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Communication: Inclusive discussions with families, providers and schools

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ECHO Autism: Early Intervention Continuing Education

- Target audience: Pediatricians, family practitioners, nurse practitioners, therapists, psychologists, community mental health professionals.
- Objective: To improve the knowledge of primary care providers and other providers who care for children with autism and other behavioral health concerns.
- The Office of Continuing Education, School of Medicine, University of Missouri is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.
- The Office of Continuing Education, School of Medicine, University of Missouri designates this live educational activity for a maximum of 1.5 AMA PRA Category 1 Credit(s)™. Physicians should only claim credit commensurate with the extent of their participation in the activity.



ECHO Autism: Early Intervention Speaker Disclosure

Current ACCME (Accreditation Council for Continuing Medical Education) rules state that participants in CME activities should be made aware of any relevant affiliation or financial interest in the previous 12 months that may affect the planning of an educational activity or a speaker's presentation(s). Each planning committee member and speaker has been requested to complete a conflict of interest statement for the *ECHO Autism: Early Intervention Series*.

Planning Committee Member and Speaker Disclosures:

- Kristin Sohl, MD, FAAP has the following relationships:
 - o Cognoa research funding
 - Quadrant Biosciences advisory board
 - Autism Navigator consultant
- No other speaker or planning committee member has a relevant financial interest



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Learning Objectives

- 1. The learner will learn how to have engaging and positive interactions with families and providers.
- 2. The learner will identify effective communication strategies to increase team cohesion.
- 3. The learner will increase efficiency in communication with team members.



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Why Communication Is Key

- Fragmented care often happens
- Providers may communicate infrequently or not at all
- Parents may be confused or have a hard time keeping track of information
- Physicians may be unaware of challenges at school
- Therapists may not know of medical and/or home challenges



The Key is Understanding

- In order to have positive interactions with families, one must understand the challenges
- Meet families where they are at that time

 - Initial diagnosis vs acceptance
 Involved parent vs struggling parent
- Listen to what the family needs or wants
- Treating families as equals



The Team Dynamic

- Children with Autism have numerous providers
 - Physician SLP

 - 0T
 - PT
 - BCBA • Teachers
 - Parents



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Family Challenges • High stress due to child's: • Cognitive impairment

- Cognitive impairment
- Behaviors
- Communication delay
- Hyperactivity
 Lack of self-care
- · Less time for normal activities
- High fatigue
- Financial Burden



Stress Continued

- Grief/Guilt
- Tension between spouses
- Tension between siblings
- Adjusting to new normal
- Multiple appointments/therapies to manage
- Being involved in other children's lives
- Medical comorbidities
- Worry about the future



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... And More Stress

- · Criticism from others
- Advice from EVERYONE
- Navigating systems
- Elopement
- Events- Church, family parties, play-dates

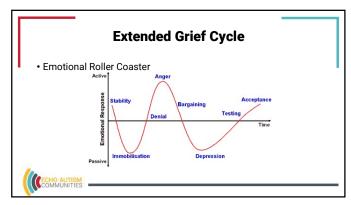


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The Journey

- Stages of Grief
 - Denial: Avoid the inevitable
 - Anger: Frustrated outpouring of bottled-up emotions
 - Bargaining: Seeking for a way out
 - Depression: Final realization of inevitable
 - Acceptance: Finding the way forward





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How to Communicate

- The best way is what will work best for families

 - Written
 Phone call
 Email
- Keep record of communication
 - School and family can see what was discussed
- · Discuss how often Daily vs weekly



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Everyone Is On The Same Team

- Families are expert on their child
 - They know what is typical for their child
 - How to manage behaviors or prevent them
 - Insight about what child is doing at home
- Families can use similar strategies at home to reinforce
 - · And vice versa



Best Practices for Talking with Families • Give positives of what happened at school

- Inquire about what struggles are happening at home
 - Open-ended question
- Discuss struggles that are happening at school
 - $\bullet\,$ But follow up with what you are doing to help
- Be willing to communicate
 - · Honor requests and don't be dismissive
- Regular communication
- Helps families feel involved and a part of their child's education
- Promotes interaction with a parent and child with limited communication



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Time to Meet

- Always start off with positive story or observation
- Ask if the family has any questions or concerns
- Use plain language
 - Varied education levels
- Avoid new labels (diagnoses) or mentioning medication
 - ADHD
 - ODD
- End on a positive note



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Being a Lifeline

- Shows you care and will be there for the family
- · Actively listen
- Celebrate successes
- Stay positive
- Prioritize next steps for the family



The Doctor Will See You Now

- Doctors are willing to hear how their patient is doing
- Communication improves ability to care for the child
- May help in making additional diagnoses
- May be able to prescribe additional resources (PT, OT, Speech)



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Lost in Translation

- \bullet Physicians may not understand the language in an IEP
 - Help to interpret goals or summary of findings
- Discuss concerns that you see in the classroom
- Make sure there is written permission for communication
- Educate or ask if the provider has any questions



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Resources: Because Knowledge is Power

- https://echoautism.org/resources/
 - 100 Day kit for Newly Diagnosed Families of School Age Children
 - A Parent's Guide to Autism
 - Challenging behaviors
 - Family services
- https://www.autismspeaks.org/
- https://www.cdc.gov/ncbddd/autism/links.html



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COMMUNITIES	

