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Access to Autism Pilot Program

Michele Kilmer, DNP, APRN, CPNP-PC

Assistant Professor

The University of Arkansas

Eleanor Mann School of Nursing

Fayetteville, Arkansas

Disclosures

- I have nothing to disclose.

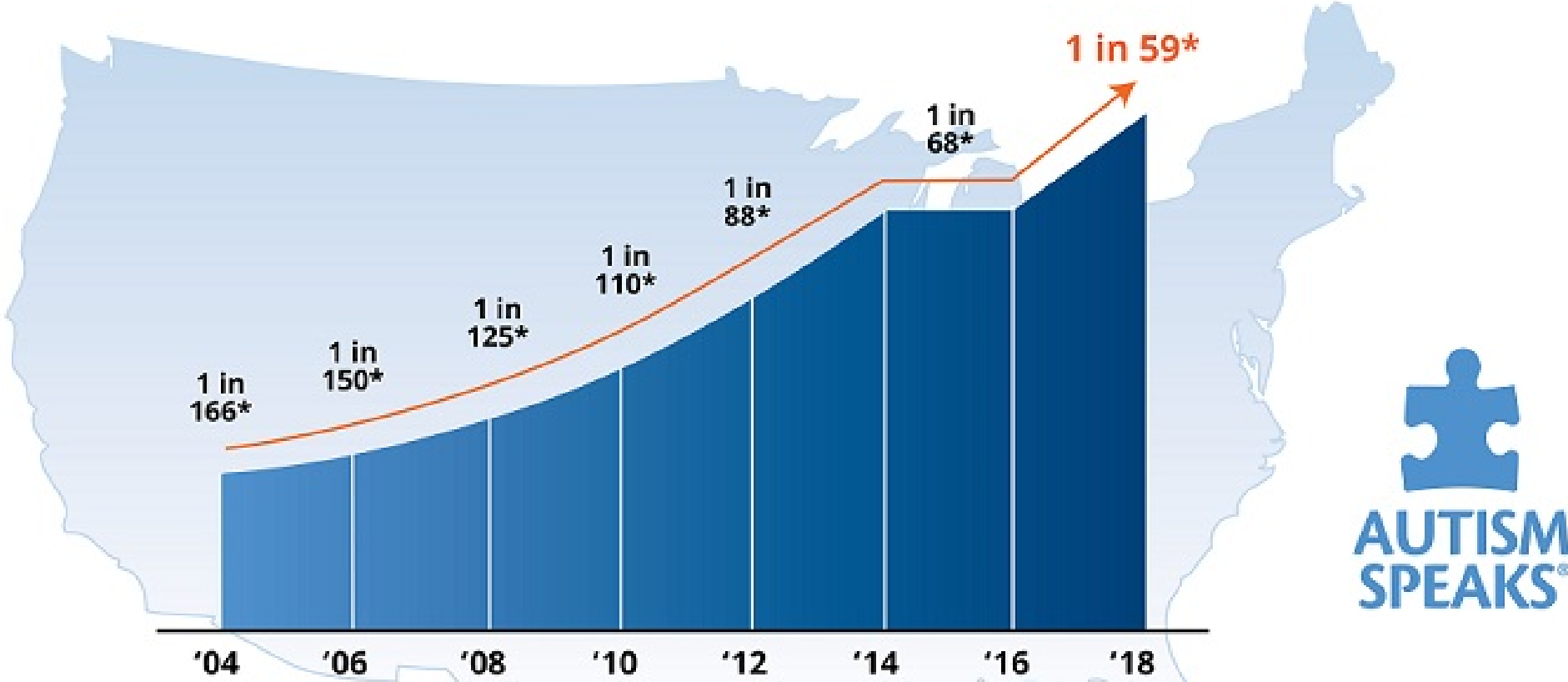


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Autism Prevalence in the United States

Estimated Autism Prevalence 2018



* Centers for Disease Control and Prevention (CDC) prevalence estimates are for 4 years prior to the report date (e.g. 2018 figures are from 2014)

Autism Facts

- Documented delay in evaluating, diagnosing, and initiating treatment
- Can be reliably diagnosed as early as age 2 years
- Evidence-based interventions and treatment initiated by age 3 years give these patients the greatest possibility to experience the best outcome
- The death rate among patients with autism is twice as high as the general population



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Autism Facts continued

- Boys are 5 times more likely to be identified with autism than girls
- Mortality rate of female patients with autism is higher than males
- White children are more likely to be identified with autism than black or Hispanic children



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Access for Autism Pilot Study



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Access to Autism: Problem Statement

- Pediatric patients with autism are not receiving evidence-based care in primary care clinics in a timely manner
- Known hindrances include:
 - Time constraints
 - Massive amount of healthcare literature
 - Non-supportive organization structure
 - Staffing concerns
 - Cultural barriers
 - Clinician resistance



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Access to Autism: Purpose Statement

- The purpose of the pilot program was to increase the amount of evidence-based care that was provided to pediatric patients between the ages of 6 months through 5 years who were identified as being at risk for autism



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Access to Autism: Setting and Sample

- Nine nurse practitioners
- Two primary care clinics
- Experience levels ranging from novice to expert
- Used the guideline for all well-child visits from 9-60 months within an 8-week implementation period



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Access to Autism: Clinical Practice Guideline

- World Health Organization 2020 Objectives
- National Institute of Mental Health
- American Academy of Pediatrics



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Access to Autism: First-Tier Interventions

Diagnostic Studies

- Chromosomal Microarray
- FMR1 DNA
- Lead
- Metabolic Screen
- Audiology Evaluation

Referrals

- Developmental Evaluation
- Speech Therapy Evaluation
- Physical Therapy Evaluation
- Occupational Therapy Evaluation
- Psychiatric/Psychology Evaluation
- Early Intervention
- Follow-Up within 4 weeks



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Access to Autism: Second-Tier Interventions

- Genetics Evaluation
- Sleep Evaluation
- Gastrointestinal Evaluation
- Neurologic Evaluation



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Access to Autism: Measurements

- Percentage of patients with:
 - Developmentally appropriate evaluations for autism during well-child examinations
 - Concerns for autism who were referred to specialists and therapies
 - Concerns for autism who receive genetic or other laboratory testing



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Access to Autism: Measurements continued

- Number of nurse practitioners who:
 - Verbalize understanding of autism diagnosis, evaluation, and management after receiving the clinical practice guideline compared to before
 - Were willing to follow the clinical practice guideline recommendations
 - Found satisfaction with the clinical practice guideline



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Access to Autism: Results

- Knowledge Survey:
 - 58 total items
 - 1 open response
 - 20 Likert scale practice statements
 - 37 True/False statements
- Pre-implementation results
- Implementation analysis
- Post-Implementation results

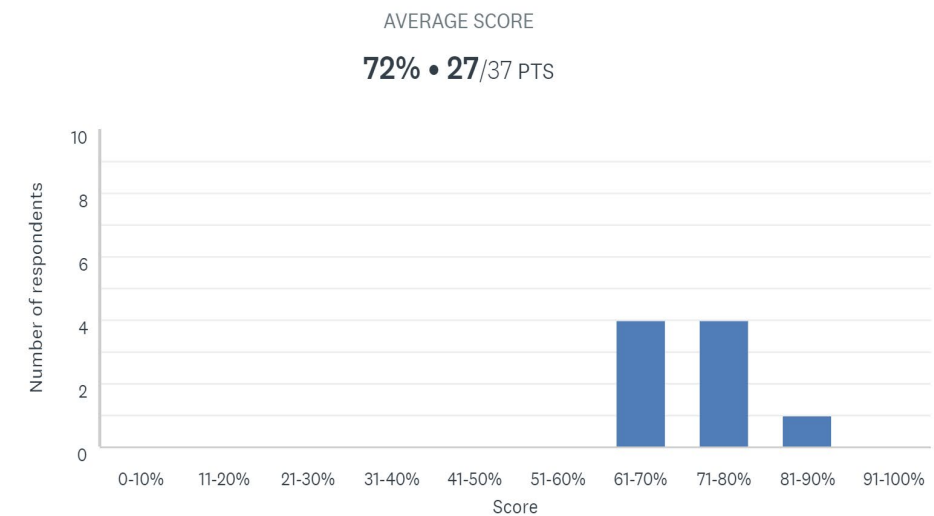


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Access to Autism: Pre-Implementation Data

- Average score: 72%; 27/37 points
- Standard deviation: 7%
- Lowest score: 62%
- Median score: 73%
- Highest score: 86%



STATISTICS

Lowest Score	Median	Highest Score
62%	73%	86%

Mean: 72%

Standard Deviation: 7%



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Access to Autism: Implementation Analysis

- 44% (4/9) providers evaluated pediatric patients that met project parameters
- 9 total patients
 - 6 male
 - 3 female
- Ages 12-49 months, median age 24 months, average age 22 months



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Access to Autism: Implementation Analysis

- 33% (3/9) patients identified with developmental delay concern
 - Speech and further developmental evaluation
 - Speech and local ECI
 - Occupational, developmental evaluation, and local ECI. Also presented with sleep dysfunction
- None were referred to audiology, physical therapy, psychiatry or psychology, gastroenterology, or genetics
- None received serum laboratory testing

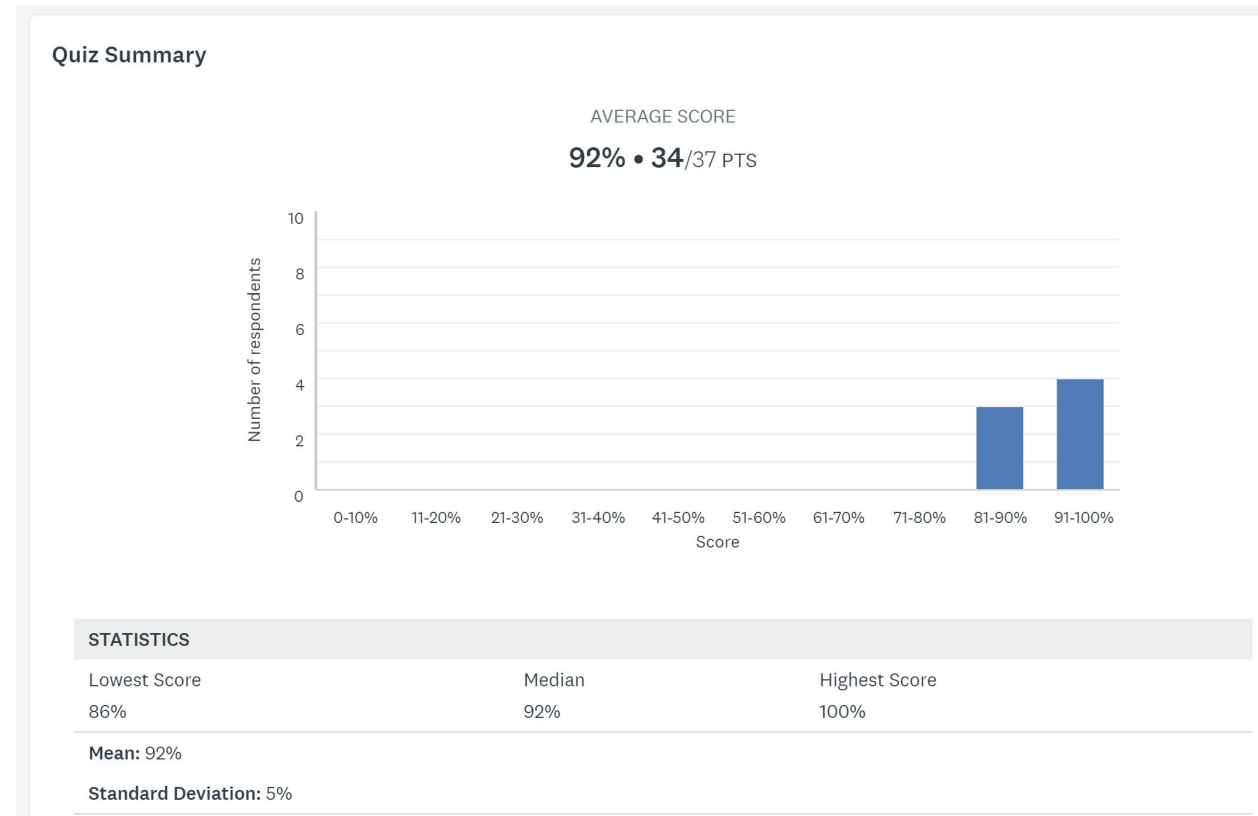


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Access to Autism: Post- Implementation Data

- Average score: 92%; 34/37 points
- Standard deviation: 5%
- Lowest score: 86%
- Median score: 92%
- Highest score: 100%



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Access to Autism: Confidence of Care

- Built practitioners' confidence in caring for pediatric patients with autism
- Program efficacy
 - Beneficial for the providers
 - Increased access to evidence-based care for pediatric patients with autism
 - Improved practitioners' knowledge of pediatric autism and appropriate interventions



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Access to Autism: Program Implications

- The number of patients identified with developmental concern was 33%
 - Higher than the documented concern that 1 in every 6 children with a developmental disorder
- Satisfaction scores substantiated use of the guideline in primary care clinics
- Identified pediatric patients at risk for autism



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Access to Autism: Program Implications continued

- Patients identified with developmental delay were referred to appropriate services in a timely manner
- Guideline can be reasonably and easily integrated into normal practice delivered to pediatric patients in primary care clinics
- Provider knowledge improved after receiving education on the use of the clinical practice guideline



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Access to Autism: Program Implications continued

- The providers picked which of the first-tier recommendations they wanted to follow
- Time constraints, staffing concerns, provider resistance, and cultural barriers persist as the top hindrances to evidence-based care practices in primary care clinics
- Future studies must assess these hindrances, recommend solutions, and test the solutions to see if they are effective



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Questions?



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Thank you!

Michele Kilmer, DNP, APRN, CPNP-PC

Assistant Professor

The University of Arkansas

Eleanor Mann School of Nursing

606 N. Razorback Rd

Fayetteville, AR 72701

michelek@uark.edu



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