Access to Autism
Pilot Program

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Disclosures

- I have nothing to disclose.

Autism- Global Prevalence

- In 2018, estimated 1 in 160 children
- Unknown in low and middle-income countries
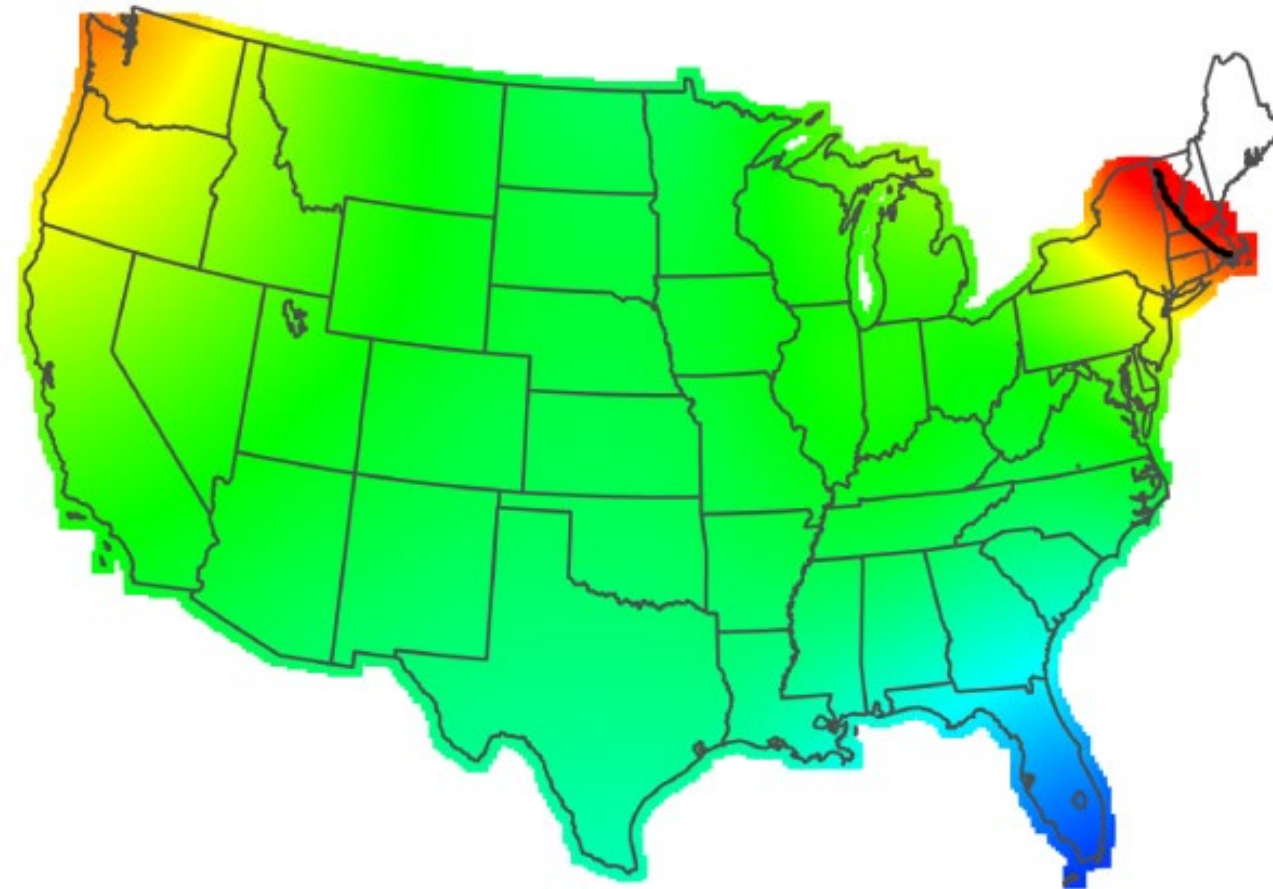- Increasing

Autism- Global Key Facts

- Subject to stigma, discrimination, and human rights violations

- Inadequate access to services and support

- 3 components: Impaired social behavior, impaired communication and language, and a narrow range of interests

Autism in the United States

Autism Prevalence in the United States

Estimated Autism Prevalence 2018

1 in 59*

1 in 68*

1 in 88*

1 in 110*

1 in 125*

1 in 150*

1 in 166*

'04 '06 '08 '10 '12 '14 '16 '18
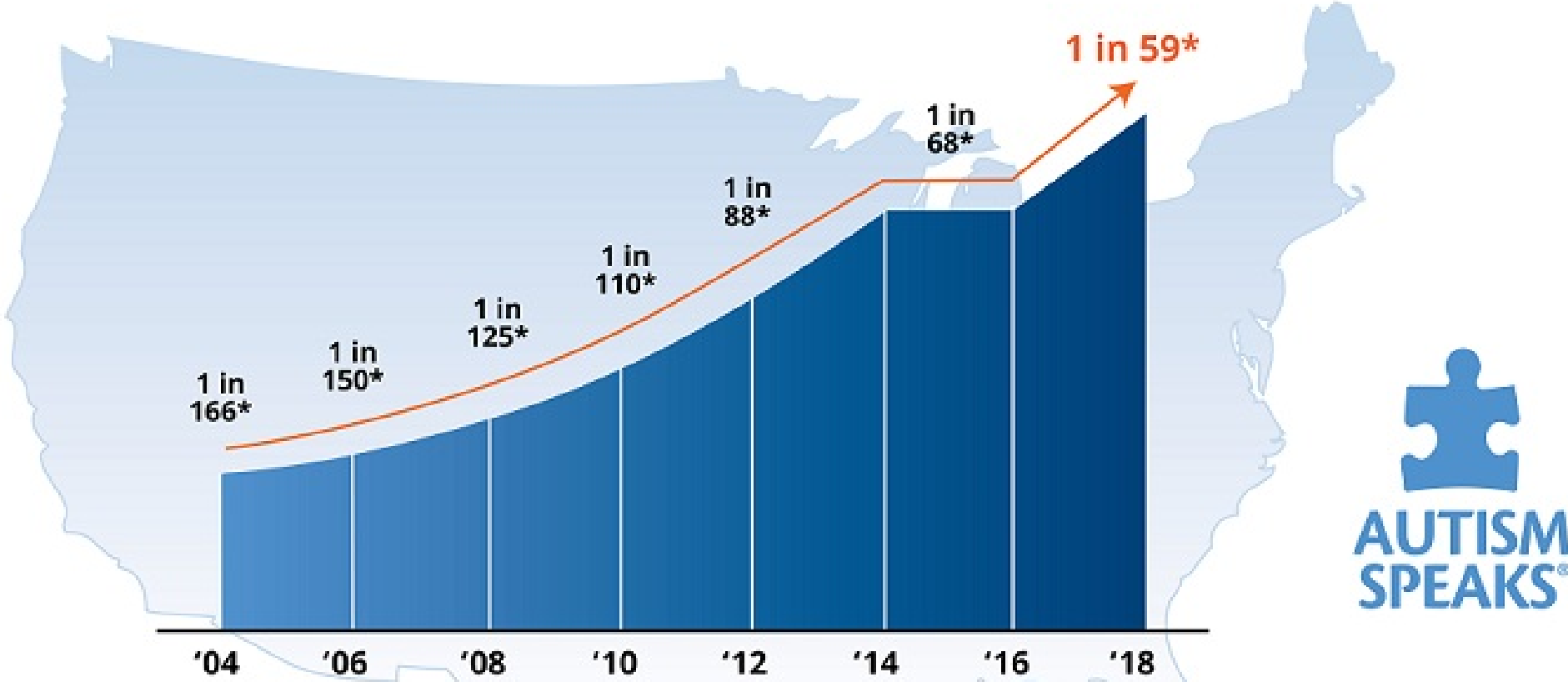
* Centers for Disease Control and Prevention (CDC) prevalence estimates are for 4 years prior to the report date (e.g. 2018 figures are from 2014)

AUTISM SPEAKS®

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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

Autism Risk Factors: Past Medical History

- Prenatal conditions

- Traumatic events that occur during birth and postnatally

- Prematurity

- Low-birth weight

- Maternal use of valproic acid and thalidomide

- Parental age

Autism Risk Factors: Family Medical History

- Fragile X
- Certain genetic concerns
- Sibling with autism

Autism Risk Factors: Social History

- Socioeconomic status

- Race

- Families with unemployed adults

- Persons with no diploma

- Immigrants

- Single-parent families

"I'm different, not less"

-Temple Grandin

- 46% have above average intelligence

- Strong visual and auditory learners

- Learn small details

- Remember learned information for prolonged time

- Excel in math, science, music, art

Access for Autism Pilot Study

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

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

Access to Autism: Setting and Sample

- Nine nurse practitioners
- Two primary care clinics in New Hampshire
- 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

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

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
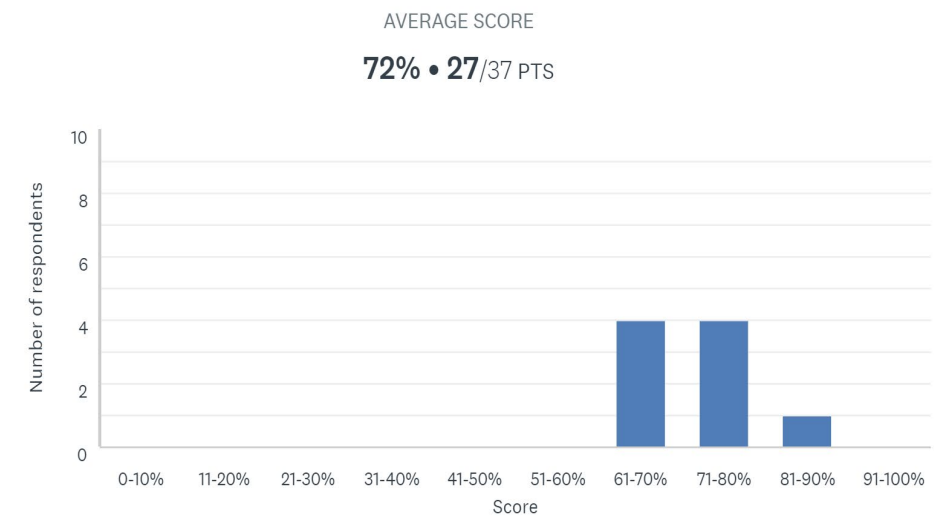- Post-Implementation results

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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%

AVERAGE SCORE

72% • 27/37 PTS

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

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
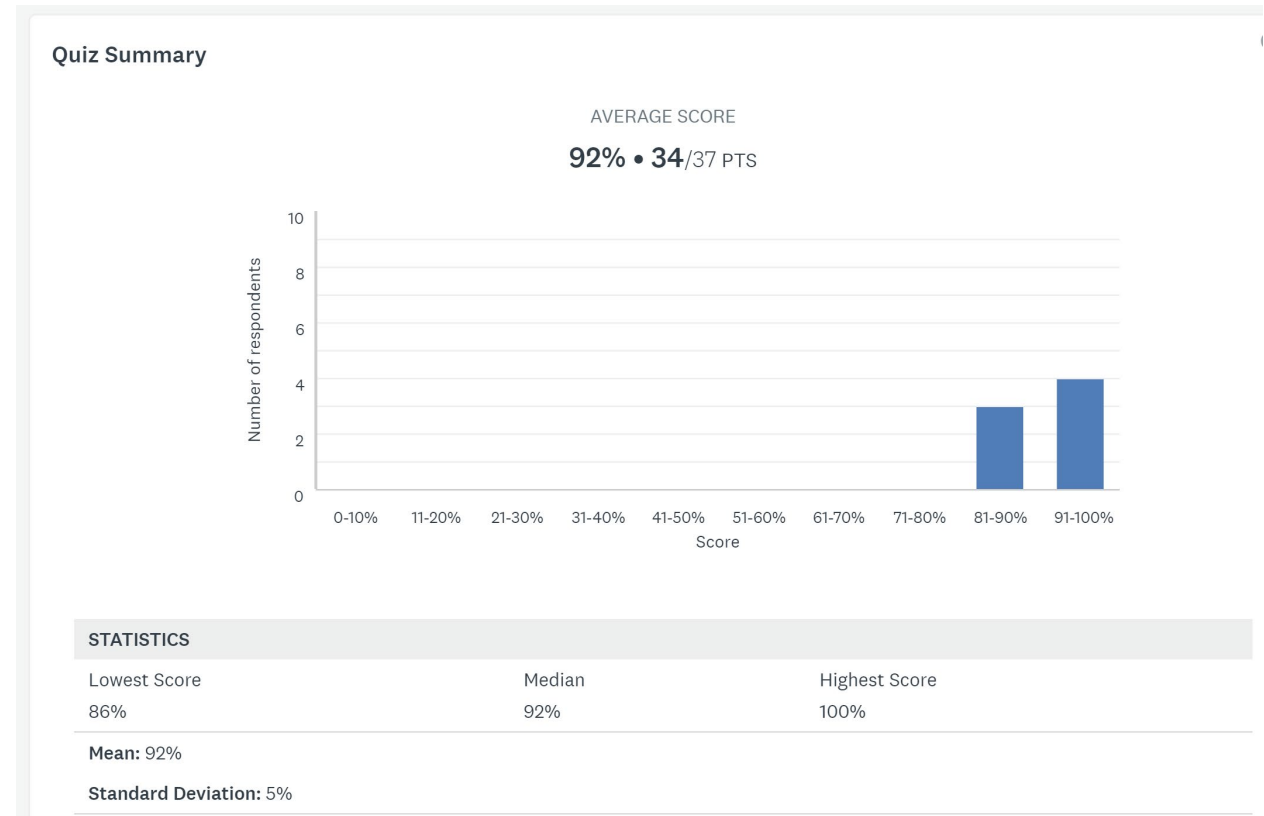- None received serum laboratory testing

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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%

Quiz Summary

AVERAGE SCORE

92% • 34/37 PTS

STATISTICS

Lowest Score	Median	Highest Score
86%	92%	100%

Mean: 92%

Standard Deviation: 5%

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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

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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Access to Autism: Research Trajectory

- Clinical Trial with at least 500 patients
  - Duration of implementation: 12 months
  - Perform PDSA evaluation to evaluate progress and recommend practice changes
  - Collaborate with local specialty therapy clinics to build a network of providers

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Access to Autism: Research Trajectory continued

- Qualitative Research
  - Assess cultural and socioeconomic factors present in local clinic
    - Develop interventions to overcome hindrances
  - Assess staffing concerns present in local clinic
    - Develop interventions to overcome hindrances

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Access to Autism: Research Trajectory continued

- Survey
  - Interview local primary care clinicians to ascertain resistance factors
  - Develop survey based on this information
  - Implement survey to clinics in northwest Arkansas

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Questions?

Thank you!

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