be completed in a school, in community settings (i.e., parks, libraries, stores), or a clinical treatment setting. Experience must be in-person.
- For the Comprehensive Multi-Disciplinary Evaluation (CMDE) and Qualified Service Professional (QSP), experience and/or training hours providing treatment or examination of people with ASD or related conditions must make up at least 50 percent of the total required amount of experience (i.e., 1,000 hours). Coursework may be counted towards the remaining 50 percent (1,000 hours).
- For the Level I provider, experience and/or training hours providing treatment or examination of people with ASD or related conditions must make up at least 25 percent of the total required amount of experience (i.e., 500 hours). Coursework may be counted toward the remaining 75 percent (i.e., 1,500 hours).
- For the Level II provider, no previous experience and/or training hours are required if the provider is enrolled or graduated from a bachelor's degree program at an accredited college or university in one of the behavioral or child development sciences or a related field (e.g., mental health, special education, social work, psychology, speech pathology, occupational therapy, etc.). The Level II provider must receive observation and direction from a qualified supervising professional (QSP) or Level I treatment provider at least twice per month until meeting 1,000 hours of supervised clinical experience.

Updates

Nicole Berning, Mariam Egal, Maychee Mua and Gail Dekker provided the following information:

- Provider numbers and locations: 47 enrolled CMDE providers and 21 agencies
- Legislative proposals for 2019: will propose increased guidelines around provider background studies
- Member terms: Two-year membership terms are going to be up at the end of the year. Notice will be coming out soon to those who are two-year members to see if you are interested in renewing your membership.

[Next advisory group meeting](#)

10 a.m. to noon Friday, Sept. 14, at the Elmer L. Andersen Human Services Building, 540 Cedar St., Room 2370, St. Paul. No visitors' badges needed.