Wisconsin Legislative Council Symposia Series on Early Access to Autism Treatment

Week 1: "Early Childhood Autism Screening and Diagnosis"

September 8, 2020

Maureen Durkin, PhD, DrPH
Angelica Salinas, MS
Maria Stanley, MD
Gail Chödrön, PhD
Lindsay McCary, PhD

Waisman Center
University Center of Excellence in Developmental Disabilities
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What do we know about the epidemiology of autism spectrum disorder in Wisconsin?

Maureen Durkin, PhD, DrPH

Angelica Salinas, MS

Population Health Sciences

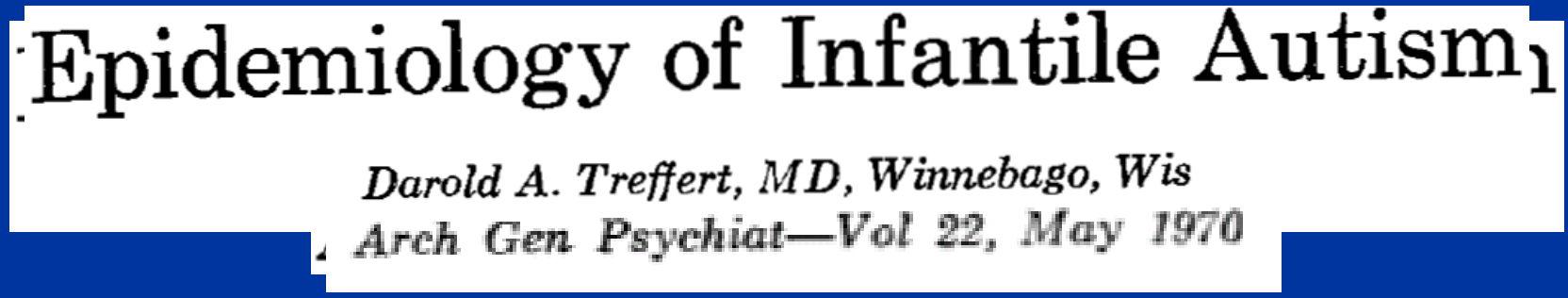
Waisman Center
University of Wisconsin-Madison

Epidemiology

- The study of the frequency & distribution of diseases, disability or other health outcomes in ***populations***

- A basis for determining
  - Prevalence, incidence and impacts
  - Service needs
  - Causes and risk factors
  - Outcomes over the life-course
  - Effectiveness & cost-effectiveness of treatments
  - Public health policy

1st epidemiologic study of autism in the U.S.



Epidemiology of Infantile Autism

Darold A. Treffert, MD, Winnebago, Wis

Arch Gen Psychiat—Vol 22, May 1970

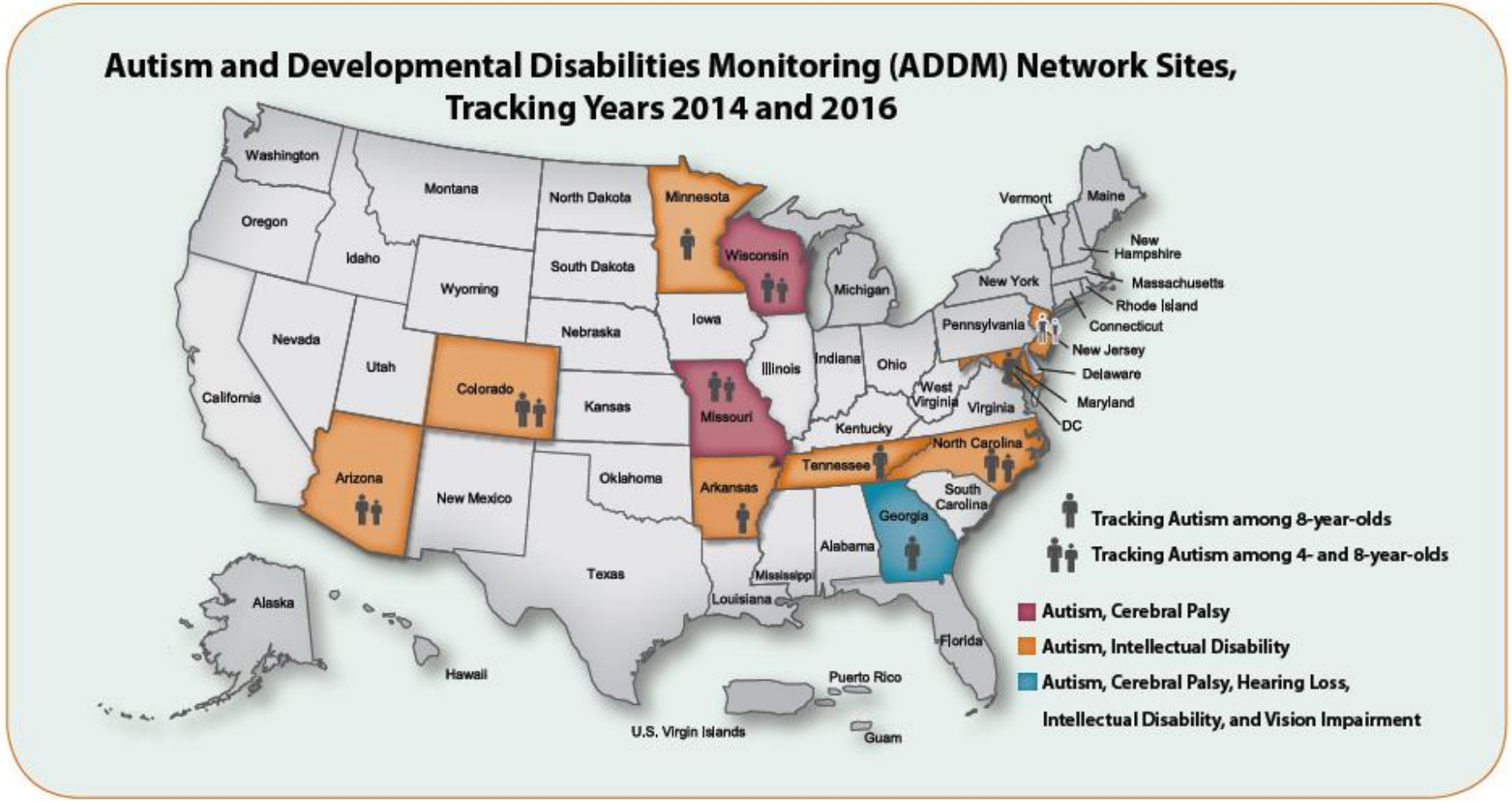
- Prevalence:

  280 cases among 899,750 **Wisconsin** children, ages 3-12 years

  - 3.1 / 10,000 (1 in 3,226 children)
  - 3.4 : 1 ratio of boys to girls

Centers of Disease Control and Prevention (CDC)
Center on Birth Defects and Developmental Disabilities

ADDM NET
Autism and Developmental Disabilities Monitoring Network

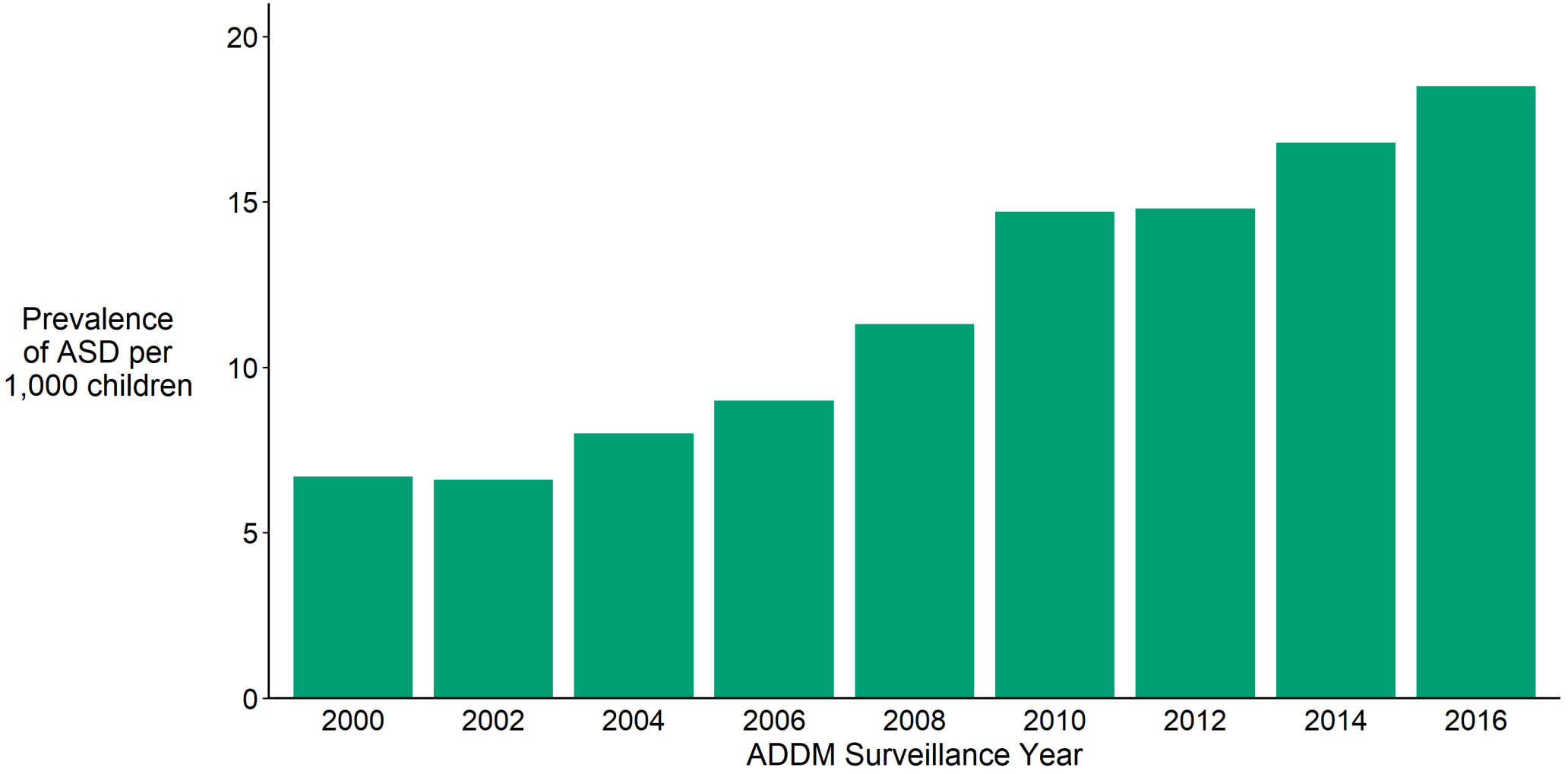


Centers for Disease Control and Prevention
MMWR
Surveillance Summaries / Vol. 63 / No. 2

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network,

Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by surveillance year

Autism and Developmental Disabilities Monitoring Network

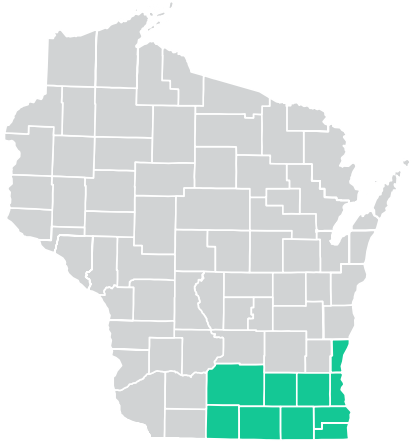



1 in 54
8-year-old children living in ADDM Network sites were identified with ASD in 2016

A Snapshot of Autism Spectrum Disorder in

Wisconsin

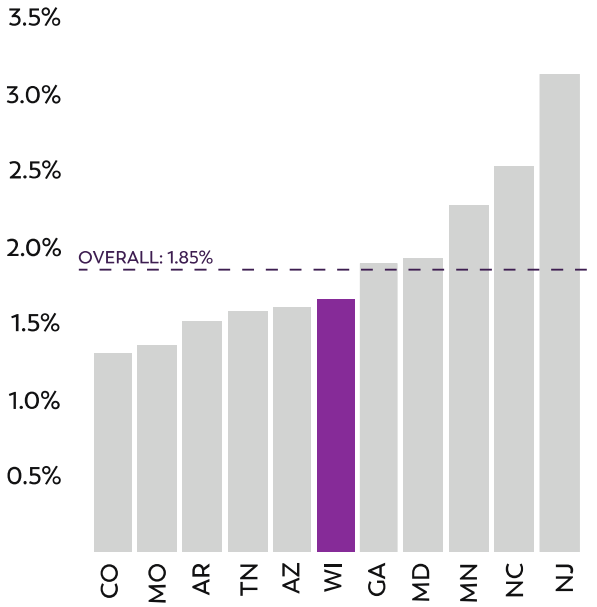
Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

1 in 60

or 1.7% of 8-year-old children in an area of Wisconsin were identified with ASD by WISADDS in 2016

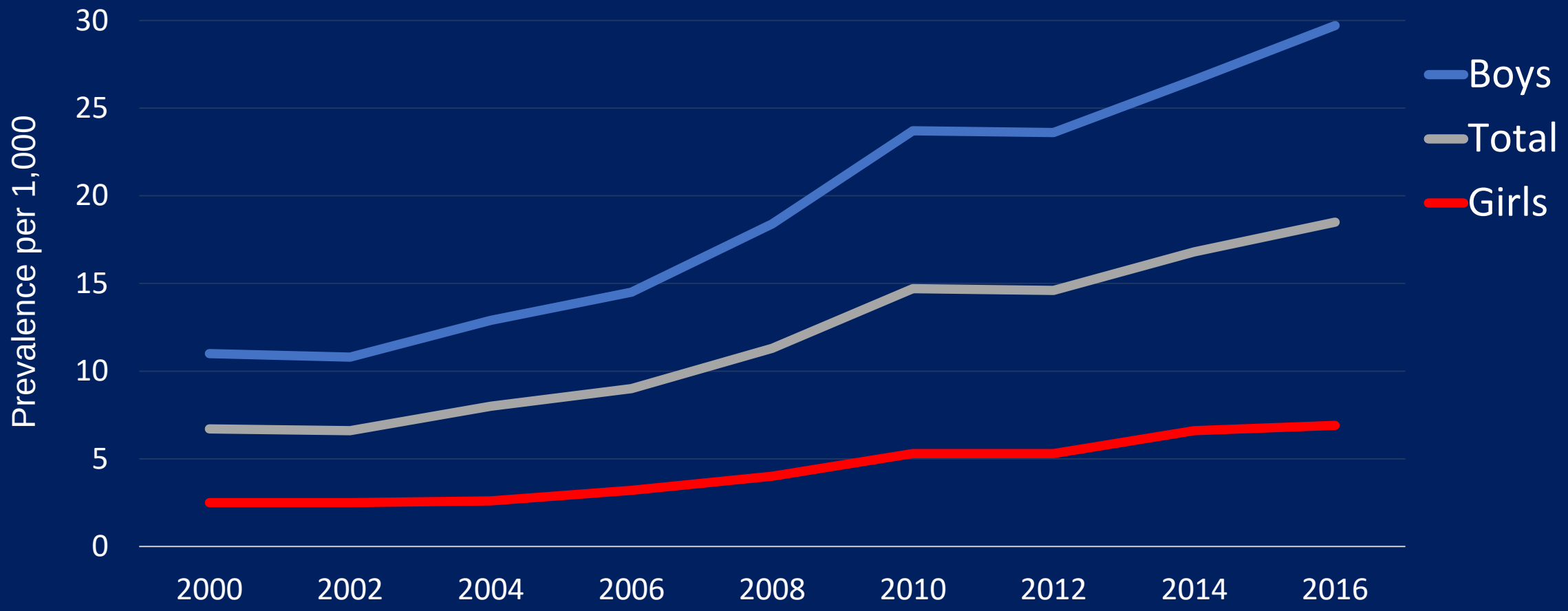


"We have the opportunity to work with a lot of different people in the communities we serve. Being able to use WISADDS data to inform parents, educators, medical personnel, social workers, and more helps us deliver trusted, accurate information that everyone can understand. Recently we have been meeting with teams around early identification and screening. The information about when something was noticed and when something was diagnosed helps our teams figure out where the gaps are in the system of care."

TIM MARKLE, Director of the Southern Regional Center for Children and Youth with Special Health Care Needs, Wisconsin

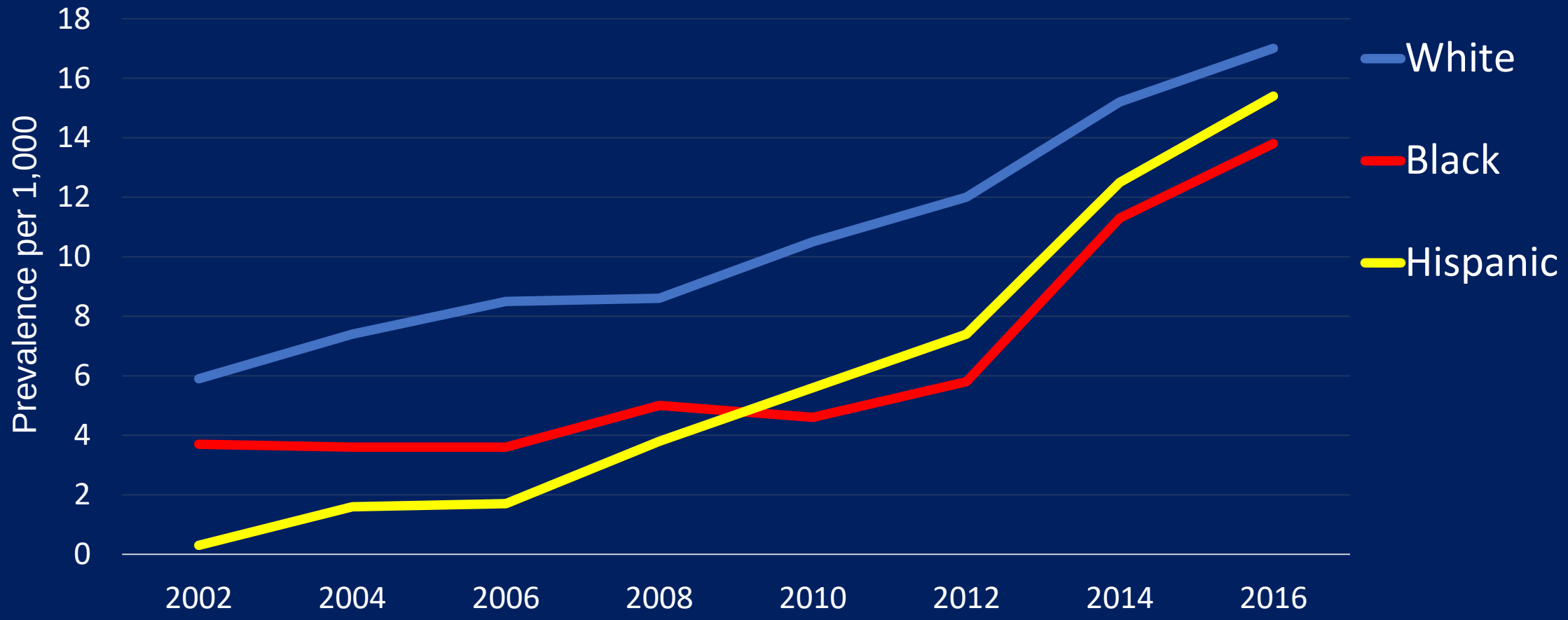
https://wisadds.waisman.wisc.edu/

Rise in Autism Prevalence Among 8 Year-Old Children in the US, 2000-2016, by Sex



Sources: CDC's ADDM Network ASD prevalence reports, MMWR, published 2007-2020.

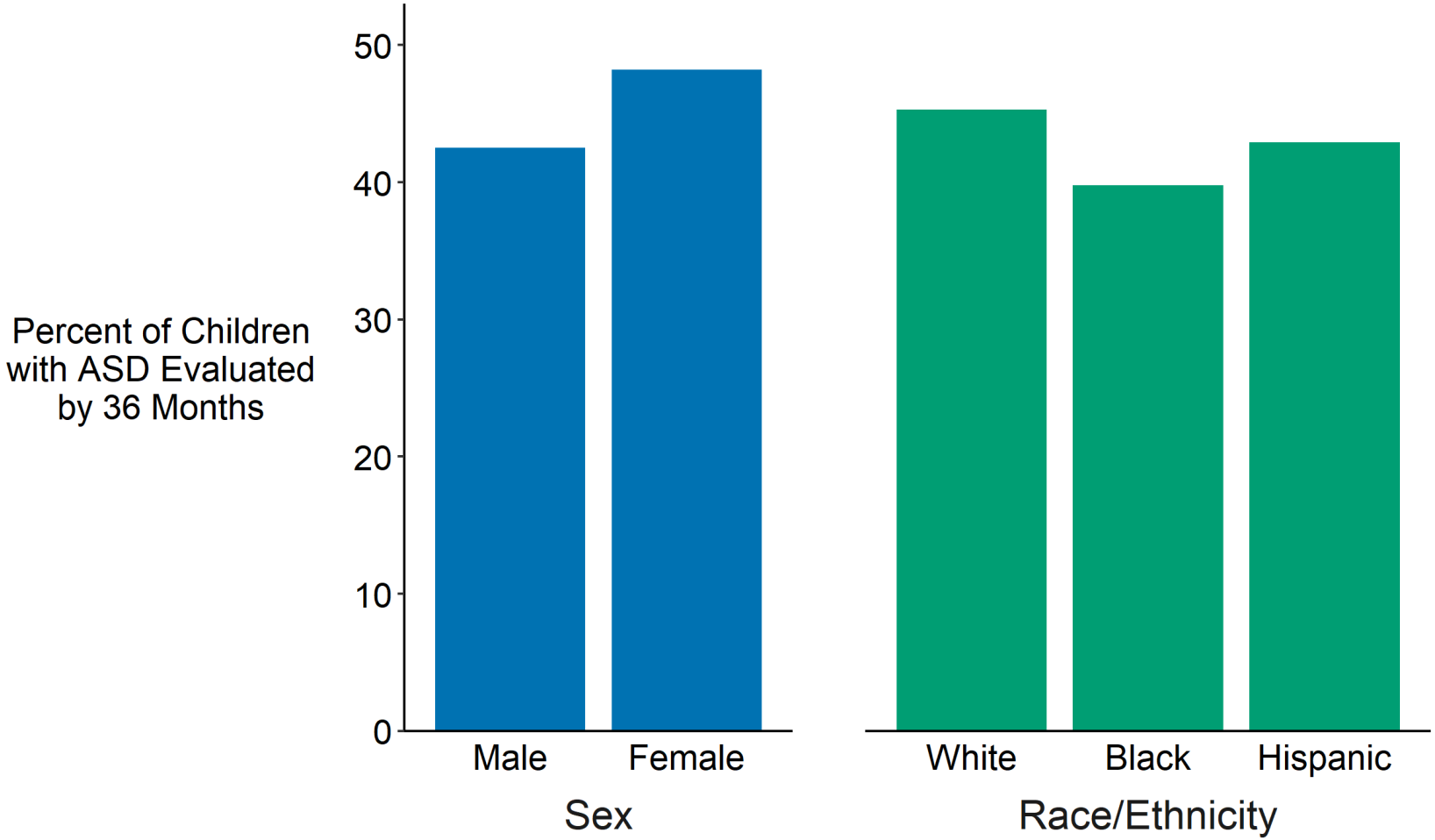
Rise in Autism Prevalence Among 8 Year-Old Children in the Wisconsin, 2000-2016, by Race/Ethnicity



Sources: CDC's ADDM Network ASD prevalence reports, MMWR, published 2007-2020.

<50% of Children with Autism Have a Developmental Evaluation by age 3 Yr

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016



In 2016, 19% of children with autism in Wisconsin had not received a diagnosis by age 8 years; among those who did, median age was >4 years.

Site/Characteristic	No. with ASD	All children with an ASD diagnosis*	
		No.	Median age (mos) at diagnosis
Site			
Arizona	282	193	57.0
Arkansas	606	489	56.0
Colorado	537	362	48.5
Georgia	456	306	55.0
Maryland	192	150	47.5
Minnesota	313	170	56.0
Missouri	213	194	56.0
New Jersey	1,036	844	51.0
North Carolina	489	280	38.0
Tennessee	405	307	51.0
Wisconsin	579	469	49.0

Among children with autism, there's a large gap between median age at first developmental concern (~12 months) and age at evaluation and diagnosis.

WISCONSIN MEDICAL JOURNAL

Socioeconomic Disparity in the Prevalence of Autism Spectrum Disorder in Wisconsin

Matthew J. Maenner, BS; Carrie L. Arneson, MS; Maureen S. Durkin, PhD, DrPH

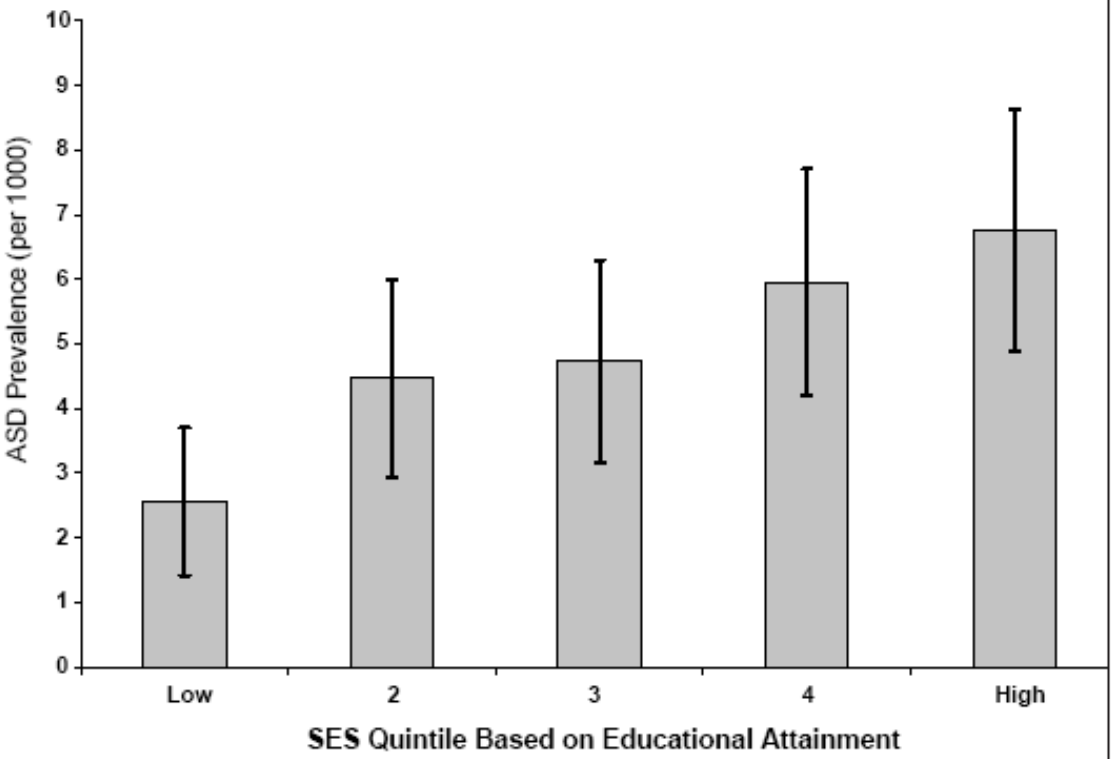
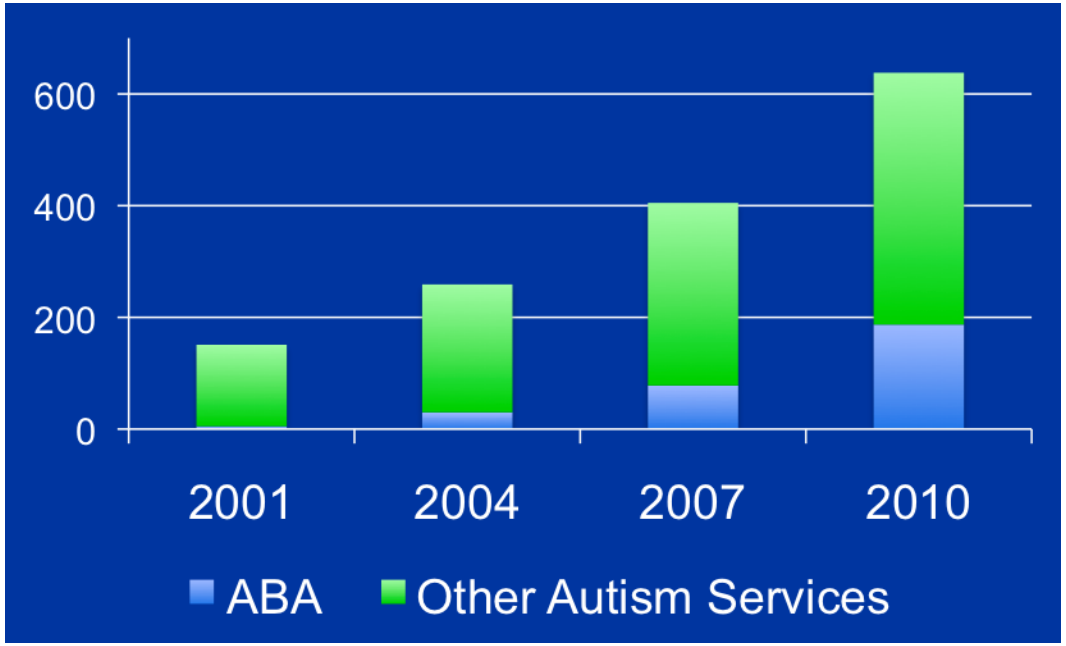


Figure 1. Prevalence of Autism Spectrum Disorder (ASD) by Socioeconomic Status (SES). Note: black bars indicate 95% confidence intervals.

- N = 181 cases, 36,989 children (age 8 years) under surveillance in 2002

Costs of Autism

- >$2,000 for a diagnosis
- >$50,000/yr for therapeutic services
- Most expensive category of special education
- Lifetime cost of ASD in US: $3.2 million



(In millions US$, Source: California Dept of Developmental Services)

http://www.latimes.com/news/local/autism/la-me-autism-day-three-html,0,3438178.htmlstory

Los Angeles Times

Conclusions

- Improvements in awareness, screening and treatment options is associated with a large increase in the prevalence of autism spectrum disorder in Wisconsin and the U.S.
- Autism likely affects at least 20,000 children (ages 0-17) in Wisconsin (~1.7%)
- Service delivery system not prepared to meet the need
- Need for ongoing monitoring and understanding of:
  - Disparities in access to autism diagnoses and services (geographic, socioeconomic, racial, ethnic)
  - Causes and risk factors
  - Primary prevention
  - Strategies for improving the health, equity and well-being of individuals with autism and their families across the life-span

Autism Spectrum Disorder: Early Identification, Diagnosis, and Treatment

Maria A. Stanley, MD, FAAP

Early Identification

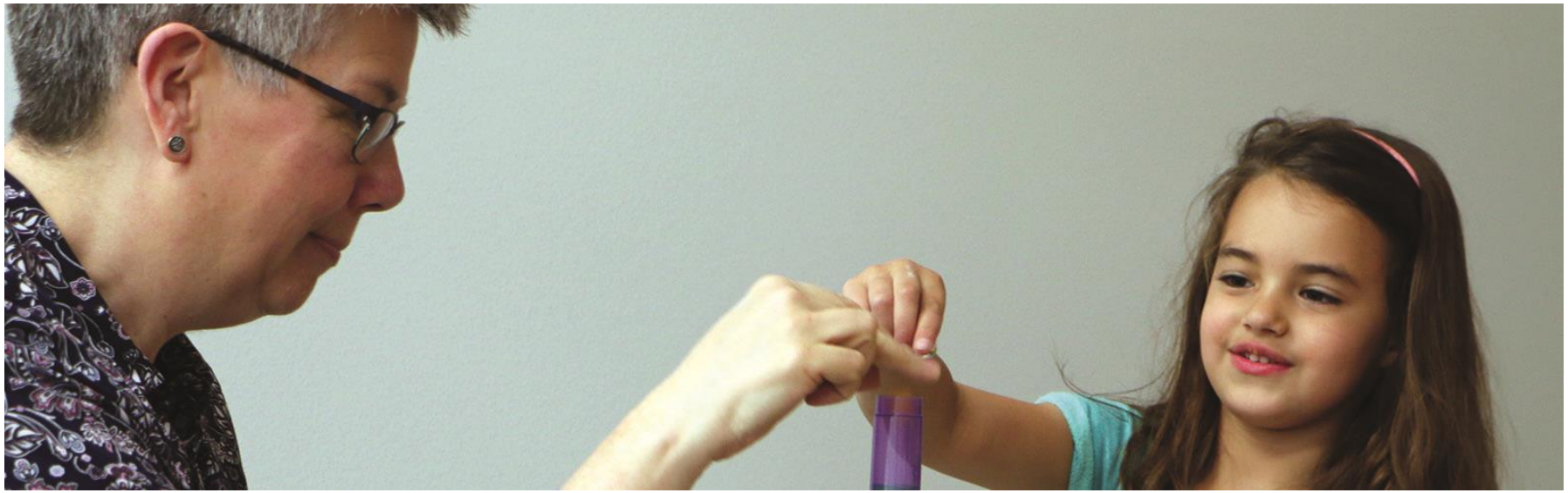
- Autism can be reliably diagnosed as early as 15-18 months
- American Academy of Pediatrics recommends screening of all children at ages 18 and 24 months using a standardized screening tool
  - Promotes early identification of concerns and supports prompt referral for diagnosis and intervention
  - Inadequate reimbursement and time for administration, scoring, counseling, referrals and tracking are barriers to full implementation

Early Diagnosis

- Autism is a clinical diagnosis
  - Unlike many other medical diagnoses, there is no lab test or imaging study that can make a conclusive diagnosis
  - Diagnosis of autism spectrum disorder (ASD) requires comprehensive evaluation, that includes use of standardized diagnostic assessment tool(s)
    - Requires highly specialized training
    - Limited providers with this training
    - Trained providers clustered in population centers
    - Long wait times for evaluation common
    - Local providers can be trained to administer screeners and to deliver preliminary diagnoses which could be used to facilitate access to care

Why does it matter?

- Early screening -> Early diagnosis-> Early treatment-> Best outcomes



Early Treatment

- Early treatment of children is associated with positive outcomes
- Wisconsin's autism insurance mandate helps to support access to services
- Access varies widely based on:
  - Payor/reimbursement
  - Geographic location
  - Family factors

What's missing?

- Several groups at risk for being identified later: girls, higher functioning individuals, milder early symptoms, racial and ethnic minorities
  - Treatment mandate and access to needed interventions may not be available at time of diagnosis

- Early treatment is crucial, but children with ASD continue to have needs at all ages

What's missing?

People with autism have frequent comorbidities:

- Behavioral challenges (including self-injury, elopement/wandering, aggression)
- Communication challenges (up to 30% do not acquire functional spoken language)
- Feeding difficulties (up to 75%)
- Intellectual disability (approximately 30%)
- Sleep problems (50-80%)
- Anxiety (40-60%)
- Depression (12-33%): increased risk for suicide attempts
- ADHD (up to 50%)
- Learning disabilities
- GI Issues
- Seizures (7-23%)

What's missing?

- People with autism spectrum disorders are *individuals*: no one treatment meets the needs of all people

What's needed?

Access to:

- Timely universal screening
- Diagnostic services
- Early intervention and treatment services
- Appropriate behavioral/mental health/psychiatry services at all ages
  - Telehealth has done a great deal to improve geographic access, but doesn't change the fact that there are not adequate providers
- Therapies: speech-language therapy, occupational therapy, social skills supports
- AAC: augmentative and alternative communication resources

What's needed?

Access to:

- Truly individualized educational plans and supports for successful transition to meaningful employment
- Knowledgeable dental care
- Medical care
  - Katie Beckett Medicaid program serves many and supports access to care
- Supports for safety: fencing, GPS tracking, ID bracelets/tags
- Family supports, including respite care and family navigation/support for care coordination
  - County administered Waiver funding is a great help!

What’s needed?

Full inclusion as valued members of the community

References:

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Identification, Evaluation, and Management of Children With Autism Spectrum Disorder
Susan L. Hyman, Susan E. Levy, Scott M. Myers and COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS
Pediatrics 2020;145;
DOI: 10.1542/peds.2019-3447 originally published online December 16, 2019;

CDC Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

Learn the Signs. Act Early.

What do we know about what hinders or helps Wisconsin families access services?

Gail Chödrön, PhD

Wisconsin Care Integration Initiative

Purpose

Increase family-centered, integrated systems of care for children with autism and other developmental disabilities with a particular focus on **medically underserved** in rural and urban settings using **quality improvement** methodology and **evidence-based strategies** to improve access to services.

Funding

HRSA Innovations in Care Integration Grant (2016-2019)

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H6MMC303087 and State Implementation Grants for Improving Services for Children and Youth with ASD. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Pathway to Diagnosis and Services

Tracking Milestones

Screening

Evaluation and Diagnosis

Intervention and Services

M-CHAT-R™

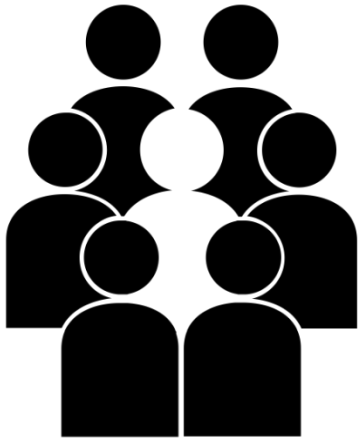
Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (For Example, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (For Example, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (For Example, furniture, playground equipment, or stairs)	Yes	No
5. Does your child make unusual finger movements near his or her eyes? (For Example, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (For Example, pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (For Example, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (For Example, does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (For Example, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10. Does your child respond when you call his or her name? (For Example, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he or she smile back at you?	Yes	No
12. Does your child get upset by everyday noises? (For Example, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15. Does your child try to copy what you do? (For Example, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch him or her? (For Example, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18. Does your child understand when you tell him or her to do something? (For Example, if you don't point, can your child understand "put the book	Yes	No

Family Experience Data Sources

Online survey (statewide)

Wisconsin Family Autism Survey administered March 2018 (n=154 respondents with open-ended responses)



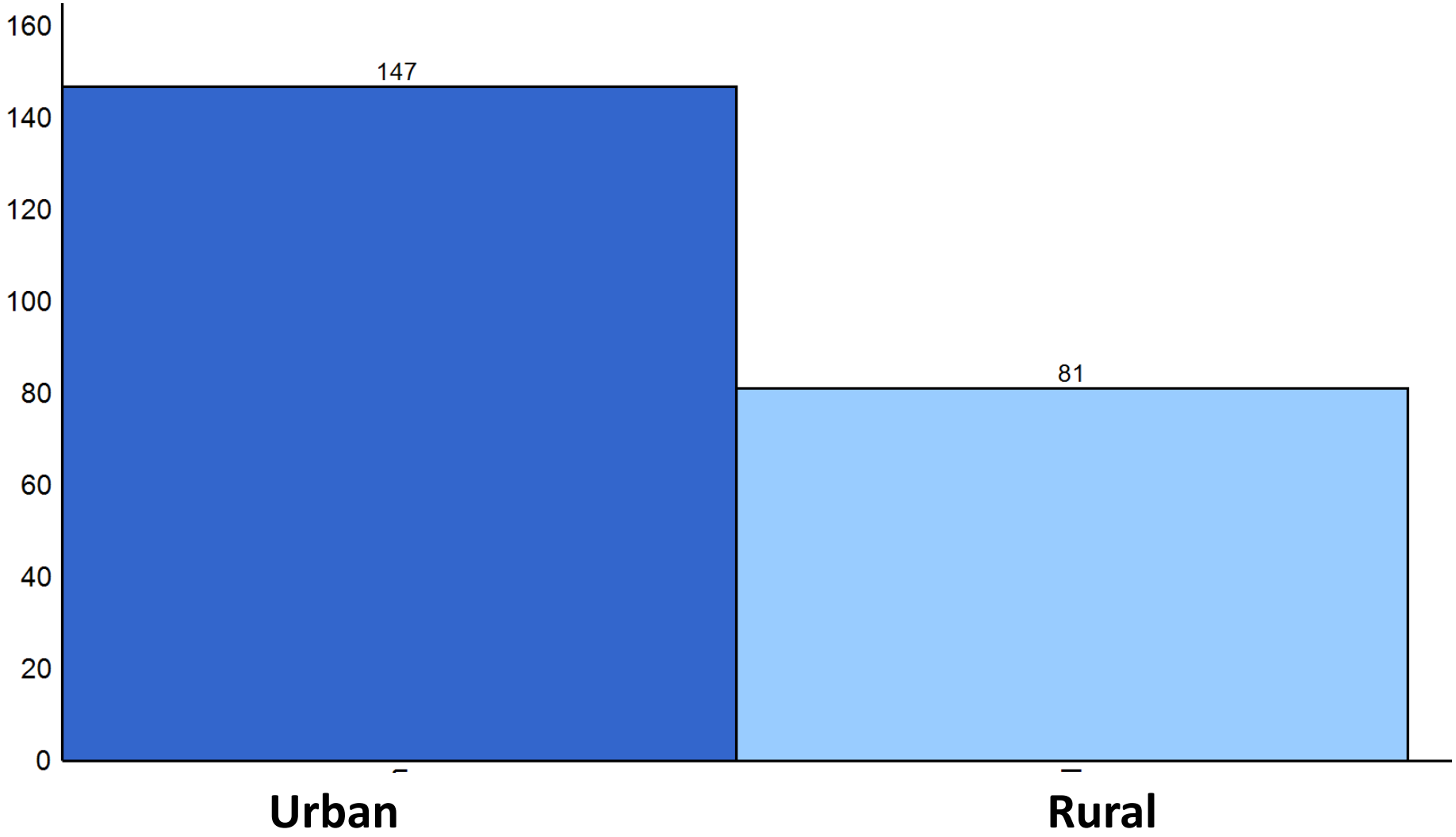
Parent focus groups

2 rural (December 2017) and 1 urban (March 2018) family focus group (n=16)

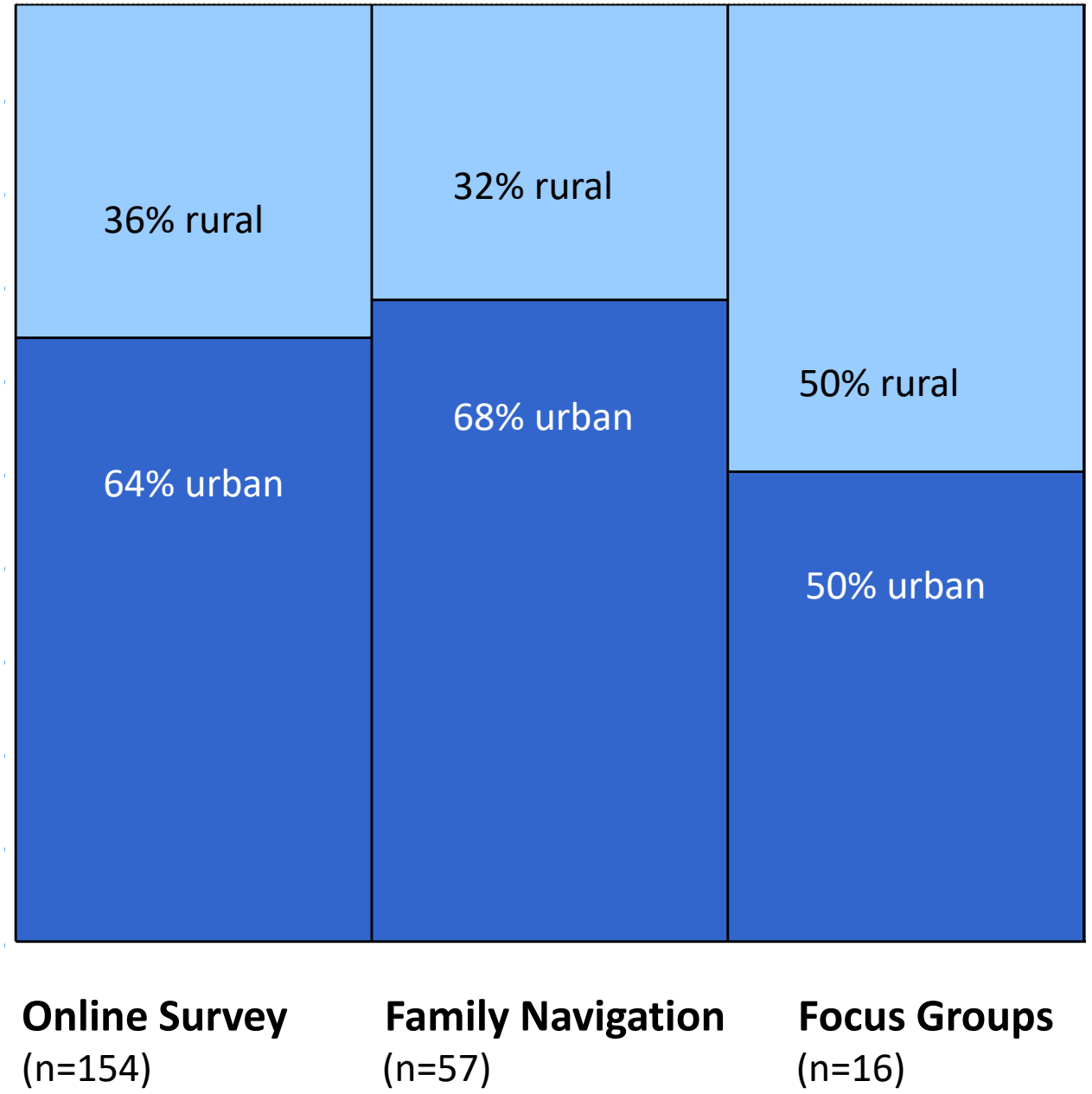
Family navigation documentation

Families enrolled in family navigation (n=57)

Qualitative data represent 228 children (**147 living in urban** and **81 living in rural** areas) in the dataset from multiple sources (family navigation, 2018 survey, listening sessions).

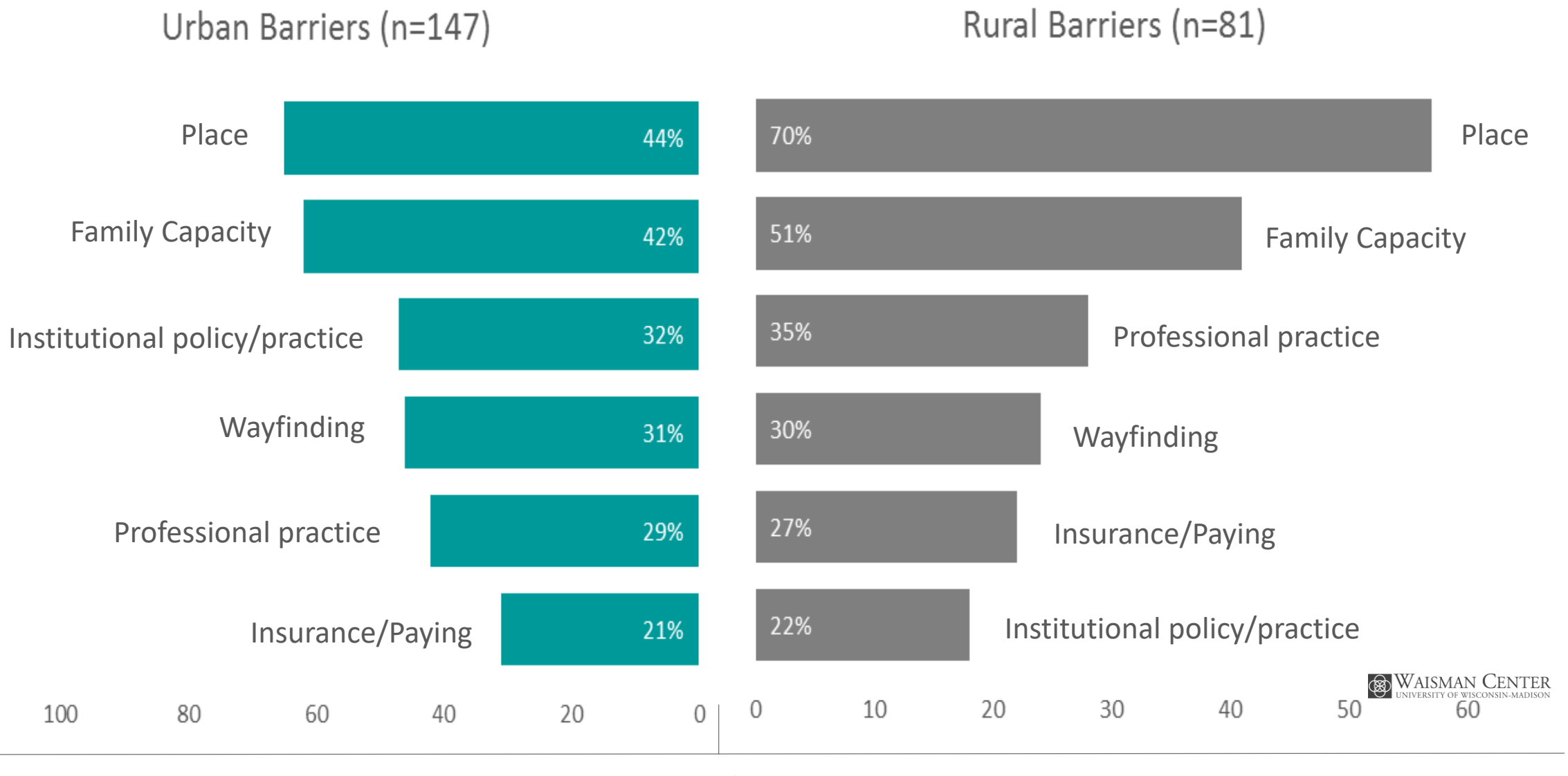


Percentage of respondents from urban or rural settings by data source



Frequency and Type of Barriers Mentioned by Respondents (Focus Group, Survey and Family Navigation)

Data about families' experiences gathered through 2 rural (December 2017) and 1 urban (March 2018) family focus group (n=16), the Wisconsin Family Autism Survey administered March 2018 (n=154 respondents with open-ended responses), and families enrolled in family navigation (n=57)



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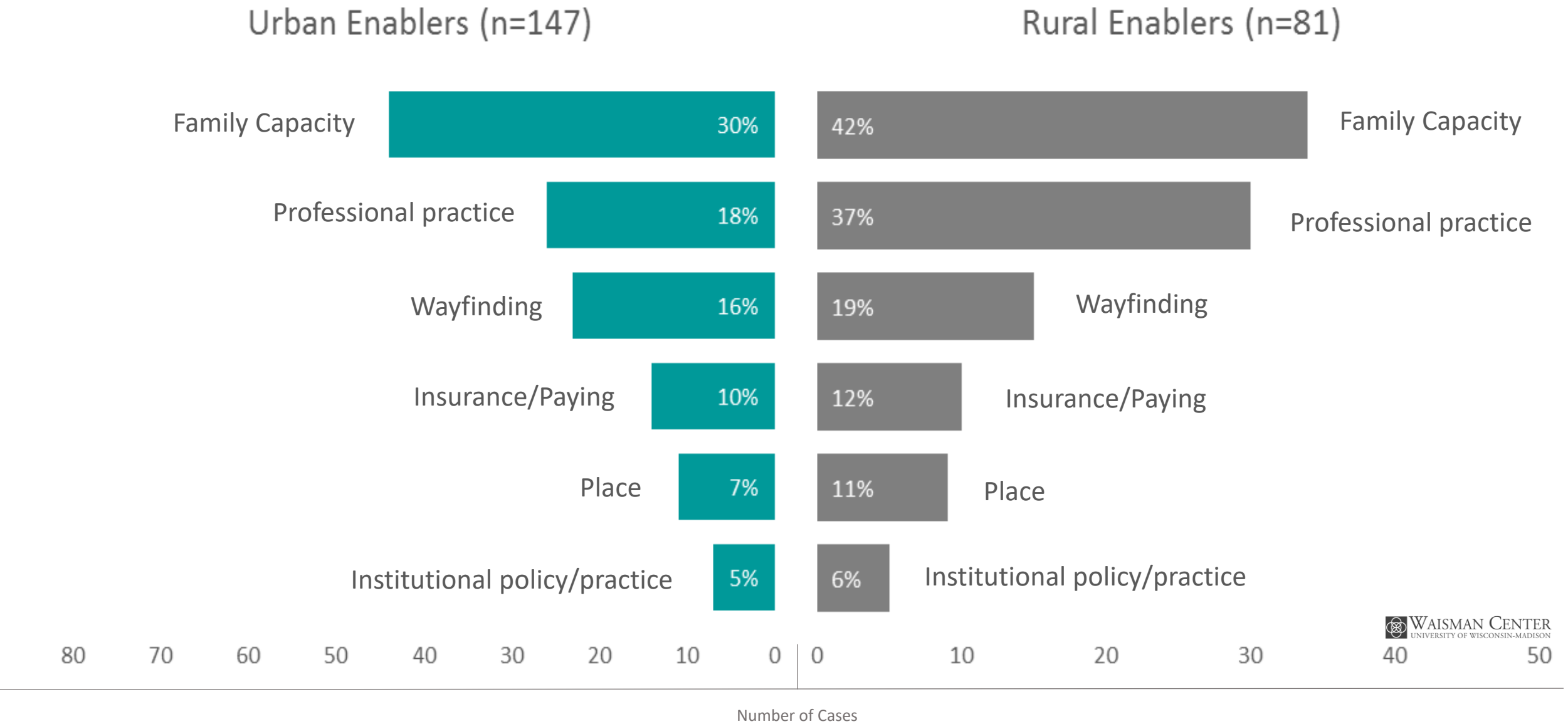
Frequency and Type of Enablers Mentioned by Respondents (Focus Group, Survey and Family Navigation)

Data about families' experiences gathered through 2 rural (December 2017) and 1 urban (March 2018) family focus group (n=16), the Wisconsin Family Autism Survey administered March 2018 (n=154 respondents with open-ended responses), and families enrolled in family navigation (n=57).



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What can we learn from evidence-based practice in other states?

Strategies to address the needs

Lindsay McCary, PhD

Expanding options for early diagnosis

Journal of Autism and Developmental Disorders (2018) 48:2846–2853
https://doi.org/10.1007/s10803-018-3548-3

ORIGINAL PAPER

Embedding Autism Spectrum Disorder Diagnosis Within the Medical Home: Decreasing Wait Times Through Streamlined Assessment

Jeffrey F. Hine[1,2] · Catherine G. Herrington[1,3] · Alice M. Rothman[2] · Rachel L. Mace[2] · Barron L. Patterson[2] · Kathryn L. Carlson[2] · Zachary E. Warren[1,2,3]

Published online: 27 March 2018

ORIGINAL PAPER

ECHO Autism STAT: Accelerating Early Access to Autism Diagnosis

Micah O. Mazurek[1] · Alicia Curran[2] · Courtney Burnette[3] · Kristin Sohl[2,4]

Training community providers

- Through the Extension for Community Healthcare Outcomes (ECHO) Model
  - ECHO Autism developed through the University of Missouri (Kristin Sohl, MD)
    - https://echoautism.org/

Project ECHO®

Diagnosis and treatment within existing early intervention programs: Embedding within Part C

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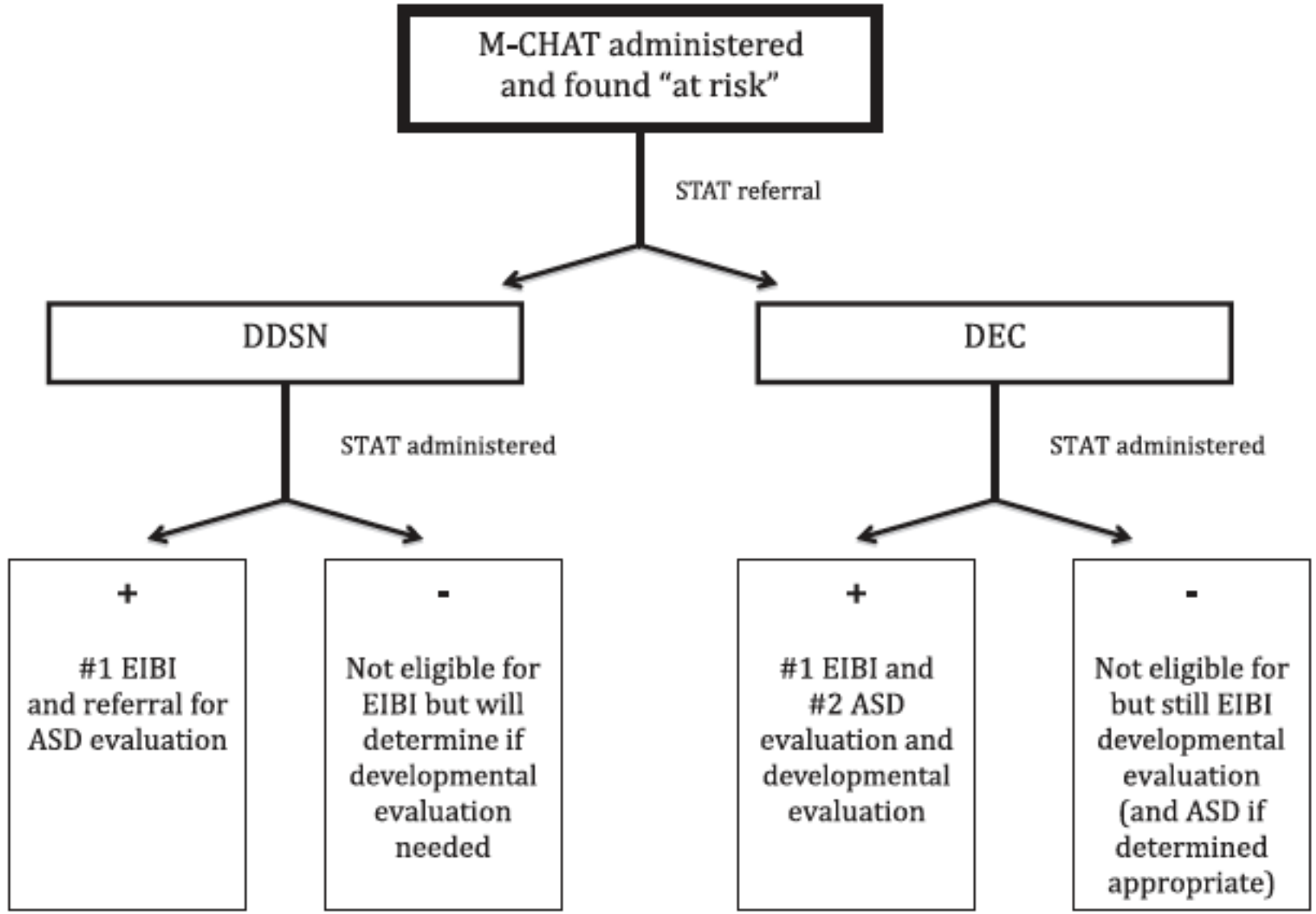
Improving Early Identification and Intervention for Children at Risk for Autism Spectrum Disorder

David A. Rotholz, Anne M. Kinsman, Kathi K. Lacy and Jane Charles

Pediatrics 2017;139;
DOI: 10.1542/peds.2016-1061 originally published online January 12, 2017;



Rotholz et al., 2017

Improving Access through Telehealth

Journal of Autism and Developmental Disorders (2018) 48:2601–2610
https://doi.org/10.1007/s10803-018-3524-y

ORIGINAL PAPER

Early Identification of ASD Through Telemedicine: Potential Value for Underserved Populations

A. Pablo Juárez[1,2,3] · Amy S. Weitlauf[1,2] · Amy Nicholson[1,2] · Anna Pasternak[1,2] · Neill Broderick[1,2] · Jeffrey Hine[1,2] · J. Alacia Stainbrook[1,2] · Zachary Warren[1,2,3,4]

Published online: 12 March 2018

Improving Access through Family Navigation

ELSEVIER

Academic Pediatrics
Available online 14 April 2020
In Press, Corrected Proof

Original Article

Improving Family Navigation for Children With Autism: A Comparison of Two Pilot Randomized Controlled Trials

Emily Feinberg ScD, CPNP [a, b], Jocelyn Kuhn PhD [c], Jenna Sandler Eilenberg MPH [b], Julia Levinson MSc [b], Gregory Patts MPH [b], Howard Cabral PhD [b], Sarabeth Broder-Fingert MD, MPH [a]

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Families' Experiences With Family Navigation Services in the Autism Treatment Network

Morgan K. Crossman, Olivia J. Lindly, James Chan, Megan Eaves, Karen A. Kuhlthau, Robert A. Parker, Daniel L. Coury, Debra H. Zand, Lisa A. Nowinski, Kathryn Smith, Megan Tomkinson and Donna S. Murray

Pediatrics 2020;145;S60
DOI: 10.1542/peds.2019-1895I

Reducing Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial

Emily Feinberg, Sc.D., C.P.N.P., Marcela Abufhele, M.D., M.P.H., Jenna Sandler, M.P.H., Marilyn Augustyn, M.D., Howard Cabral, Ph.D., Ning Chen, M.S., Yaminette Diaz Linhart, M.S.W., M.P.H., Zhandra Cesar Levesque, M.P.H., Megan Aebi, M.P.H., Michael Silverstein, M.D., M.P.H.

Published Online: 2 May 2016 | https://doi.org/10.1176/appi.ps.201500162

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Week 1: “Early Childhood Autism Screening and Diagnosis”

Thank you!

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