

## EIDBI Advisory Group

Department of Human Services  
Elmer L. Andersen building, 540 Cedar St., St. Paul  
Sept. 15, 2017

### Meeting minutes

#### Oath:

- Please sign and return to us.
- If you were not in attendance at this meeting in person, please sign at the next EIDBI advisory group meeting in November.

#### Greater Minnesota meetings:

- Rochester: Lori and Melissa attended
  - Reported that parents would like to see meetings in the evening to accommodate those who have to work
  - Attended by about 16 people including parents, county workers and providers
  - Message was that there need to be more service providers in that area
  - Many frustrations with financial assistance
- Alexandria:
  - Attended by more than 40 people including county workers, providers and parents
  - Kara Tempel attended and spoke about Help Me Grow services
  - Many questions on financial assistance
  - Barriers to accessing services and lack of service providers in that area

#### State plan and legislative updates:

- State plan submitted to CMS Sept. 14, 2017
- DHS is seeking federal approval to establish variances to address the Level II provider qualifications
- Looking to add more requirements for background studies to our 2018 EIDBI legislative proposal

#### Disability Hub MN:

- Rebranded
- Information and resources available to hand out to families
- Information on participating in the panel on the PowerPoint presentation.

#### ASD Strategies in Action

- Contact [ASD.DHS@state.mn.us](mailto:ASD.DHS@state.mn.us) for a free subscription

#### Autism website:

- Will be launched soon at [mn.gov/autism](http://mn.gov/autism)
- Link to test environment on the PowerPoint

#### Parent panel:

- Why did you join the advisory group?
  - Accessing services is very challenging and need to work to create solutions
  - Educate yourself as a parent and try to explain to your families
  - Other parents were most helpful in helping to find resources and letting you know what to expect in the future. Parents want to be advocates for other parents.
- Diagnosis:
  - Don't know what to do first after you receive a diagnosis. Wish someone had told us there were red flags early on (e.g., Early Childhood Family Education, day care)
  - Didn't know the signs and symptoms to watch for and were told the wrong things (i.e., could be hearing loss, developmental delay, etc.)

- One parent reported being told, for cultural reasons, to wait and not rush in to concerns or go into doctor to get a checkup
- Parents feel they want to compensate for their children
- Parent felt they were to blame for the diagnosis
- Parents are made to feel guilty
- Parents feel angry and feel that their children's autism diagnosis was unfair
- Parents are overwhelmed with the sudden news from the doctor and overwhelmed with all the resources given. Frustration and anger
- People often said hurtful things and expressed strong opinions about what you should do to treat your child. People tend to lack understanding and they project their experience on you.
- Feeling of strange relief at least to know what is wrong.
- Providers often don't have experience with how to talk to parents. They act scared and like they don't want to be the ones to break the news.
- Want doctor to be honest and tell you in a caring way. Want someone to confirm your concerns and not just dismiss you
- Having a diagnosis does not get easier; it only gets more complicated.
- Every child with autism or a related condition is different
- Clinical diagnosis is different from an educational diagnosis
- Services and supports:
  - Filling out forms over and over again that ask the same questions because providers don't accept others' forms
  - Parents are reminded of the pain of the diagnosis each time they are required to complete a form
  - Parents are stressed; raising a child is challenging enough without a diagnosis.
  - Some communities are supportive and have resources available.
  - Certain school districts have more resources.
  - So many services available but challenging to find the right services
  - Paper work is overwhelming; parents may need support to answer questions. Parents are already exhausted. It is challenging to have to do one more thing.
  - Encounter waiting lists. Told early intervention is best but can't get in early enough
  - Mariam Egal (multicultural training coordinator) has been a great resource in connecting multicultural parents to support groups.
  - Other parents give you hope
  - Most helpful assistance comes from other parents.
  - Early intervention has given hope. Children acquire skills like being toilet trained, dressing themselves, talking and communicating. Decrease challenging behaviors
  - Services give hope that there is light at the end of the tunnel.
  - Challenging to find child care for children with sensory and behavior challenges. Rapid turnover
  - Parents and children are isolated and going to supermarket, parties or other places with other children is challenging (e.g., allergies).
  - It is a fight to get services.
  - Try to use person first language when addressing children and their parents
  - Parents should be able to interview professionals working with their children to see if they are a good fit for the family.
  - There are not enough providers.
  - Coordinating providers with competing priorities makes scheduling difficult.
  - Providers and parents must communicate but challenging because it takes time away from working with the child
  - Need to see how we can help to ensure the child and the person with a diagnosis are getting what they want and we aren't just making decisions for them
  - Need to be the voice for the parents who don't have one
- Financial assistance:
  - Takes a ton of time and a lot of research
  - Heard about most things by word of mouth

- The cost is burdensome and services often require parents to quit their jobs
- Stress is hard on marriages and all of the family.
- Providers and others (e.g., babysitters) are often telling parents about certain financial assistance options (MA-TEFRA, grants, personal care assistance money, etc.) Very helpful.
- Parent worried that the budget plan presented to her by her county would not be sufficient to meet the needs of her child
- Successes and challenges:
  - Facebook parent groups are a helpful resource.
  - The system does not work together.
  - People need to follow through and not leave families hanging.
  - Parent reported her distress at her child's level of autonomy. People are always making decisions for children with autism without an understanding of what they want.
  - Having multiple children with different challenges and needs makes it difficult to balance.
  - Need to admit you need help and what type of help
  - Understand that a parent has already likely called many other people
  - People need to be willing to meet with you and go with you on the journey.
  - Parents are grateful and appreciative of the sacrifices that providers make and the help and support they give.
  - Case workers are overworked and have too many cases. But parents need them to be on time and to follow through.
  - State assessments for long-term supports and services might not be capturing fully the needs of children with autism.
  - Parents reported that sometimes errors occur in their assessment process for receiving services and supports
  - Parents would like to be a part of the training and development of forms.
- What do you wish you had known and what one thing do you want providers to know?
  - Promote new autism website
  - Doctors, please talk to the child and not only to parent.
  - Parents can stand up and advocate for their child and the right service.
  - Find a social worker to help you in the process.
  - Parent wishes she had known about options like MA-TEFRA
  - All autism-related items in one-stop shop website
  - Know the steps
  - Accessible to people who can't read or write
  - Training for the people who are coming in and doing assessments. Make sure they have training on autism and related conditions.
  - Wish I had known other parents
  - You are enough and good parents
  - You need to schedule things way in advance
  - Parents not always presenting to providers their best selves
  - There are ups and downs and there will be another up very soon, so hang in there.
  - Trust your gut and know you are strong. Don't be deferred or shut down by others.
  - You can laugh through the struggles. There is a lot of love that comes along with this.
  - Providers should participate in and engage with the families' lives.

Next advisory group meeting:

- Friday, Nov. 3, at Elmer L. Andersen Building, room 2380, 540 Cedar St., St. Paul, MN 55101
- 2018 meeting schedule available online and handout

To contact DHS, please email us at [ASD.DHS@state.mn.us](mailto:ASD.DHS@state.mn.us)

## Principles to participate

As a member of the EIDBI advisory group, I agree to:

- Respect others
- Attend bimonthly meetings
- Complete assignments on time
- Participate constructively in discussions
- Collaborate in seeking solutions that meet the needs of all parties

## DHS commitment

As Disability Services Division staff supporting the work of the EIDBI advisory group, we will:

- Distribute agendas and supporting documents in advance of advisory group meetings
- Provide documents in alternate formats upon request
- Provide context, communicate clearly and facilitate effectively at advisory group meetings
- Be available to answer questions and address concerns between meetings
- If there are assignments between meetings, allow sufficient time to complete the work requested
- Consider your recommendations in the context of our legal authority and mandates, alignment with the Department of Human Services' strategic direction and financial feasibility.
- Report back to the advisory group on the status of your recommendations as DHS makes decisions