Transforming Primary Care for Children with Autism

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Autism on the Rise

1 in 68 children have autism spectrum disorder (ASD)

almost 5x more common in boys than girls

SOURCE: CENTERS FOR DISEASE CONTROL AND PREVENTION

Chart is updated from Autism Speaks: adds CDC 2012

Autism Awareness
The Costs of Autism

• Estimated lifetime societal cost for one individual with autism at $3.2 million
• Early intervention reduces the long term cost and improves outcomes
• Billions of dollars of savings when applied across populations of children with autism
• PCPs are the front lines for this recognition and initiation of services
Supply and Demand

• Rise in autism awareness
• Rise in referrals
• “Whole Care for the Whole Family”
• Primary Care readiness for ASD?
• Shortage of specialists
What if...

- Primary Care Providers were equipped to screen more thoroughly and could send more detailed referrals?
- Primary Care Providers took additional steps to help children while waiting for a formal diagnosis?
- Primary Care Providers felt more comfortable treating medical conditions in children with autism?
- Parents felt confident in going to their PCP for their autism and developmental questions?
What if...

• There were communities equipped to care for individuals with autism without traveling to a specialist?

• Tertiary and quaternary specialists shared there knowledge and mentored PCPs to do this well?

• Specialists could **stratify** follow-up need based on severity and not lack of other options?
ECHO® Autism Clinic

Biweekly 2 hour clinic
Introductions 10 minutes
Case #1 35 minutes
Didactic 20 minutes
Case #2 35 minutes
Wrap Up 20 minutes

Hub team
- Developmental Behavior Pediatrics and/or Child Psychiatry
- Dietician
- Family Navigator
- Parent Expert
- Psychology
MISSOURI - 2010 Census Results
Total Population by County

Source: U.S. Census Bureau, 2010 Census Redistricting Data Summary File
For more information visit www.census.gov

Missouri ECHO Autism participants
Current Research

AIMS:

• Increase local access to high quality health care for children with ASD and other behavioral health concerns by providing PCPs with specialized case-based tele-education/mentoring to increase self-efficacy in assessing and treating

• Increase PCP self-efficacy with identification of ASD symptoms in children between 12 months and 18 years of age

• Increase PCP self-efficacy in assessing and treating common medical and psychiatric comorbidities in children with autism
The Pilot Numbers

• Number of Participants – 226
• Number of Unique Participants – 71
• CME Claimed – 134.5 hours
• Number of New Cases – 17
• Number of Return Cases – 7
• Number of Unique Case Presenters – 12
• Average Attendance – 18.8
• Highest Attendance – 25
• Lowest Attendance – 12
What are PCPs Learning?

• “Managing anxiety in children with ADHD and sleep problems”
• “A wealth of knowledge to help better facilitate resources to my patients”
• “Additional labs that should be done to r/o medical issues”
• “To not wait to start therapies on children who I suspect have ASD”
• “Constipation treatment options “
• “CBT is effective for depression and anxiety for patients with autism spectrum disorders”
• “new techniques to aide in helping my patients w/ sleeping issues that may help avoid medication”
What practice changes will PCPs make?

• “Early referral for services and parents understanding their shared role”
• “Be more proactive in my screening for ASD”
• “Looking for more details into comorbid diseases with Autism”
• “Starting the process of getting local resources for children with autism and screening for sleep problems”
• “I plan on using more of the picture/charts to help my patients w/ their structured sleep routines”
• “Continue to look for environmental issues over medications if applicable”
• “Will look to be a change agent in providing these interventions more fully for our patients”
ECHO® Autism Replication though the Autism Treatment Network
ECHO® Autism Network

University of California-Irvine

Arkansas Children's Hospital

Cincinnati Children's

Toronto Children's Hospital

Massachusetts's General Hospital

University of Rochester

Children's Hospital of Philadelphia

University of Pittsburg

Nationwide Children's

Vanderbilt University

University of Missouri

ECHO® Autism Network sites

ECHO® Autism Network Missouri participants
Research

• Pre- and post-intervention knowledge tests in ASD
  – Screening
  – Assessment and treatment of common medical comorbidities (sleep and constipation)

• Pre- and post-intervention chart reviews to measure PCP clinical practice/behavior change

• Self-efficacy in ASD
  – Screening and identification of ASD
  – Screening, identification, treatment of medical comorbidities (sleep and constipation)
Measuring Outcomes

Effectiveness of ECHO® Autism in increasing:
1) Rates of ASD screening during 18 month well-visits
2) Proportion of children with ASD screened and treated for sleep problems and constipation
3) Proportion of children with ASD on psychotropic medications with appropriate monitoring
Thank You

- Attendees
- Staff and providers at the Thompson Center
- Missouri Telehealth Network
- Families of children with autism
- Health Resources Services Administration/Autism Intervention Research for Physical Health
- Missouri Telehealth Network
- Sears Departmental Trust
- WellCare Health Plan
Bringing Best Autism Care to Primary Care
Changing the World, Fast!