

EI Recommendations

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Record ID

3

ECHO Autism Early Intervention

Ages 0-8 Years

Recommendations Form

**Brett Moore, DO; Brittney Stevenson, MOT, OTR/L;
Michelle Dampf, MA, CCC-SLP; Laura Barnes, MS, BCBA, LBA;
Michelle Haynam, MS Ed.**

Email our clinic coordinator **Sarah Towne** at sarahtowne@health.missouri.edu if you have any questions or comments.

PLEASE NOTE: Project ECHO case consultations do not create or otherwise establish a provider-patient relationship between any UMH clinician and any patient whose case is being presented in a Project ECHO setting.

Presenting Provider Name: Andi Heller

ECHO ID: EI0045

Presentation date: 11-13-2023

Presenting Question:

See Below

Additional Identified Concerns:

How can the IEP team best manage the amount, type, and frequency of challenging behaviors while also doing our best to prepare this student for kindergarten?

Within the school setting, how can the IEP team navigate the current situation, including possible mental health concerns and the effects of medicine trials, when staff may not feel equipped to do so?

Per parent report, "how can we help this child participate and engage across his environments while remaining safe towards himself and everyone around him? How can we manage his internal struggle related to this? It seems that over the last year, his happiness and bright attitude has often times been replaced with increased frustration and agitation often from within himself. Transitions are getting harder every day on him." Parent welcomes any advice on what route to take or where to go from here to best help this child.

After review of information provided and discussion of the case, the following recommendations are provided:

1)

- Continue on path of ruling out all medical contributions to his behavior (brain anomalies, sleep apnea, dietary deficiencies, etc). Encourage mom to track a few behaviors that are important to her about his participation and then she will have that data to more objectively share with physicians/psychiatrist.
- Continue to explore strategies to support his emotional regulation such as structuring his day in a way where he has automatic access to comfort items during difficult/triggering tasks, etc.
- For transition to Kindergarten, do as much data gathering as possible on which strategies you've tried and which have been most successful along with some detail on what you were working on. Possibly a list of 1. Works often, 2. Sometimes Works, 3. Never worked for us - could help new IEP team make decisions. Also, pass along strengths/weakness and big DO's and DON'Ts for when working with him (such as not talking about him in front of him).
- Especially since you said he really needs a bond to feel comfortable, pass on information to the new team on the best ways to connect well with him and what helps repair the relationship after something hard.

2)

- Check in with current BCBA to see if they have suggestions or if they are seeing similar challenges with his behaviors
- Keep a log with observations that can be shared with parent and physician to help navigate medication changes, this will also help with dx of any future mental health dx
- Continue with all the visual supports and share with kindergarten teacher and learning specialists that he will be working with
- See if parents are connected with Boone County Family Resources
- Continue to encourage others to not talk about him in front of him...I encourage families and educators to also be cautious of this with all children, especially those with complex communication needs. Typically children pick up way more than you would ever guess
- Continue working so closely with the family, you are doing a great job with incorporating family values and working to encourage communication and follow through in all of his areas of life
- Continue encouraging his family to teach life skills even though it may not be easy and they may encounter behaviors. One resource that I like to recommend to families is: How to Teach Life Skills to Kids with Autism by Jennifer McIlwee Myers

3)

Ensure that staff are providing high-quality attention in his preferred ways when he is doing well/engaging in behavior you would like to see more of in the future. Collecting and sharing data on staffs' allocation of attention during short intervals (e.g., 5-10 min) can be helpful to help them realize and change their behavior, too!

4)

I would not hesitate to have family contact the Thompson Center for resources if they have concerns and FACE of Boone County if not already done.

Eating toolkit might be useful. If family is really struggling, recommendations for feeding clinic may be appropriate.

Reach out to Dr. Brooks for any recommendations.

Make sure IEP stays updated as the child gets older with any new diagnosis and is monitored closely for OCD and ADHD that is being suspected as both are common with children with autism.

5)

• Genetic testing: KIDINS220

Information about this gene can be found at <https://www.ncbi.nlm.nih.gov/gene/57498#summary> and I would also recommend talking with a genetic counselor if this has not been done yet.

57498 - Gene Result KIDINS220 kinase D interacting substrate 220 [(human)]

This gene encodes a transmembrane protein that is preferentially expressed in the nervous system where it controls neuronal cell survival, differentiation into axons and dendrites, and synaptic plasticity. The encoded protein interacts with membrane receptors, cytosolic signaling components, and cytoskeletal proteins, serving as a scaffold that mediates crosstalk between the neurotrophin pathway and several other intracellular signaling pathways. Aberrant expression of this gene is associated with the onset of various neuropsychiatric disorders and neurodegenerative diseases, including Alzheimer's disease. Naturally occurring mutations in this gene are associated with a syndrome characterized by spastic paraplegia, intellectual disability, nystagmus and obesity. Alternative splicing results in multiple transcript variants. [provided by RefSeq, Feb 2017]

www.ncbi.nlm.nih.gov

6)

If there are snoring episodes and patient not sleeping well, this might get fixed if the tonsils are big and then get removed. If very restless, the sleep clinic usually recommends checking iron if not already done.

7)

8)

9)

10)

11)

12)

The following toolkits/resources may be helpful:

General ASD Information

- A Parents Guide to Autism
- A Grand Parents Guide to Autism
- 100-Day Kit

Medical

- Managing Constipation Guide
- Dental Guide
- Exploring Feeding Behavior in Autism
- Sleep Strategies Guide
- Sleep Strategies for Teens Guide
- A Parent's Guide to Toilet Training

Medications

- Melatonin Guide
- Medication Decision Aid for Parents
- Safe Medication Toolkit

Behavior

- ADHD Resources- https://www.aacap.org/AACAP/Families_and_Youth/Resource_Centers/ADHD_Resource_Center/Home.aspx
- Anxiety Strategies Guide
- A Parent's Guide to Applied Behavior Analysis
- Behavioral Health Treatment Guide
- Challenging Behaviors Tool Kit
- Haircutting Training Guide
- A Parent's Guide to Pica
- Visual Supports

Adolescent/Transition

- Healthy Bodies for Boys
- Healthy Bodies for Girls
- Puberty and Adolescent Guide

Safety

- Big Red Safety Toolkit

Financial

- Financial Resources in Missouri
- Financial Planning Tool Kit

Websites

- Autism Navigator - www.autismnavigator.com
- Essentials for Parenting Toddlers and Preschoolers - <https://www.cdc.gov/parents/essentials/videos/index.html>
- OCALI - www.ocali.org
- Learn the Signs Act Early - <https://www.cdc.gov/ncbddd/actearly/index.html>

Additional comments and recommendations:

We recommend that you present this case again in:

Signature: *Brittney Stevenson, MOT, OTR/L ; Michelle Dampf, MA, CCC-SLP*

Date:

Form Status

Complete?