

ADX RECOMMENDATION Form

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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: Trixie Pujol

ECHO ID: DX109

Presentation date: 01-24-2024

Presentation type: New

Presenting Question:

16 y/o female, question of ASD.

Additional Identified Concerns:

Gender identity concerns
Anxiety and Depression
Cultural and familial challenges given place of residence (Kenya)
In-patient on a couple of occasions

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

1)

Consider connecting with other sources of collateral information like prior school teachers or similar from when she was younger. Ideally, it would help if there was more information about what her social communication skills were like from early development.

2)

The prior recommendation gets at the importance of developmental history: a child with phonologic disorder history, maybe autism, maybe Bipolar Type II (med induced), deserves genetic testing--which could POTENTIALLY (if positive) lead to a sort of confirmation of her own intuition. Consider discussing with parents the possibility of having genetic testing completed to help clarify diagnosis. The genetic testing, professionals would be looking for a known genetic cause of autism--a negative test doesn't rule out autism, but a positive test is substantially confirmatory...and potentially predictive of other (medical) complications. For all people with autism who manifest this level of symptoms and history in adolescence, the "yield" for a positive test would be 10-20%.

3)

These recommendations regarding diagnostic clarity get back to the issue of how a diagnosis would help her (the function of a diagnosis). Consider thinking through the difference between justification for gender identity versus how to reconcile self-reproach for failing to make friends. Or has she lost hope that she will ever secure strong friendships?

4)

Consider helping her understand what autism is and how the diagnosis is made. It may be helpful to her if she can hear more about how it is a social communication disorder and how that is the type of information we are trying to better gather to determine if autism is a good fit diagnosis for her or if what she is experiencing may be better explained in other ways.

5)

Consider asking additional questions about her social media interactions and what may be influencing her current thoughts and social circle.

6)

Encourage the parents to find support for themselves. Given the personal beliefs and the fact that their child's sexuality is illegal where they live, that is a lot to process for parents. Them gaining more understanding of how their CHILD feels may help the parents know how to support this young lady's choices.

7)

The next time you meet with this young lady, consider asking specific questions to reveal the true underpinning of her seeking an autism diagnosis. Is it that she is looking for a community of people to belong to? Does she believe that autism is the diagnosis that best fits how she experiences life? OR Could it be that she believes if she is autistic, her gender identity and sexuality may be "more accepted" by her family/friends/community, given that gender identity and sexuality are more varied in people on the spectrum compared to the non-autistic population?- Meaning, she may believe it shifts the "blame" to autism rather than her. Just a thought to consider.

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-Davis 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:

Thank you Trixie for bringing this case to our ECHO session today. This family is very lucky to have found you to help them through the diagnostic process and next steps.

Signature: Valeria Nanclares-Nogues, PsyD

Date:

01-24-2024

Form Status

Complete?

Complete ▾