Preventing Injuries in Children with Autism

July 23, 2024

2:00PM-3:00PM ET

EDC.ORG

CSN Children's Safety Network

Funding Sponsor

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under the Child and Adolescent Injury and Violence Prevention Resource Centers Cooperative Agreement (U49MC28422) for $5,000,000 with 0 percent financed with non-governmental sources. 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.

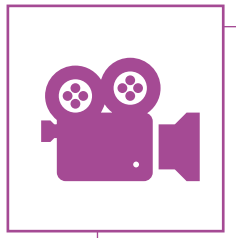
Children's Safety Network

Technical Tips

Join audio via your computer if possible

Use the Q/A button found at the bottom of your screen to ask questions

If you experience audio issues, dial a phone number found in the Zoom invitation and mute your computer speakers



This session is being recorded and will be posted publicly

You are muted

Closed captions can be viewed by clicking the CC button at the bottom of your Zoom screen

Resource files and links will be shared in the chat

CSN Children's Safety Network

Moderator

Dr. Judy Qualters

CDC

Children's Safety Network

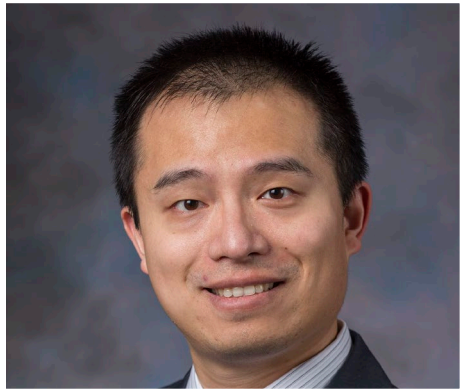
Presenters

Sarah Tinker, Ph.D., MPH

Centers for Disease Control and Prevention (CDC)

Shericka Harris, MSPH

Centers for Disease Control and Prevention (CDC)



Jiabin Shen, Ph.D.

University of Massachusetts Lowell (UML)

Yan Wang, Ph.D.

University of Massachusetts Lowell (UML)

Overview of Autism Spectrum Disorder

Sarah C. Tinker, PhD, MPH
Child Development and Disability Branch

Children's Safety Network Webinar
July 23, 2024

Autism Spectrum Disorder (ASD)

- **Developmental disorder characterized by:**
  - Deficits in social interaction and communication
  - Presence of restricted and repetitive behaviors

- **Diagnosis is a multistep process**
  - No single medical test
  - Clinicians look at developmental history and behavior

- **There is no one cause**
  - Combination of environmental and genetic factors

https://www.cdc.gov/ncbddd/autism/facts.html

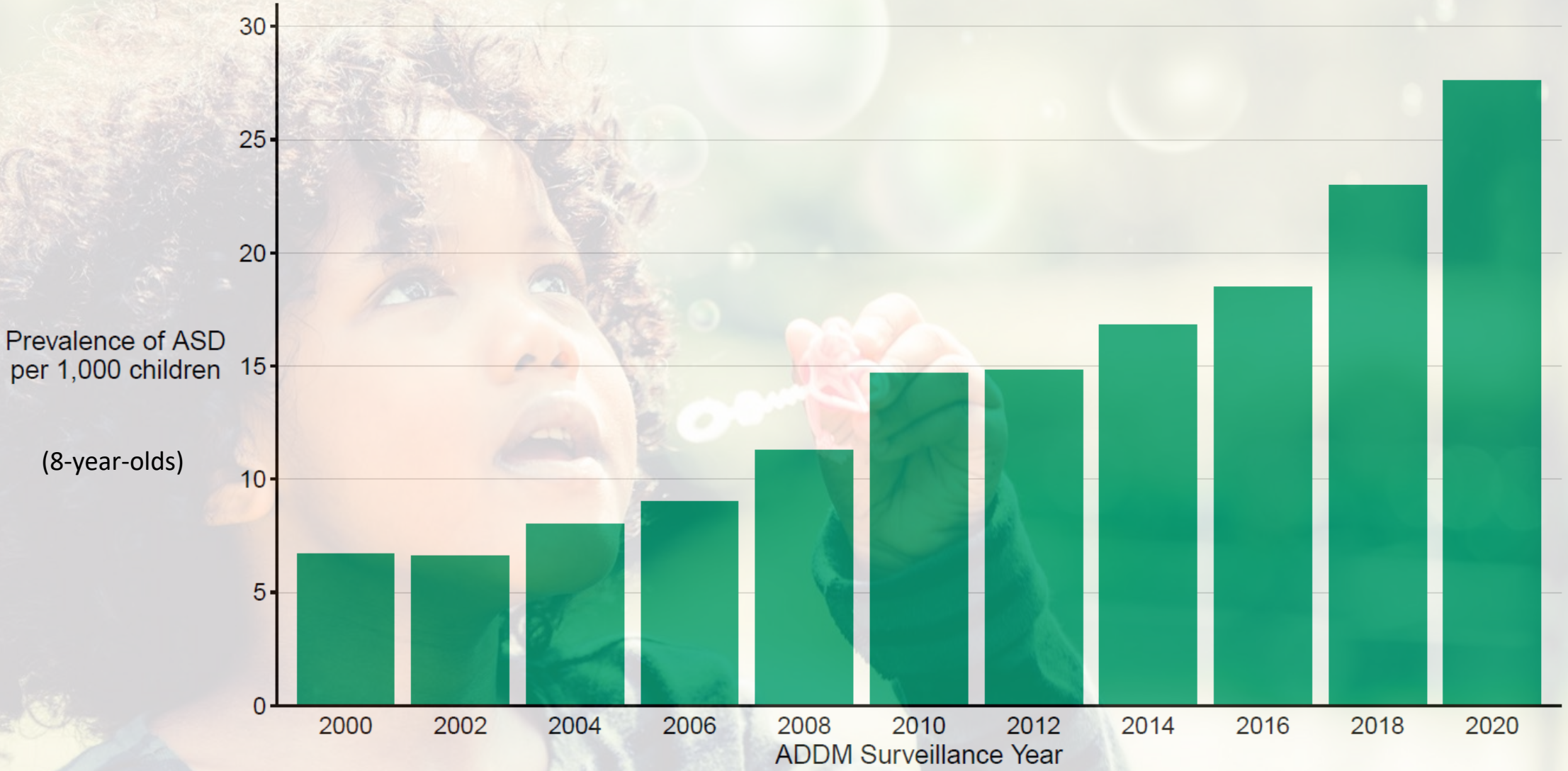
Prevalence of ASD in the United States

1 in 36 (2.8%)
8-year-old children in 2020

Based on tracking within 11 communities in the
Autism and Developmental Disabilities Monitoring (ADDM) Network

Maenner et al., MMWR Surv Sum. 2023;72(2):1-14

Prevalence of ASD has increased over time



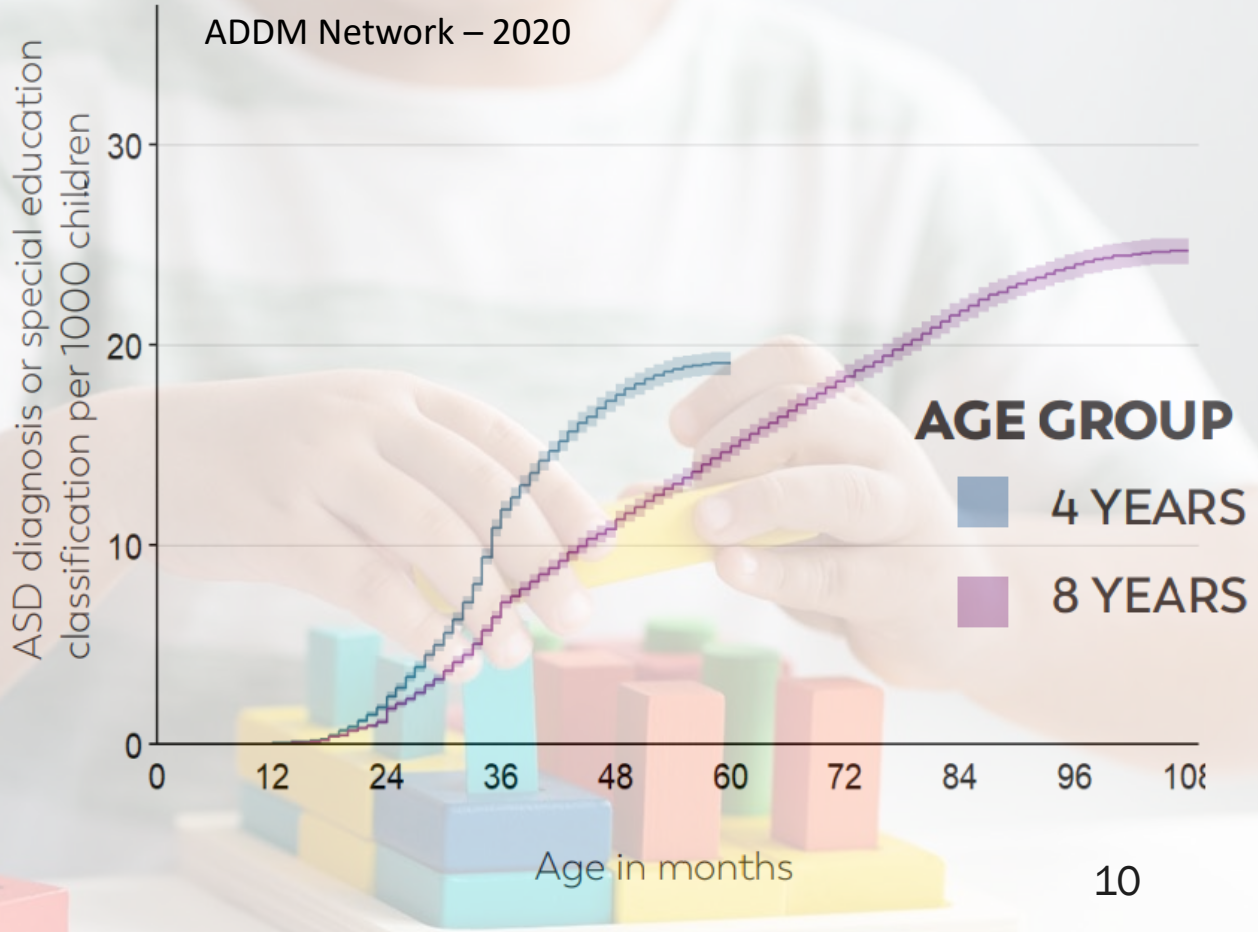
https://www.cdc.gov/ncbddd/autism/addm-community-report/documents/Slides-ADDM-SY2020-508.pptx

Age of ASD diagnosis

- Can be reliably diagnosed by age 2 years
- Diagnosis typically occurs later and depends on many factors
- Average age of diagnosis influenced by adults with new diagnoses

More children are being identified with ASD by 48 months

ADDM Network – 2020



Shaw et al., MMWR Surv Sum. 2023;72(1):1-14

ASD is ~4 times more common among boys

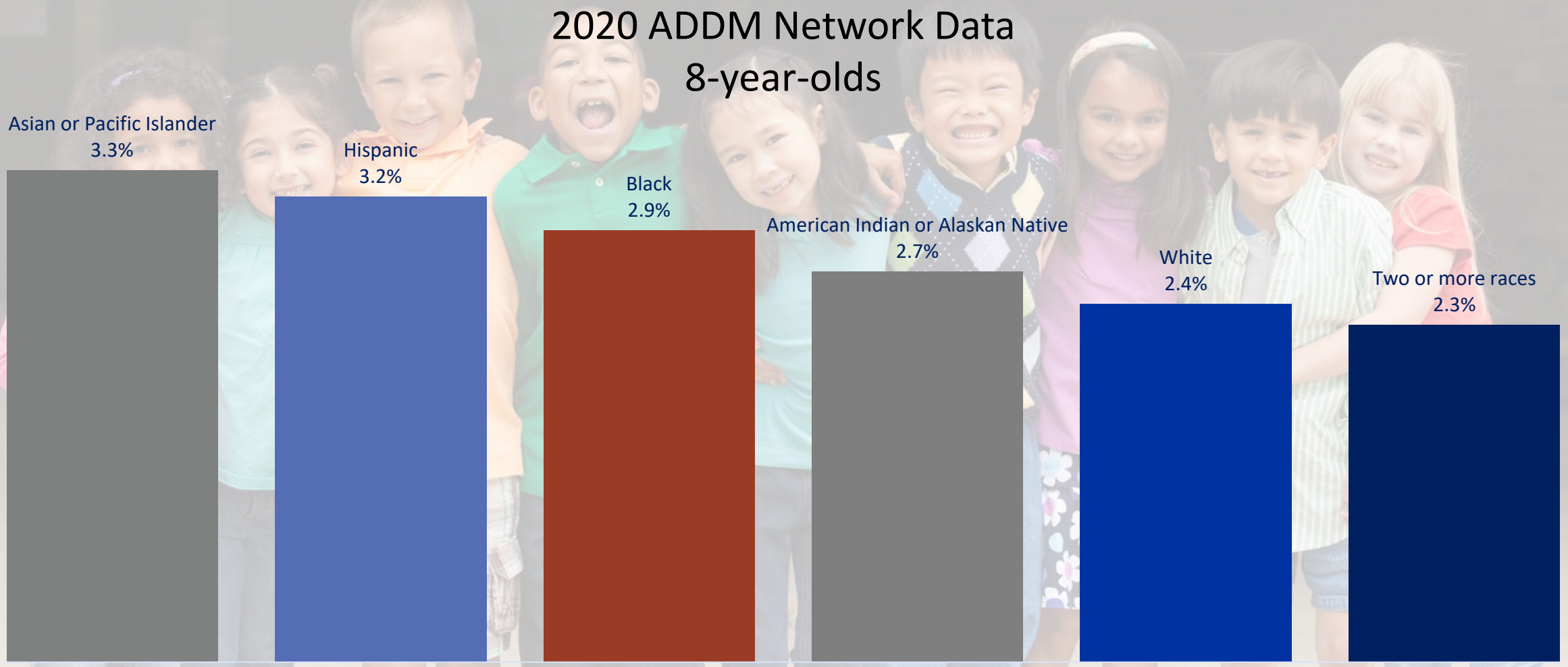
1.1%
of 8-year-old GIRLS

4.3%
of 8-year-old BOYS

2020 ADDM Network Data

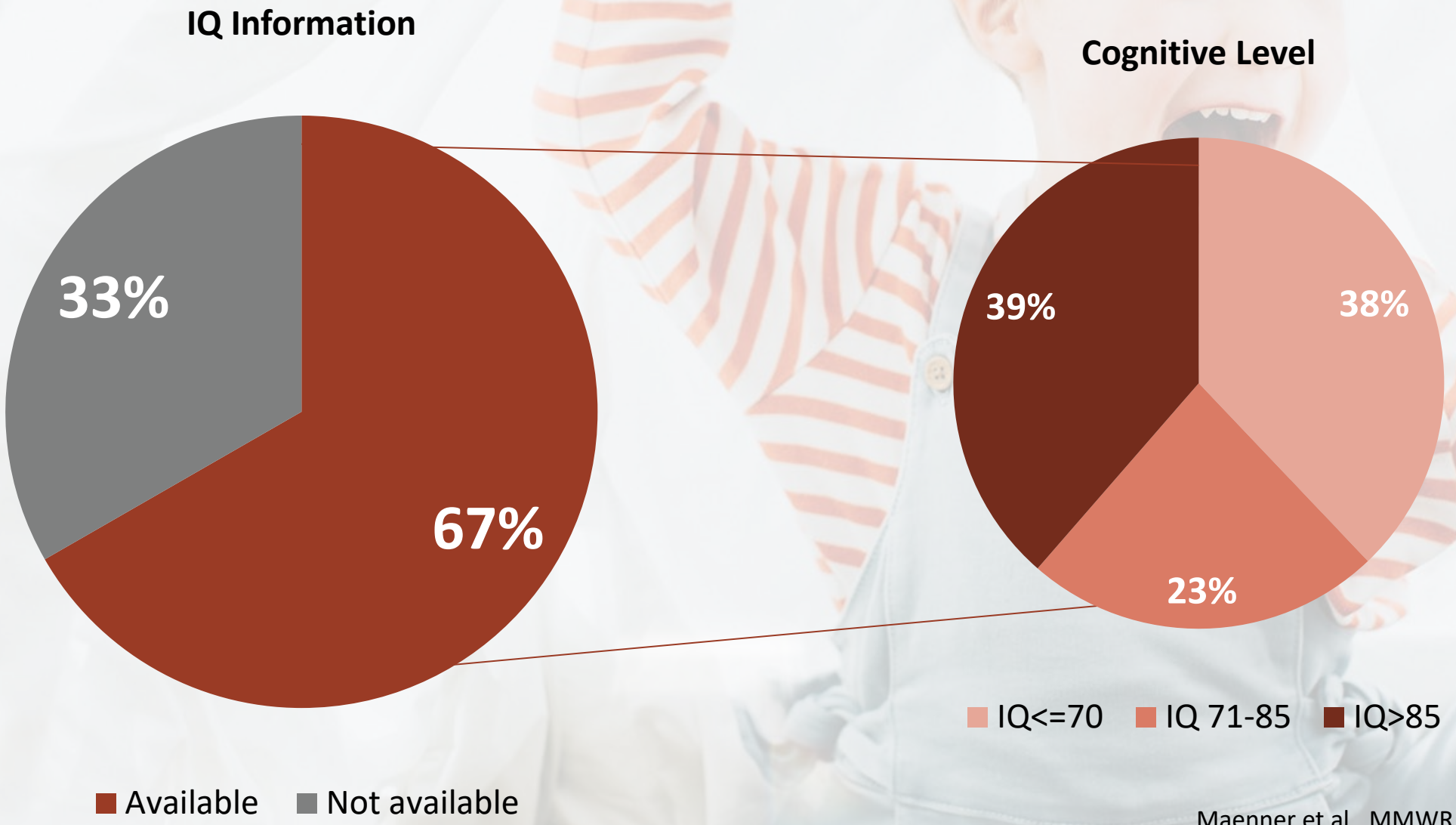
Maenner et al., MMWR Surv Sum. 2023;72(2):1-14

ASD affects children of all races and ethnicities



Maenner et al., MMWR Surv Sum. 2023;72(2):1-14

Many people with ASD also have intellectual disability (ID)



Maenner et al., MMWR Surv Sum. 2023;72(2):1-14

Profound Autism

- **Defined as being nonverbal, minimally verbal, or having an IQ<50**
- **More likely to:**
  - Have self-injurious behavior
  - Have epilepsy
  - Require around-the-clock supervision

26.7%

of 8-year-olds with autism
2000-2016 ADDM Network Data

Hughes et al., Public Health Reports. 2023;138(6):971-980

ASD Co-Occurring Conditions

- Other conditions that co-occur with autism

Hearing problems 4x ↑

Vision problems 7x ↑

Language delay 7x ↑

ADHD 10x ↑

Motor delay 14x ↑

Wiggins et al., J Autism Dev Disord 2015;45:3183-3194

Wandering / Elopement

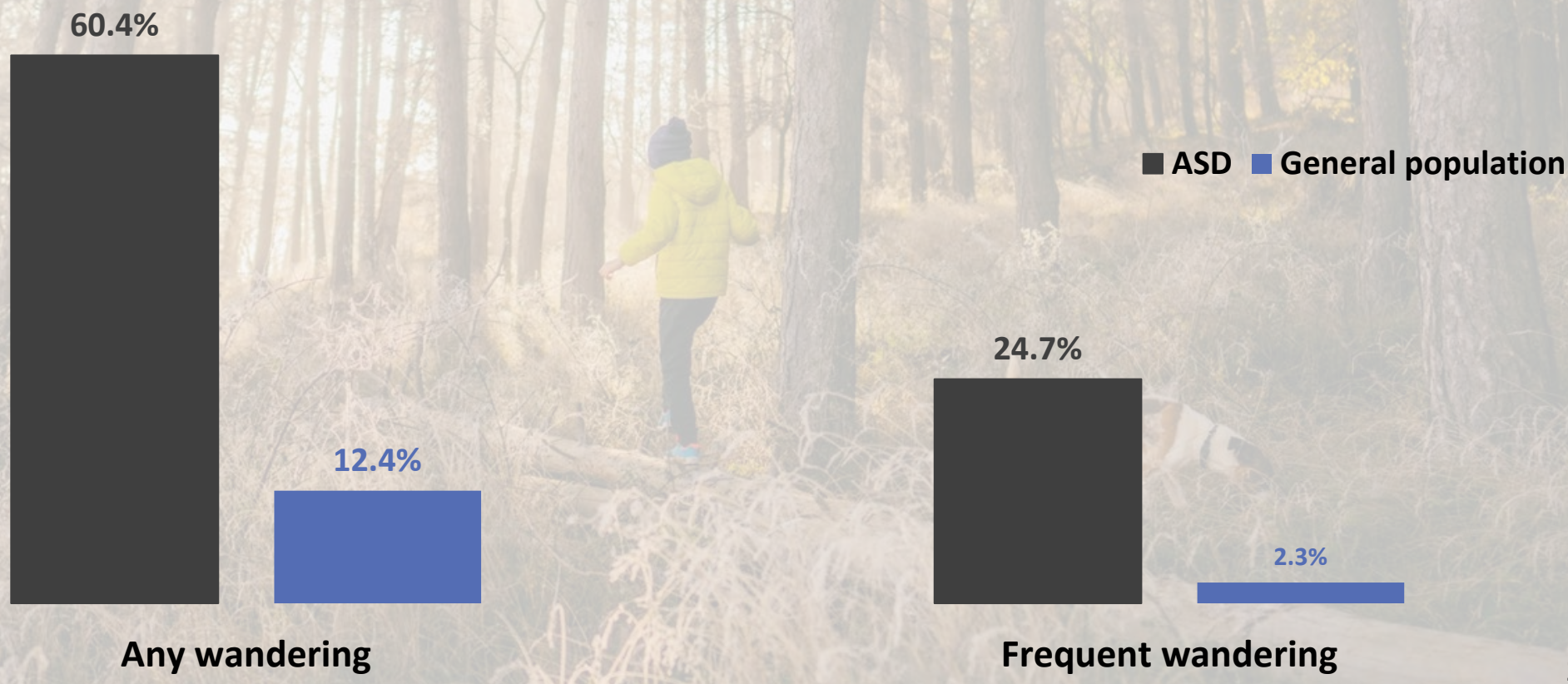
- **Leaving a safe area or a responsible care giver**
  - Typically involving situations where a person may be injured or harmed as a result

- **Children with ASD may have challenges understanding safety issues and communicating with others**

Disability and Safety: Information on Wandering (Elopement) | CDC

Wandering / Elopement

- Data from CDC's Study to Explore Early Development (SEED)



Wiggins et al., J Dev Behav Pediatr 2020;41:251-257

Wandering / Elopement

- **Compared to a population sample of 4–5-year-old children without developmental disabilities (including ASD), wandering was:**

3.0 times more likely among children with attention deficit/hyperactivity problems

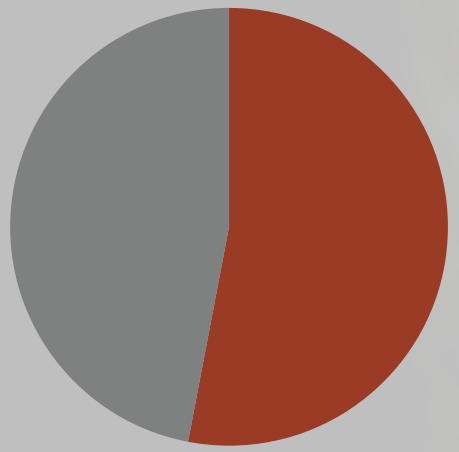
3.8 times more likely among children with ASD

2.5 times more likely among children with very low developmental level

Wiggins et al., J Dev Behav Pediatr 2020;41:251-257

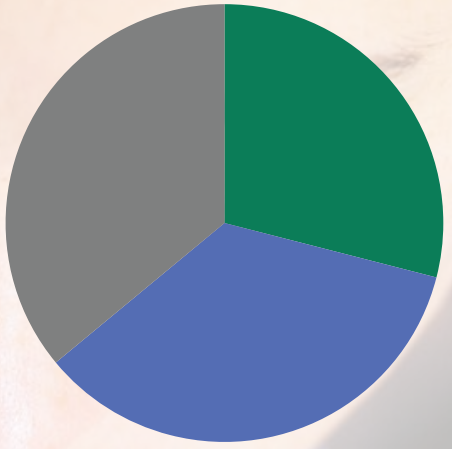
Wandering / Elopement

- **Data from a parent survey of children with ASD aged 4-17 years**



53%

of children who eloped were missing for **long enough to cause concern**



29% of parents reported that their child attempted to elope **multiple times per day**

35% of parents reported that their child attempted to elope **multiple times per week**

Children were missing an average of

41.5 minutes

Anderson et al., Pediatrics 2012;130(5):870-877

Wandering / Elopement

- **Data from a parent survey of children with ASD aged 4-17 years**

Close calls among children with ASD who eloped

65%

with traffic injury

24%

with drowning

Anderson et al., Pediatrics 2012;130(5):870-877

Other Developmental Disabilities: ADHD

- **Trouble paying attention and/or controlling impulsive behaviors**
  - Make careless mistakes or take unnecessary risks
  - Have a hard time resisting temptation
- **Common: ~10% of children 3-17 years of age**
- **Associated with increased mortality**
  - Particularly accident/injury mortality

https://www.cdc.gov/ncbddd/adhd

Bitsko et al, MMWR Suppl 2022;71(2):1-48
Dalsgaard et al, Lancet 2015;358:2190-96

Implications

- **Children with autism may be at increased risk for drowning and other injuries due to wandering behavior and symptoms of co-occurring conditions.**

- **Data to understand the potentially unique risk factors for injuries among children with autism are critical but lacking.**
  - This information can be used to inform efforts to prevent similar deaths in the future.

Unintentional Drowning Deaths Among Children and Adolescents with Autism Spectrum Disorder in the United States, 1999-2022

Shericka Harris

CSN Webinar on Injury Disparities among Children with Autism
July 23rd, 2024

Drowning in the United States

All ages: over **4,500** fatal drownings and over **8,000** non-fatal drownings every year

Children <18: over **800** fatal drownings and over **6,000** non-fatal drownings every year

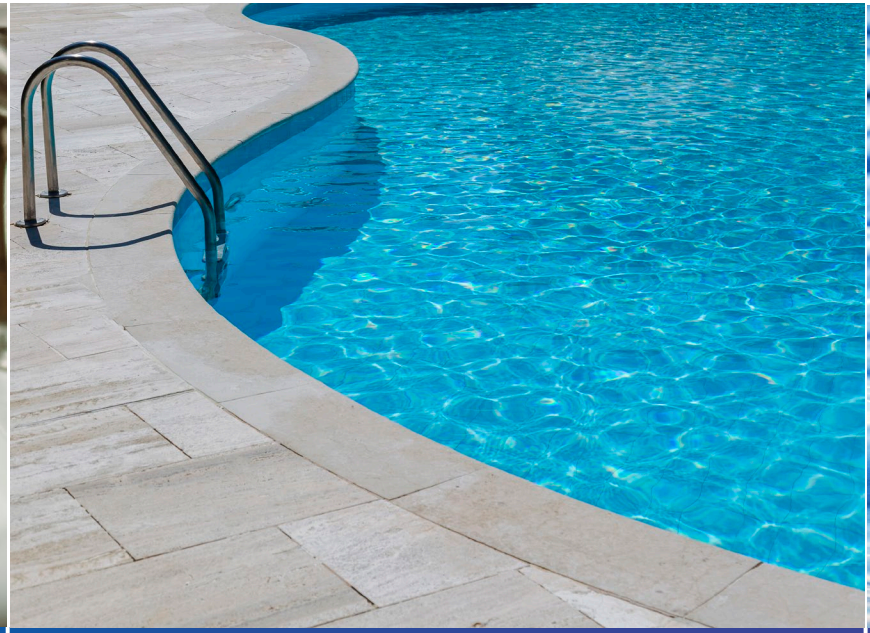
Drowning is the leading cause of death among children 1-4 years of age

https://www.cdc.gov/drowning/data-research/facts/index.html

Clemens et al., *MMWR* 2024;73:467–473.

Drowning Locations Vary by Age Group

Infants <1 year: bathtubs



Children 1-4: home swimming pools

People 15 and older: natural waters

https://www.cdc.gov/drowning/risk-factors/index.html

What do we know about drowning and autism spectrum disorder (ASD)?

- **1 in 36 children in the U.S. have ASD**
  - Boys are 4 times more likely to be diagnosed
- **Increased risk of drowning among children with ASD**
- **Wandering/elopement increases the risk of drowning among children with ASD**

https://www.cdc.gov/autism/data-research/index.html
https://www.cdc.gov/drowning/risk-factors/index.html
Guan, J., Li, G., *Inj. Epidemiol.* **4**, 32 (2017).

Increased Risk of Drowning among Children with ASD

Characteristics of Unintentional Drowning Deaths in Children with ASD

- **Study analyzed news articles in the United States from January 2000-May 2017 and found:**
  - 23 fatal unintentional drowning incidents among children 3-14 years
  - Most frequent locations were ponds (52%), rivers (13%), and lakes (13%) close to the victim's home
  - Wandering led to most drownings, accounting for 74% of the incidents

Guan, J., Li, G., *Inj. Epidemiol.* **4**, 32 (2017).

Objective: To explore unintentional drowning deaths in the United States among children and adolescents where ASD was identified as a contributing cause of death

Methods

Death certificate data 1999-2022 from the National Vital Statistic System (NVSS) for children and adolescents (<20 years)

ICD 10 codes

- Drowning: W65-W74, V90, and V92
- Autism: F84.0, F84.3, F84.5, F84.8, F84.9

Calculated descriptive statistics

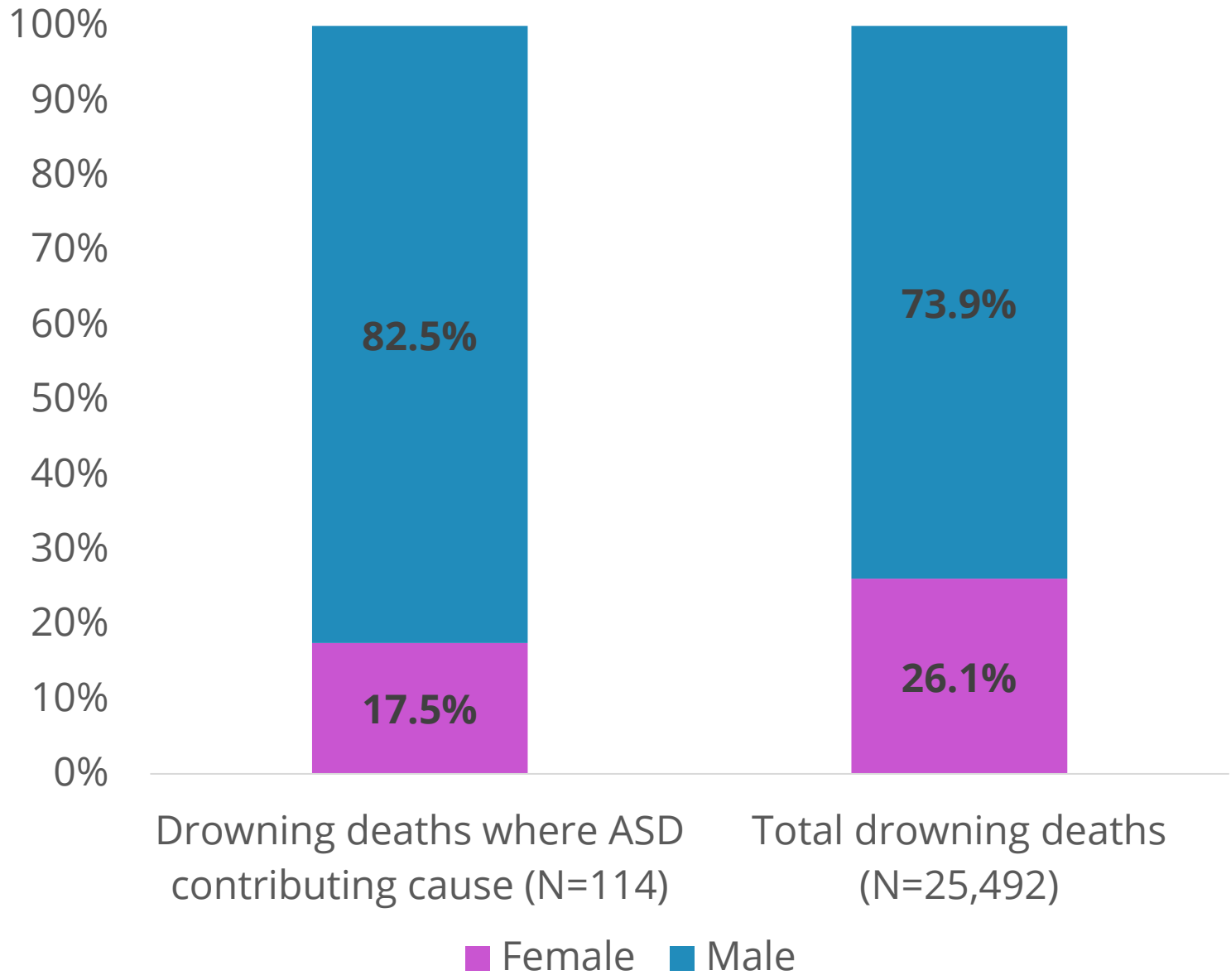
Drowning deaths among children (<20 years), 1991-2022, United States

- Total: 25,492
- With ASD as a contributing cause: 114 (0.4%)

Death certificate data 1999-2022 from the National Vital Statistic System (NVSS) for children and adolescents (<20 years)

Total Drowning Deaths Compared to Drowning Deaths with ASD on Death Certificate by Sex, <20 years, 1999-2022, U.S.

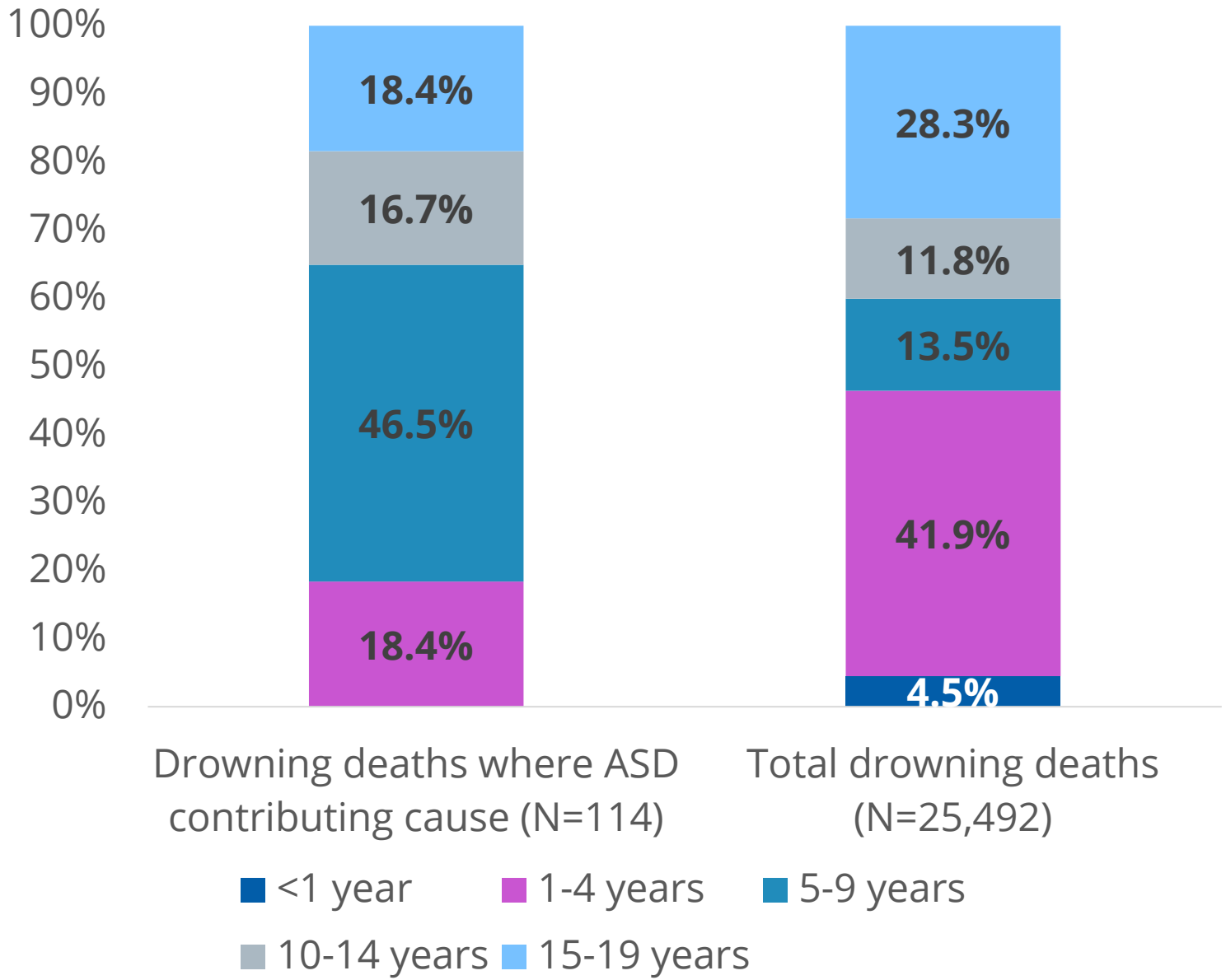
- Males accounted for most drowning deaths among children with ASD as a contributing cause of death



Death certificate data 1999-2022 from the National Vital Statistic System (NVSS) for children and adolescents (<20 years)

Total Drowning Deaths Compared to Drowning Deaths with ASD on Death Certificate by Age Group, <20 years, 1999-2022, U.S.

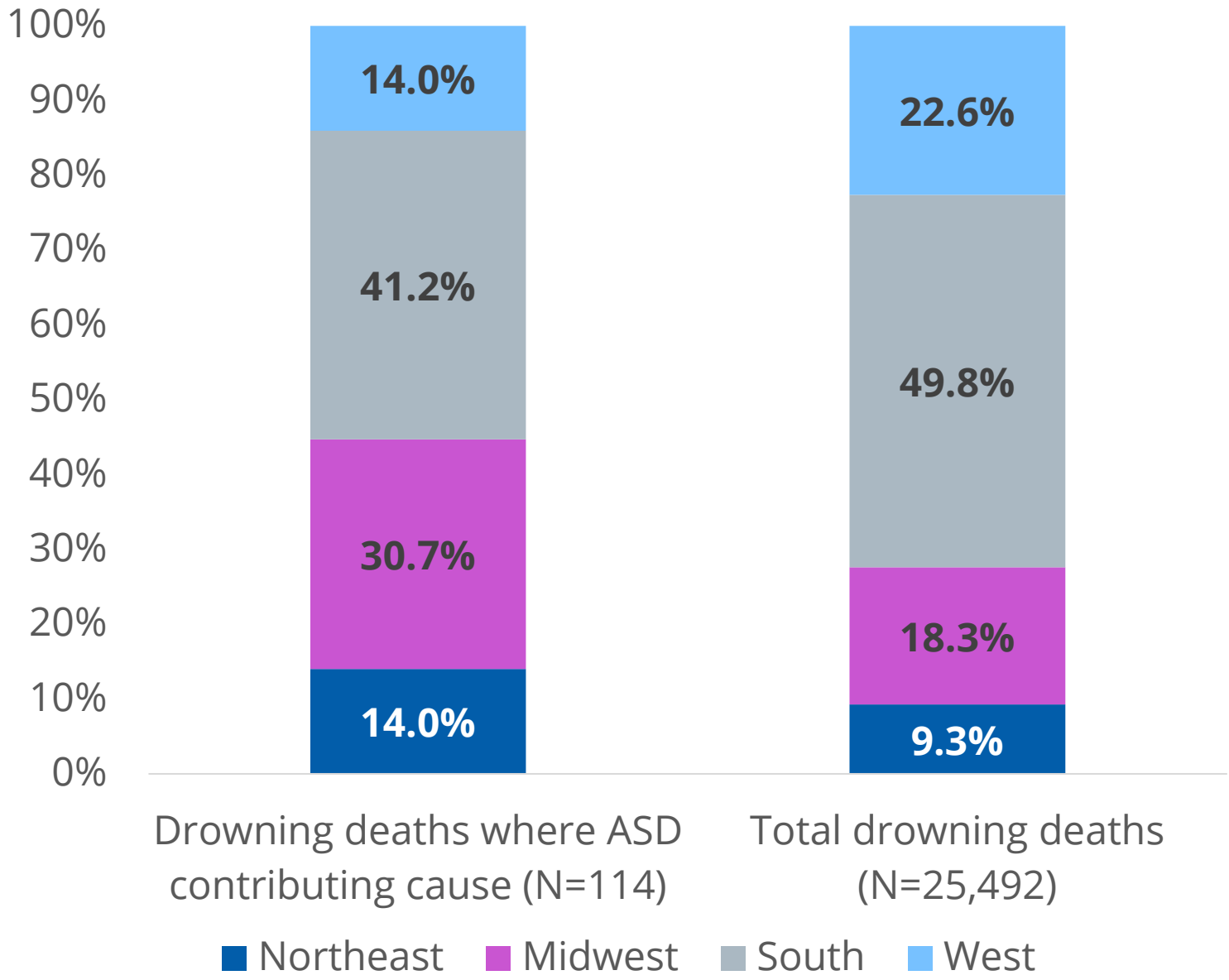
- Children aged 5-9 years accounted for almost half (46.5%) of drowning deaths where ASD was a contributing cause of death



Death certificate data 1999-2022 from the National Vital Statistic System (NVSS) for children and adolescents (<20 years)

Total Drowning Deaths Compared to Drowning Deaths with ASD on Death Certificate by Census Region, <20 years, 1999-2022, U.S.

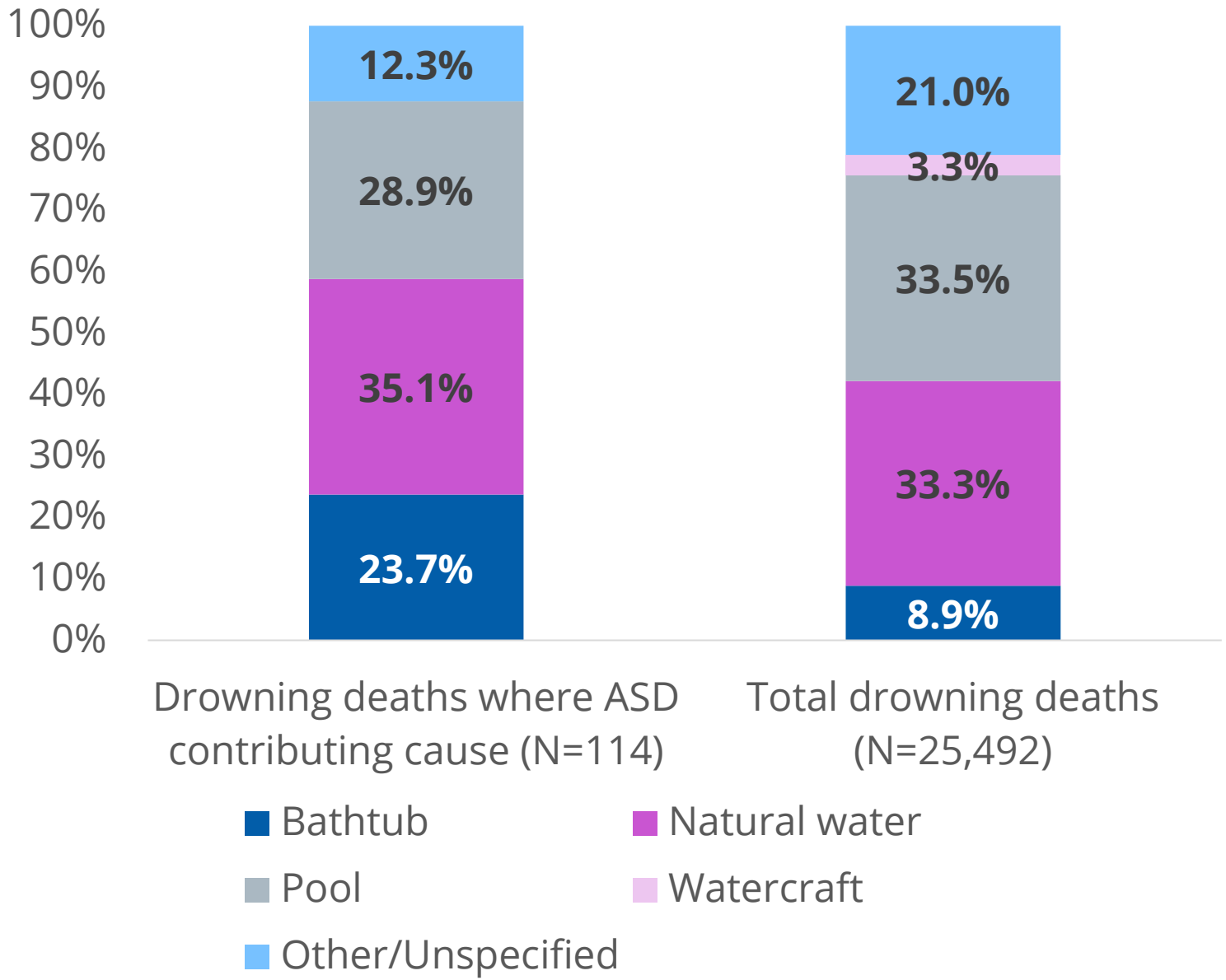
- Drowning deaths where ASD was a contributing factor occurred most frequently in the South followed by Midwest



Death certificate data 1999-2022 from the National Vital Statistic System (NVSS) for children and adolescents (<20 years)

Total Drowning Deaths Compared to Drowning Deaths with ASD on Death Certificate by Water Body Type, <20 years, 1999-2022, U.S.

- Drowning deaths where ASD was a contributing cause of death most often occurred in natural water followed by bathtubs and pools



Death certificate data 1999-2022 from the National Vital Statistic System (NVSS) for children and adolescents (<20 years)

Limitations

- Diagnosis of ASD often occurs after 4 years of age, and this may explain the higher percentage of drowning deaths occurring after age 4
- Due to limitations in death certificate data, the number of children and adolescents with ASD who fatally drowned is likely underestimated in this analysis
  - These data do not capture drownings among all children with ASD – only those for which it was listed as a contributing cause

Summary

- Children 5-9 years of age accounted for almost half of the drowning deaths with ASD listed as a contributing cause
- Most drowning deaths among children with ASD listed as a contributing cause occurred in natural water followed by bathtubs and swimming pools

Drowning can be prevented

- Learn swimming and water safety
- Build and maintain fences
- Supervise closely
- Wear a lifejacket
- Avoid alcohol

Drowning can be prevented

- Learn CPR
- Know the risks of natural water
- Use the buddy system
- Take precautions for medical conditions
- Don’t hyperventilate

CDC is working with community partners to improve swimming and water safety skills among children with ASD

Partnered with YMCA to adapt a basic swimming and water safety skills training program for children with ASD

Goal is to increase access to swim lessons for children with ASD and evaluate the swim skills generated through lesson delivery

Project Overview: YMCA Autism Swim Skills Project

- 9 YMCA Associations ranging in size from 1 community center to 20 community centers
- Each YMCA location has provided swim training to 50 youth with ASD
- Each session has included eight 30–40-minute Safety Around Water lessons
- Lessons are taught by certified swim instructors who were provided with additional training and assessment tools to test during lessons
- Pre and post swim skills assessment data is being collected on each student
- Local Y project leads have completed a survey about their experience working on this project and using assessment tools
- Data collection and evaluation will be completed on 7/31/2024

Preliminary qualitative data findings from YMCA project

- Feedback and interests expressed by parents indicate a need for swim safety programs for children with ASD
- Program provided skill improvement for youth
- Program provided an activity that families can enjoy together
- Program sustainability is important moving forward
- More research needed about the effectiveness of private lessons vs. small or typical size group lessons

References

- Clemens T, Moreland B, Mack KA, Thomas K, Bergen G, Lee R. Vital Signs: Drowning Death Rates, Self-Reported Swimming Skill, Swimming Lesson Participation, and Recreational Water Exposure — United States, 2019–2023. MMWR Morb Mortal Wkly Rep 2024;73:467–473. DOI: http://dx.doi.org/10.15585/mmwr.mm7320e1
- Guan, J., Li, G. Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Inj. Epidemiol.* **4**, 32 (2017). https://doi.org/10.1186/s40621-017-0129-4

Acknowledgements

Co-authors

Briana Moreland[1], Sarah Tinker[2], Tessa Clemens[1]

1. CDC National Center for Injury Prevention and Control

2. CDC National Center on Birth Defects and Developmental Disabilities

Thank you!

www.cdc.gov/drowning

Shericka Harris
stharris@cdc.gov

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Burden of Injury in Autistic Children

Presenters: Jiabin Shen PhD & Yan Wang PhD

Department of Psychology

University of Massachusetts Lowell

Background

The World Health Organization (WHO) identifies injury as the leading cause of disability and fatality in children around the globe

CDC lists injury as the No.1 leading cause of deaths and non-fatal Emergency Department visits in U.S. children

Emerging research suggests injury poses an especially significant burden for autistic individuals

Background

Autistic individuals are at higher risk of

Suicidal ideation (up to 66%)	Suicidal attempts (up to 35%)	ED visits related to self-inflicted injuries (5x)

Autistic adolescents under 15 are three times more likely to die from unintentional injuries than the general population

Literature Gaps

There is a lack of population-based approach to the examination of the impact of injury to autistic children from the full developmental spectrum

Little is known on the economic burden and its disparities incurred as a result of healthcare service costs associated with injuries across multiple payment sources among autistic children

The Present Study

To provide up-to-date national estimates of the health burden imposed by injuries on autistic children

To examine disparities in injury-related medical seeking behavior and medical expenditures in autistic children

To develop precise and tailored interventional programs to reduce the injury-related health and healthcare burden for autistic children

Methods: Data Source

The Medical Expenditure Panel Survey (MEPS) 2000-2021 Data

- Sponsored by Agency for healthcare Research and Quality (AHRQ)
- Nationally representative cohorts of civilian, non-institutionalized households
- Provides population-based national estimates of healthcare service utilizations

Specific MEPS data files to be used in the present study are:

- 2000-2021 Full Year Consolidate Data files
- 2000-2021 Medical Condition Files
- 2000-2021 Medical Event Files

Public vs. Restricted Data Files

Methods: Variables of Interest

Outcome Variables

- Presence of Injury
- Presence of Injury-related treatment event
- Injury-related medical expenditures paid by family or insurance

Predictor Variables

- Child Demographics (age, sex, race/ethnicity)
- Family Demographics (income, insurance, education, marriage, employment, perceived health, region)

Methods: Sample

- Autism Diagnosis
  - ICD-9-CM code of 299.00 or ICD-10-CM code of F84.0
- Sample Characteristics
  - Sample size: 1050 autistic children across all 22 years

Age	*0-4 yrs*	18%
	5-9 yrs	38%
	10-14 yrs	29%
	15-17 yrs	14%
Sex	*Male*	82%
	Female	18%
Race/ Ethnicity	*White/Other*	63%
	Black	10%
	Hispanic	22%
	Asian	5%
Injury History	*Yes*	10%
	No	90%

Results

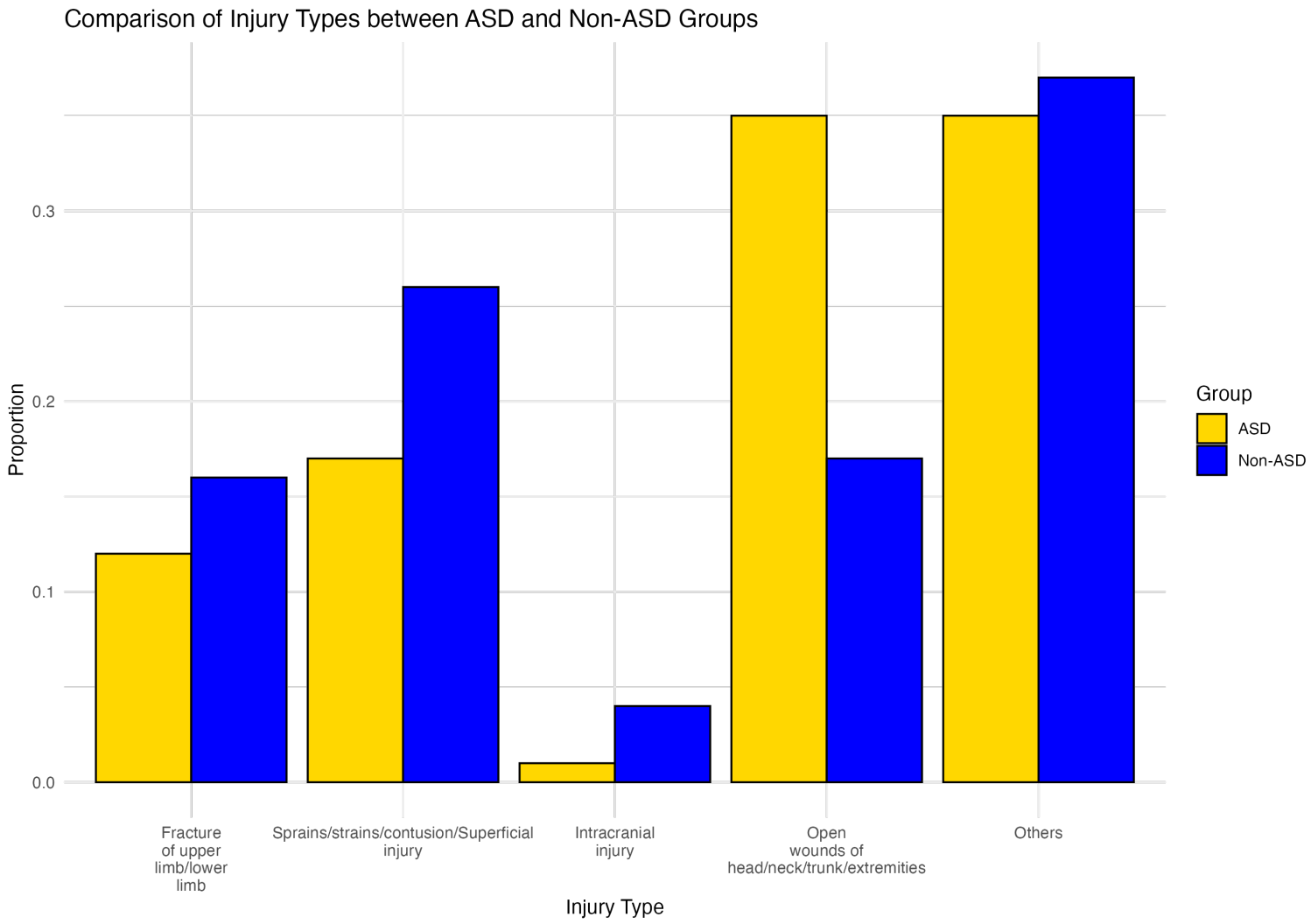
Annualized National Estimates

Overview

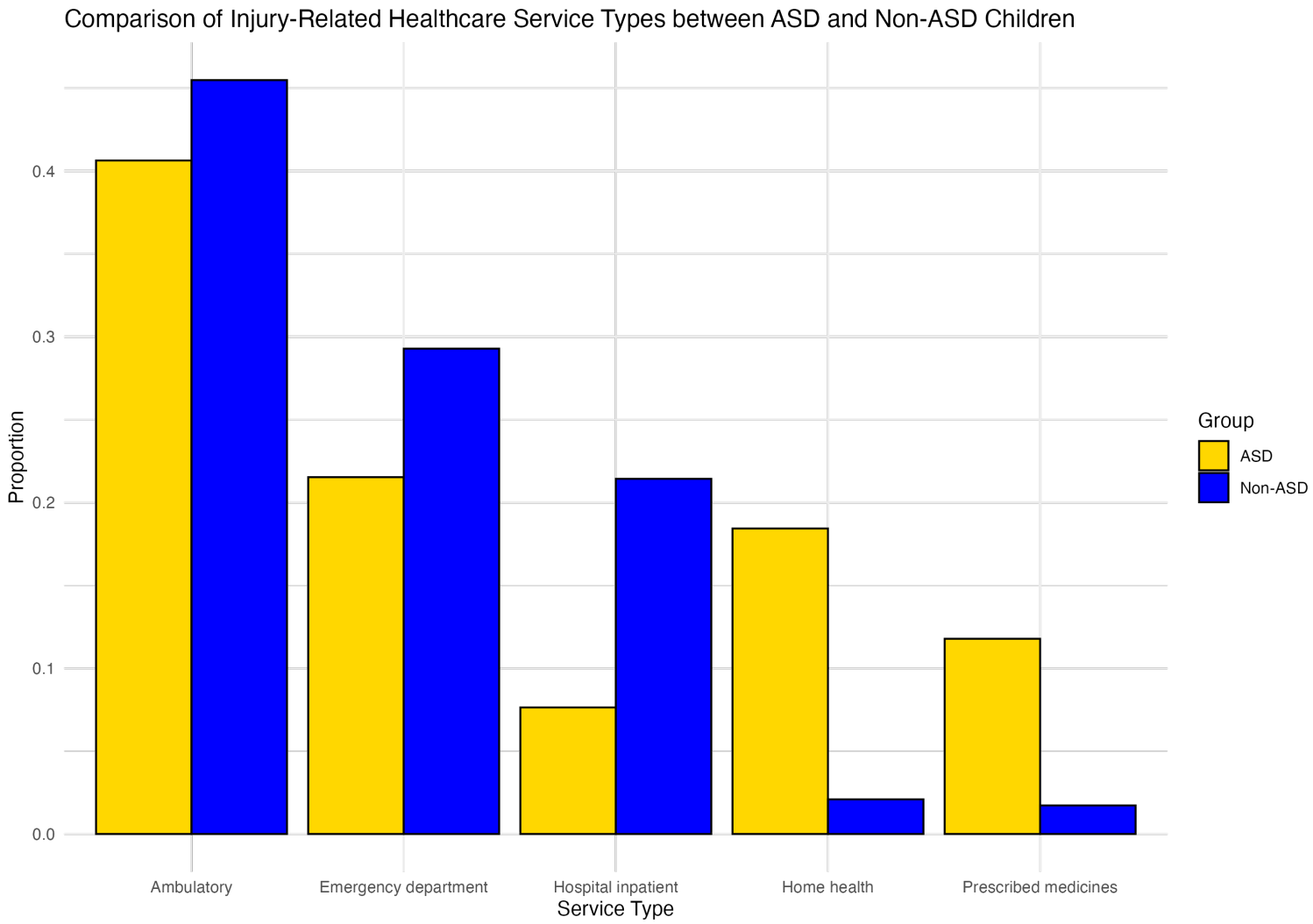
	National Estimate	95% CI
Number of autistic children	439,415	(393,531 - 485,299)
Number of autistic children who were had an injury	45,187	(34,417 - 55,956)
Number of injured autistic children who…		
sought medical care	36,739	(27,527 - 45,951)
*were treated at ED**	16,582	(10,572 - 22,591)
*were treated inpatient/hospitalized**	1,155	(0 - 2,565)
Injury-related medical expenditures (median, IQR)		
Total medical expenditures per child	$252.33	($63.27 - 1,065)
Insurance-paid medical expenditures per child	$241.69	($18.61 - 1,041)
Family/self-paid medical expenditures per child	$0.00	($0.00 - 45)

*The two subcategories reported in this table for those who received inpatient care and those received ER care are not mutually exclusive cases

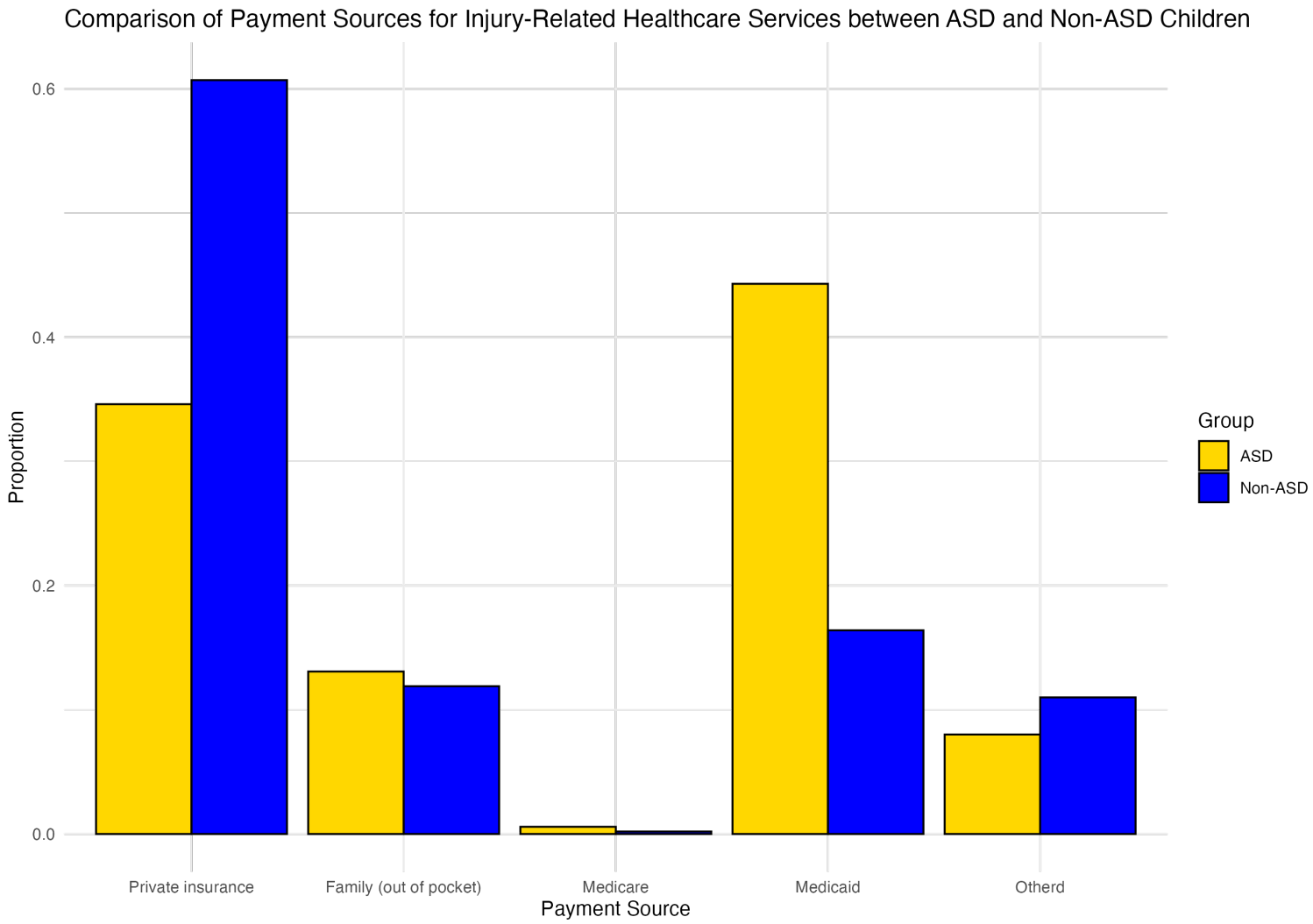
Injury Types



Service Types



Payment Sources



Significant Predictors

		Injury Incidence			Medical Seeking Behavior			Total Medical Expenditure		
		OR[b]	95% CI		OR[b]	95% CI		Coeff.[b]	95% CI	
Age	0-4 yrs (ref.)									
	5-9 yrs	1.046	0.554	1.977	0.78	0.218	2.786	1.2307	0.32469	4.66
	10-14 yrs	**0.439**	0.211	0.913	0.364	0.072	1.831	0.6807	0.08824	5.25
	15-17 yrs	0.835	0.396	1.762	2.629	0.201	34.473	3.6611	0.49243	27.22
Race/ Ethnicity	White/Other Race (ref.)									
	Black	0.883	0.447	1.745	**0.121**	0.018	0.798	0.386	0.07337	2.03
	Hispanic	0.557	0.278	1.118	0.451	0.058	3.486	0.3479	0.04899	2.47
	Asian	0.396	0.103	1.525	0.394	0.044	3.543	0.9706	0.09229	10.21
Parental Education	Less than high school (ref.)									
	High school	2.585	0.976	6.847	0.901	0.079	10.216	0.5329	0.03135	9.06
	College and higher	**3.857**	1.486	10.013	0.457	0.037	5.702	0.7888	0.03596	17.3
Parental Marriage Status	Both parents (ref.)									
	Single parents	1.227	0.71	2.12	**6.838**	1.494	31.3	1.9757	0.44689	8.73
	No parents	1.55	0.477	5.033				3.2477	0.5357	19.69
Perceived Mental Health	Excellent (ref.)									
	Very Good	0.847	0.387	1.854	0.511	0.049	5.304	2.1893	0.43842	10.93
	Good	1.041	0.505	2.149	1.558	0.194	12.498	0.3679	0.05715	2.37
	Fair	1.259	0.57	2.78	0.389	0.035	4.286	0.1113	0.00934	1.33
	Poor	0.662	0.201	2.186				**32.484**	2.56419	411.52
Geographic Region	Northeast (ref.)									
	Midwest	1.734	0.807	3.727	1.106	0.108	11.27	0.8906	0.17101	4.64
	South	1.051	0.49	2.257	0.449	0.078	2.598	0.4507	0.10328	1.97
	West	**2.553**	1.224	5.325	0.412	0.079	2.148	0.5835	0.11898	2.86

Summary

Autistic children are at comparable risks of injury as the general population

However, autistic children are more likely to

Suffer open wound injuries	Be hospitalized after an injury	Receive home health and prescribed medicine for injuries	Use Medicaid/Medicare and pay out of pocket for injury treatments

Summary

Predictors of Burden of Injury

- Age, parental education and geographic regions → Injury risk
- Race/ethnicity and parental marriage status → Medical seeking behavior
- Perceived mental health → Medical expenditures

Trend from 2000 to 2021

- Increase of autistic children among general population
- Increase of injury-related economic burden for healthcare services
- Injury rate and healthcare service utilization fluctuates over time

Acknowledgements

Collaborators at UMass Lowell

- Yan Wang PhD – Department of Psychology (Co I)
- Ashleigh Hillier PhD – Department of Psychology (Senior Co-I and Mentor)
- Wenjun Li PhD – Department of Public Health (Senior Co-I and Mentor)
- Tonghui Xu – School of Education (Graduate Student Assistant)
- Jie Cheng – Center for Health Statistics (Biostatistician)
- Junxin Shi – Nationwide Children's Hospital (Consultant)

Community Advisory Board

HRSA Autism Secondary Data Analysis Research Program

Questions

Please enter your questions in the Q/A section at the bottom of your screen

Children's Safety Network

Thank you!

1. Please fill out our brief evaluation:

3. Visit our website: childrenssafetynetwork.org

2. Follow us on social media:

- Children's Safety Network
- Children's Safety Network
- @ChildrensSafety
- Children's Safety Network

Children's Safety Network