

ADX RECOMMENDATION Form

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Record ID

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ECHO **Autism**: Advanced Diagnosis Recommendations Form

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Email our clinic coordinator **Michael Hansen** at michaelhansen@health.missouri.edu if you have any questions or comments.

PLEASE NOTE: Project ECHO de-identified case discussions do not create or otherwise establish a clinician-patient relationship between any University of Missouri Health Care clinician and any patient whose case is being discussed in a Project ECHO setting. All information is deidentified and the participants and content experts are engaged in case-based learning.

Presenting Clinician Name: Raquel Craney

ECHO ID: DX110

Presentation date: 02-14-2024

Presentation type: New

Presenting Question:

17 year, 8 month old female, question of ASD

Additional Identified Concerns:

Brother with ASD who passed away
Family hesitant to complete evaluation for diagnosis

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

1)

Validation of Identity

Encourage the family members to validate the client's curiosity and relatability to identifying on the autism spectrum, even if a formal diagnosis does not end up happening.

2)

To best help the family understand more about autism as it presents in women, you may consider sharing some education about autism and women. Attached you will find several resources, and you can choose which ones are most appropriate to share.

3)

It may be helpful to talk with the family about the benefits to receiving a diagnosis of autism for if their daughter should need more supports in the future. A diagnosis may provide support for this young woman when the parents are not able to provide the level of support she may need later in life.

4)

Co-Existing Conditions

Consider re-examining the possibility that the client may have Tourettes. This is important because if it's determined that she has it, there are specific medications and treatments she can pursue to help with management.

Consider continuing to "check-in" with her on her mental well-being (for any underlying PTSD, other traumas). Many autistic women are extremely good at camouflaging/masking.

5)

Resources

The Art of Masking: Autistic Women who Mask: <https://www.tiimoapp.com/blog/art-of-masking-women-with-autism>

The Cost of Camouflaging Autism: <https://www.spectrumnews.org/features/deep-dive/costs-camouflaging-autism/>

Masking Infographic: <https://www.autisticallity.co.uk/masking>

6)

Resources

Practical Strategies for Supporting Mental Wellness of Teenage Girls and Women with ASD

Autistic Masking: A Dangerous Survival Mechanism (TEDx Talks)

The 4 Types of Autistic Masking

7)

Consider sharing some additional resources to enhance social functioning. The client may benefit from resources that provide "scripts" for social interactions (email, conversations, how to respond to compliments, etc.).

8)

9)

10)

11)

12)

The following tool kits/resources may be helpful:

Services to Support Developmental Progress

- Speech Language Therapy (SLP)**
- Occupational Therapy (OT)**
- Physical Therapy (PT)**
- Applied Behavioral Analysis (ABA)** - (The goal of behavior therapy is to increase behaviors that are helpful and decrease behaviors that are harmful or affect learning. Family may benefit from the implementation of techniques for understanding and changing behavior based on the principles of applied behavior analysis)
- State-based Early Intervention program (e.g., First Steps)** - (Every state has a program to support children birth to 3 who are at-risk or identified with developmental delay. Autism is typically considered an automatic qualifying diagnosis for supports and services. It is a critical first step for many children with developmental delays.)

- Early Special Education Services** - (Local school districts have early childhood programs for children between 3 and 5 years old with developmental delays who are determined to be eligible for services. Classroom based support and peer interactions are critical at an early age)
- Head Start/Early Head Start** - (This federal program supports local child learning centers to provide high-quality, developmentally appropriate learning for children. Local communities offer different programs. This website can help determine what is available in the community: <https://headstartprograms.org/>)
- Parent/Caregiver Skills Training** - (Parent training allows parents to become active participants in their child's learning and development. It can help parents learn about effective ways to support their child's skills, building and learn strategies to manage their interfering behaviors. *Help is in your hands* is a free resource by University of California-Davis with modules to show parents and clinicians how to help young children with autism connect, communicate, and learn through various activities and play exercises. Family can create a login and access all modules and videos for free at <https://helpisinyourhands.org/course>)
- Picture Exchange Communication System (PECS)** - (PECS can be successful at helping children understand the idea of symbolic communication in a manner that maximizes their visual strengths as well as how to initiate communication. Link to website <https://pecs.com/>)
- ADEPT (Autism Distance Education Parent Training)** - (Clinicians at the University of California-David developed these online, on-demand learning modules to help parents/caregivers learn more about behavior and autism. The following are particularly helpful: Module 1: Strategies for Teaching Functional Skills; Module 2: Positive Behavior Strategies for Your Child with Autism)
- Other**

Community Resources/Connections

- Regional Office** - (To access support coordination and referral to the Missouri Autism Project. Find the local regional office and contact information by county. The website can be found at <https://echoautism.org/new-diagnosis-under-age-4/> then scroll down to Missouri Resources)
- ParentLink Warm Line** - (ParentLink connects you with a Family Support Specialist who offers no-cost parenting strategies, behavior and resource guidance. Call Toll Free at 1-800-552-8522 / Local 573-882-7323, Text: 585-FAMILY1 (585-326-4591), OR email parentlink@missouri.edu your parenting questions to parenting experts. Available Monday-Friday 8:00 am - 10:00pm and Saturdays and Sundays 12:00pm - 5:00pm. The website can be found at <https://echoautism.org/new-diagnosis-under-age-4/> then scroll down to Missouri Resources)
- Autism Speaks Rapid Response Team** - (Personalized autism information and resources for any step in the autism path can be found at <https://www.autismspeaks.org/autism-response-team-art>)
- United for Children** - (This organization supports daycare professionals in helping successfully integrate children with autism and other developmental needs into daycare settings. They may also have some funding available for inclusion-based daycare. Call 1-800-467-2322 ext 32 OR visit www.unitedforchildren.org)
- Parents as Teachers** - (This is a parent education program that helps to establish positive partnerships between home, school and the community and plays a vital role in supporting families and children from the very beginning toward school readiness. Contact the local school district for more information.)

Co-Occurring Conditions

- Sleep**
- Constipation**
- Feeding**
- Seizures**
- Other**

Tools to Learn more about Autism Spectrum Disorder

- Tool Kit: A Parent's Guide to Autism** - (This guide provides information about what autism is, shares common reactions to getting the diagnosis, reminding parents to take care of themselves, tips to manage the stress that they may experience, sharing tips for supporting siblings, advocating for your child, and building a support network, vignettes of stories from families and frequently asked questions. This tool kit can be found at <https://echoautism.org/new-diagnosis-under-age-4/> then click *A Parent's Guide to Autism*)
- Tool Kit: 100 Day Kit for Young Children** - (This guide is designed to provide you with the information and tools you need to make the best possible use of the days following the diagnosis. It is a comprehensive tool filled with facts and resources such as information about symptoms, treatment, legal rights and advocacy. This tool kit can be found at <https://echoautism.org/new-diagnosis-under-age-4/> then click *100 Day Kit for Newly Diagnosed Families of Young Children*)
- Tool Kit: A Grandparent's Guide to Autism** - (This guide will help provide a better understanding of autism, as well as tips, tools, and real-life stories of how to guide and support the child and family immediately after the diagnosis and beyond. This tool kit can be found at <https://echoautism.org/family-support/> then click *A Grandparent's Guide to Autism*)
- Tool Kit: An Introduction to Behavioral Health Treatments** - (This toolkit provides behavior basics and information that may help the family understand the functions of a child's behaviors, in addition to basic strategies of increasing appropriate behavior. This tool kit can be found at <https://echoautism.org/behavior-basics/> then click *Introduction to Behavioral Health Treatments*)
- Sibling Developmental Monitoring** - (Given the increased autism risk in siblings of children with a diagnosis of ASD, consider sharing the CDC's "Learn the Signs. Act Early." resources with the family to monitor the younger sibling's developmental milestones.)
- Autism Navigator - About Autism in Toddlers and Video Glossary** - (This self-paced program will teach families about autism symptoms and supports and intervention to help their child thrive. Autism Navigator also has information about evidence-based supports for everyday activities and developmental growth charts to recognize and monitor meaningful outcomes. Family can create a login and access modules and videos at <https://autismnavigator.com/courses/>)
- Behavior Videos** - (The following videos offer some practical tips that may be helpful for this family: ABCs of Behavior and Reinforcement. The videos can be found at <https://echoautism.org/behavior-basics/> then click *Video Tool Kit: ABCs and Video Tool Kit: Reinforcement*)
- Other**

Support for Parents/Family/Caregivers

- Family to Family Peer Mentor Program** - (This program is a parent to parent/peer support network for parents/caregivers of children with developmental disabilities or special healthcare needs. This is a support system where families can ask questions, problem solve and receive support from peer mentors with similar experiences. You can find the link to their website at <https://echoautism.org/new-diagnosis-under-age-4/> then scroll down to *Missouri Resources*)
- Missouri Parents Act (MPACT)** - (This organization provides families training and/or an advocate to support them in navigating the education system related to school-based supports and services through the Individuals with Disabilities Education Act (IDEA) and the Individual Education Plan (IEP) process. The link to the Missouri programs can be found at <https://echoautism.org/education/> then click *MPACT Parent Training & Information*. Information about programs in other states can be found at <https://www.parentcenterhub.org/find-your-center/>)
- Other**

Additional comments and recommendations:

Signature: Valeria Nanclares-Nogues, PsyD

Date:

02-16-2024

Form Status

Complete?

Complete ▾