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Autism Translational Research Program: Increasing Access to Evidence-Based Care for Pediatric Patients With Autism

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The purpose of this presentation is to discuss the prevalence of pediatric autism and the endorsed, evidence-based practices for management of these patients. Pediatric autism is currently at its highest rate. A recent estimate states that one in 59 children, ages 3 through 17 years, are being diagnosed with the autism (Autism Speaks, 2015; Autism Speaks, 2018). Autism can be reliably diagnosed as early as age 2 years and early intervention provides the best opportunity for optimal outcomes. Evidence-based interventions and treatment initiated by 3 years of age gives these patients the greatest possibility to experience the best outcomes (Centers for Disease Control and Prevention [CDC], 2016). Despite this, analysis of current evidence in pediatric autism evaluation, treatment, and management shows that pediatric patients with autism are not receiving accurate and timely evidence-based care in primary care settings. As an example, in a recent seven state case study, 72% of children identified with autism had a diagnosis in their records, however, most of the children were not diagnosed until age 4 years and 4 months (CDC, 2016). Of these children, 20% had documented symptoms of autism in their records, but were not receiving special service as they were still awaiting an official evaluation for and diagnosis of autism (CDC, 2016). Data collected in 2007 showed that only 22.6% of children aged 10-35 months were screened for autism (Rice, C., Braun, K., Kogan, M., Smith, C., Kavanagh, L., Strickland, B., & Blumberg, S. J; 2014). Unfortunately, in many areas, these rates have not improved in the past 10 years (CDC, 2016). Hindrance to evidence-based practice has been identified as a critical concern in the care of pediatric patients with autism (CDC, 2016). Time constraints, massive amount of healthcare literature, and a non-supportive organizational structure are known barriers to implementing evidence-based practices in healthcare (Majid, S., Foo, S., Luyt, B., Zhang, X., Theng, Y., Chang, Y., & Mokhar, I. A., 2011; Wallis, 2012).

As the incidence of pediatric autism continues to rise, it is imperative for healthcare leaders to work together and create strategies that improve access to evidence-based care in a timely manner to better serve these children. (CDC, 2016). While all healthcare leaders have the obligation to respond to the steadily increasing prevalence of pediatric autism, much responsibility is placed on primary care clinicians to manage their complex care. As front-line providers, primary care clinicians administer developmental screenings, order and interpret diagnostic tests, make referrals, and oversee complications and co-morbidities that are associated with autism. This presentation is designed to equip primary care clinicians in understanding the complexities of pediatric autism and increasing the clinician's confidence in managing the care of these complicated patients.

The economic concerns associated with pediatric autism serve as an important factor in adjusting the care these patients are receiving in primary care clinics. caring for

pediatric patients with autism is estimated to cost at least \$17,000 more per year than caring for a child without autism (CDC, 2016). Nationally, this equates to over \$11.5 billion yearly (CDC, 2016). Costs include health care, education, autism-related therapy, family-coordinated services, and professional caregiver assistance (CDC, 2016). The estimated cost to the United States for autism care in 2015 was \$268 billion, with projected costs rising to \$461 billion in 2025 if autism's prevalence remains at today's rates (Leigh & Du, 2015). Mothers with children who have autism have reported the need to stop working to care for their child (CDC, 2016). Typically, mothers are employed work about 7 hours less per week and earn 56% less than mothers of children with no major health issues (CDC, 2016). Another reason why it is imperative to improve access to evidence-based care for pediatric patients with autism is so these children are able to function and thrive to their fullest potential. It is important to value the strengths and abilities of those who have autism. An estimated 46% of individuals with autism have above average intelligence (CDC, 2016). Individuals with autism can be strong visual and auditory learners; can learn things in detail; can remember the learned information for a prolonged time; and can excel in math, science, music, or art (National Institutes of Mental Health [NIMH], 2016). They have a place in our society, and we will benefit as a society from their contributions.

The presentation will cover the implementation and results of the Access to Autism pilot project that occurred in the winter of 2018. The purpose of this pilot project was to decrease the time it took for pediatric patients with autism to receive evidence-based treatment through the use of a clinical practice guideline designed especially for primary care clinics. This guideline filled the knowledge gap regarding how to get up-to-date, evidence-based care of pediatric patients with autism from research to practice. The clinical practice guideline was specifically created to be used in primary care clinics for pediatric patients from ages 9 to 60 months who present to primary care clinics for a well-child evaluation. It lists appropriate screening tools and offers step-by-step recommendations for healthcare providers to follow when a pediatric patient is identified as being at-risk for autism. The guideline was implemented for 8 weeks by 9 primary care healthcare providers. Surveys were utilized to evaluate provider satisfaction of the guideline, and to assess provider knowledge of pediatric autism care before and after the implementation period. Descriptive statistics explaining the project's results will be displayed during the presentation.

It is expected that discussing the Access for Autism pilot project among healthcare providers will continue to positively affect the percentage of pediatric patients who receive early intervention. The clinical practice guideline aligns clinical practice with the Healthy People 2020 objectives and the American Academy of Pediatrics recommendations. During this presentation, these most current recommendations will be explained, along with billing and coding references for clinicians to use to be fully compensated for their services. Practice changes should reflect a growth in the number of children with autism who are enrolled in special services such as physical, speech, developmental and occupational therapy, by age 48 months in keeping with current recommendations (Healthy People 2020, 2017). The insight gained from this project serve as the first steps in seeking to remove barriers to evidence-base care in this rapidly growing, vulnerable population, and will be beneficial for all of the participants at the Sigma Theta Tau convention.

Title:

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Keywords:

Autism, Pediatric and Primary Care

References:

Autism Speaks. (2015). National Health Interview Survey underscores gap between the number of kids diagnosed with autism and the number receiving services. Retrieved from <https://www.autismspeaks.org/science/science-news/new-government-survey-pegs-autism-prevalence-1-45>

Autism Speaks. (2018). Autism Prevalence. Retrieved from <https://www.autismspeaks.org/what-autism/prevalence>

Centers for Disease Control and Prevention. (2016). Community report on autism. Retrieved from https://www.cdc.gov/ncbddd/autism/documents/community_report_autism_arkansas_web.pdf

Healthy People. (2017). Increase the proportion of children with ASD enrolled in special services by 48 months of age. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/Maternal-Infant-and-Child-Health/objectives#4874>

Majid, S., Foo, S., Luyt, B., Zhang, X., Theng, Y., Chang, Y., & Mokhar, I. A. (2011, July). Adopting evidence-based practice in clinical decision making: Nurses' perceptions, knowledge and barriers. *Journal of the Medical Library Association*, 99(3), 229-236. <http://dx.doi.org/10.3163/1536-5050.99.3.010>

National Institute of Mental Health. (2016). Autism Spectrum Disorder: Overview. Retrieved from <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>

Rice, C., Braun, K., Kogan, M., Smith, C., Kavanagh, L., Strickland, B., & Blumberg, S. J. (2014). Screening for developmental delays among young children: National Survey of Children's Health. Retrieved from *Morbidity and Mortality Weekly Report*: https://www.researchgate.net/publication/265516534_Screening_for_Developmental_Delays_Among_Young_Children_---National_Survey_of_Children%27s_Health_United_States_2007

Wallis, L. (2012, December). Barriers for implementing evidence-based practice remain high for U.S. nurses. *American Journal of Nursing*, 112(12), 15.
<http://dx.doi.org/10.1097/01.NAJ.0000423491.98489.70>

Abstract Summary:

As pediatric autism prevalence continues to rise, primary care clinicians must be equipped to assume more responsibility in the management of these vulnerable patients. This presentation details evidence-based recommendations for primary care clinicians to improve their diagnostic, treatment, and referral practices in the care of pediatric patients with autism.

Content Outline:

Introduction: Prevalence of pediatric autism and documented delay in receiving evidence-based care.

1. Statistics regarding prevalence increasing.
2. Statistics regarding documented delay in receiving evidence-based care.
3. Introduction of Access for Autism EB Guideline

Body:

1. Main Point #1: Screening is essential and early intervention is vital.
 - Statistics regarding screening inadequacies in primary care.
 - AAP/CDC recommendations
 - WHO recommendations
 - Hindrances to implementing EB care
 - Provider Resistance
 - Cultural Barriers
 - Financial Restraints
 - Time Constraints
 - Staff Concerns
2. Main Point #2: Autism Risk Factors
 - Past Medical History
 - Family History
 - Social History
3. Main Point #3: First-Tier Interventions
 - Blood Test
 - Audiology Evaluation
 - Developmental Evaluation
 - Speech Therapy
 - Physical Therapy
 - Occupational Therapy
 - Follow-up Evaluation
4. Main Point #4: Second-Tier Interventions
 - Genetics
 - Sleep Evaluation
 - Gastrointestinal Evaluation
 - Neurological Evaluation
5. Main Point #5: Access for Autism Program Pilot Results

- Implementation Period Results
 - Provider Knowledge Score
 - Provider Satisfaction Score
- Conclusion: Future Implications for Access for Autism Program
1. Repeat Study with Larger Number of Participating Clinics
 2. Disseminate Findings
 3. Survey Providers to Evaluate Resistance

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Author Summary: Dr. Michele Kilmer has been advocating for pediatric patients with autism since 2006. The study of pediatric autism is her life's work, and she is committed to inspiring health care providers to be a part of the solution for these vulnerable patients. Through the Access for Autism program, Dr. Kilmer is working to create and disseminate guidelines and recommendations for overcoming barriers preventing pediatric patients from receiving evidence-based care in primary care clinics.