



AUTISM SPEAKS™
It's time to listen.

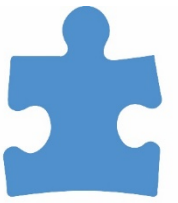
Living Life: Health, School, Workforce, and Independent Living

Arun Karpur, MD, MPH

April 2, 2019

**World Autism Awareness Day Interagency
Roundtable**

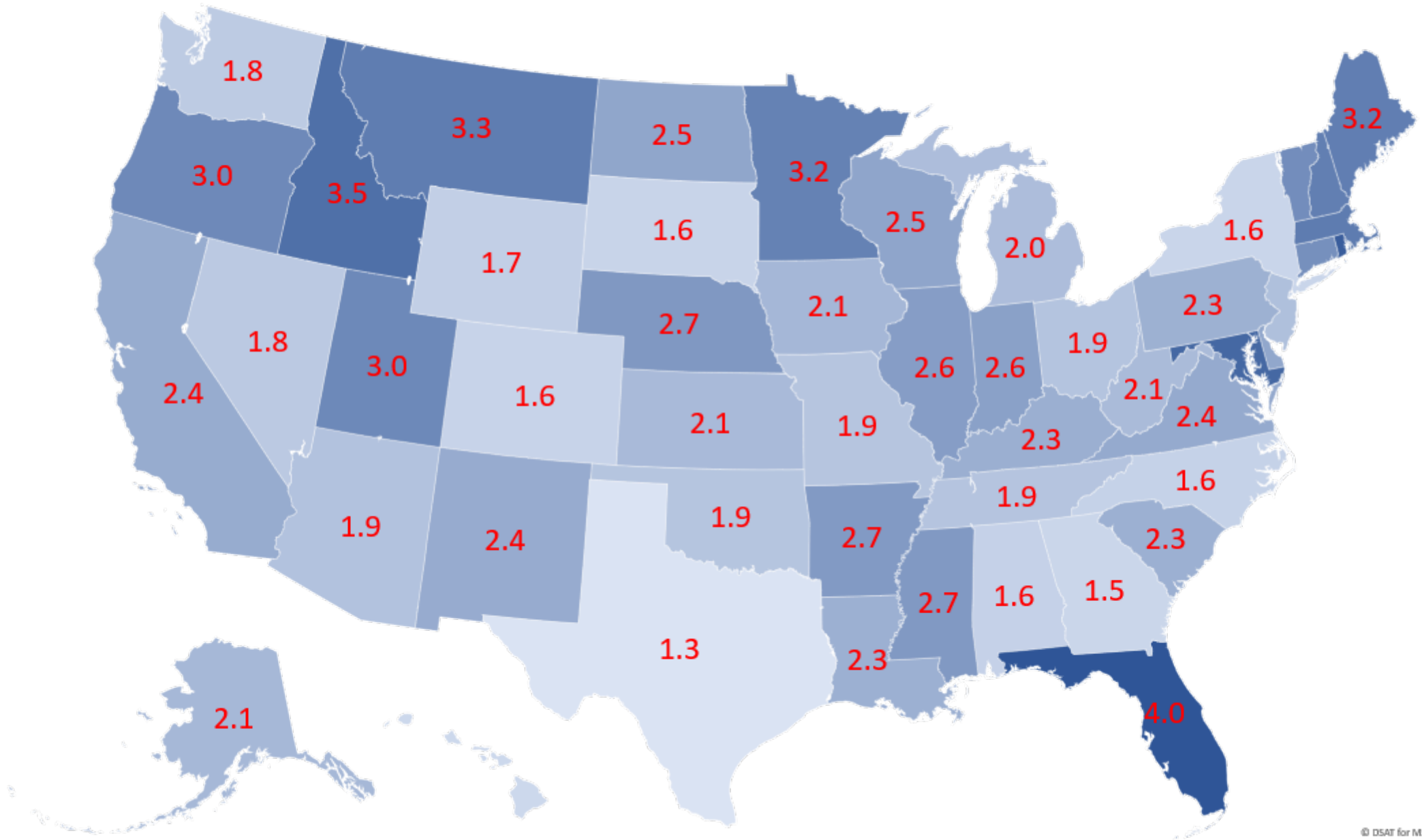
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Background

- One in 59 children has ASD diagnosis in U.S.
- ASD is under-identified or identified late in low-income and minority population.
- Access to early intervention services, appropriate psychoeducational or Applied Behavior Analysis (ABA) services continue to be difficult for children with ASD.
- Transition-age youth with ASD continue to experience poorer outcomes in health, employment, education, and overall well-being.



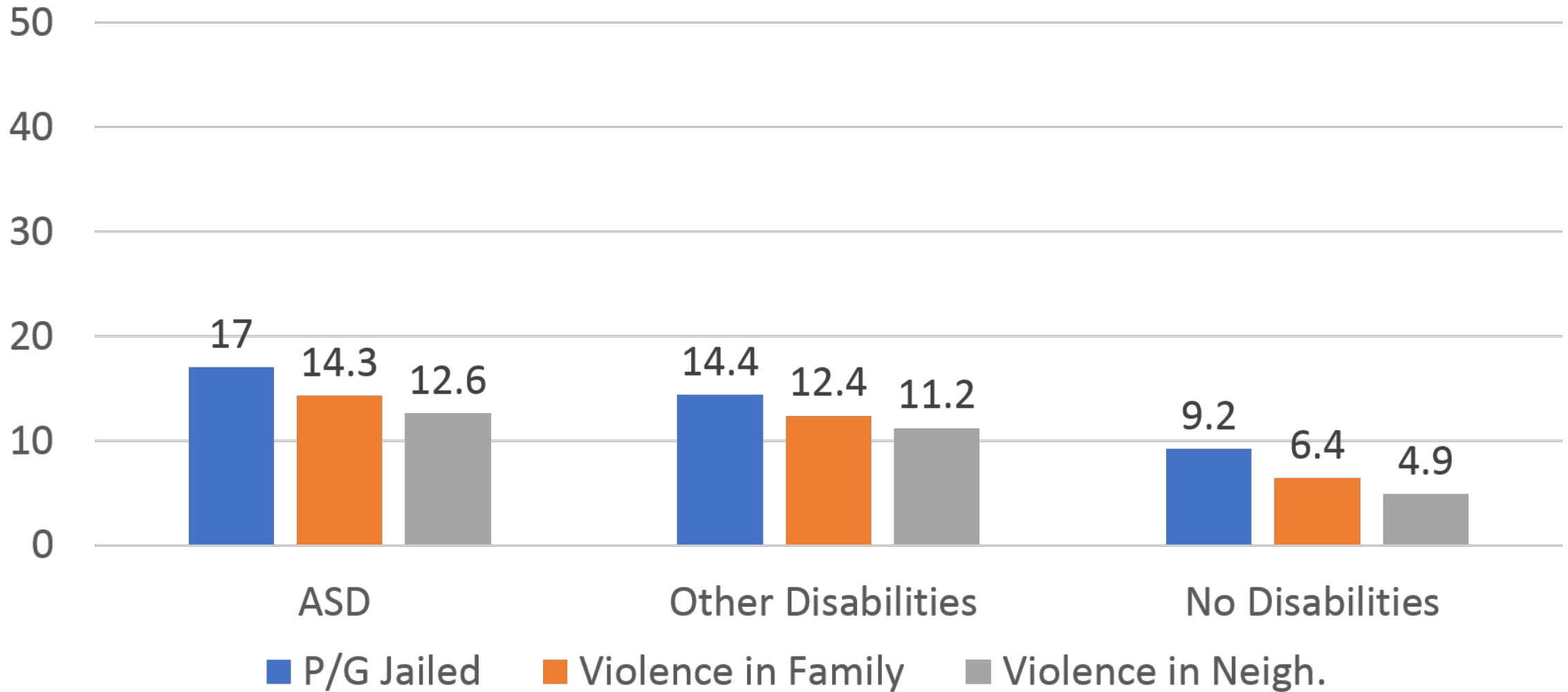
Individual Characteristics

- Children with ASD are:
 - 4 times more likely to be males;
 - 1.2 times more likely to be Non-Hispanic Whites;
 - 1.5 times more likely to be poor (i.e., < 100% FPL); and
 - 2 times more likely to be obese, compared to children without disabilities.
- 72 % of children with ASD had four or more co-occurring medical conditions; compared to 30% children with other disabilities.

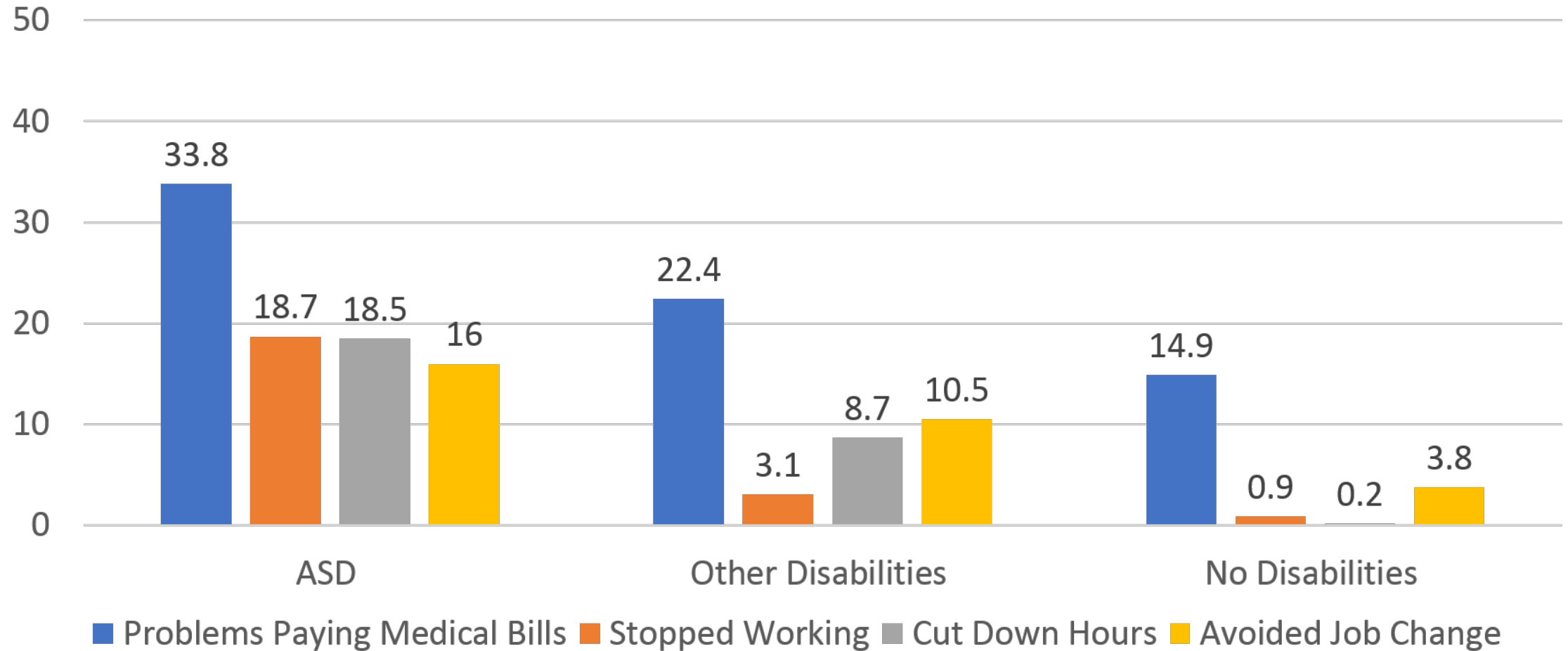
Family Characteristics

- One quarter of children with ASD belong to single-parent families compared to only 16% of children without disabilities.
- 35% of parents of children with ASD received welfare benefits compared to 19% of parents of children without disabilities.
- Parents/caregivers are 3 times more likely to experience hardships, 2.5 times more likely to have poor health, and 15 times more likely to be unemployed/stopped working compared to parents/caregivers of children without disabilities.
- 15% of children with ASD experience three or more adverse family events compared to 5% of children without disabilities.

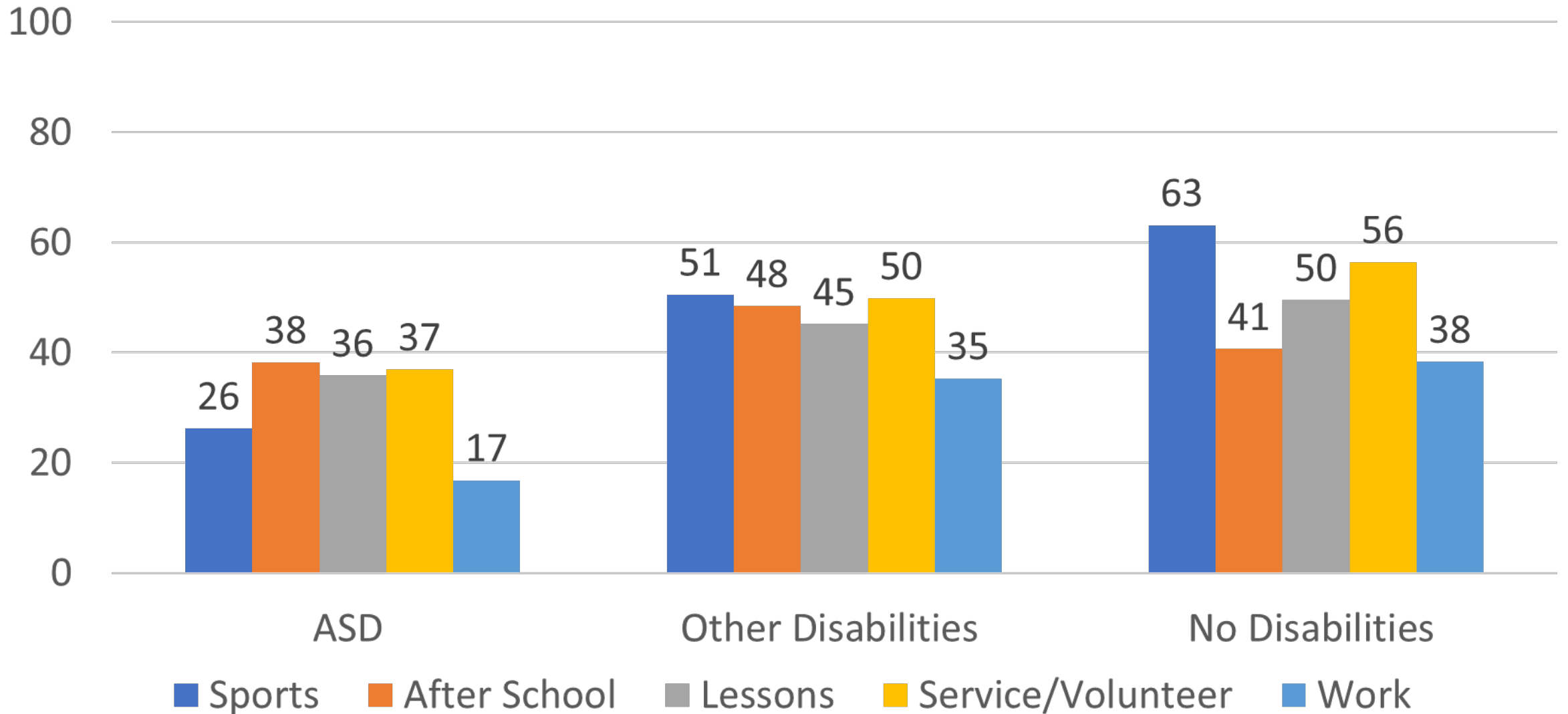
Exposure to Family Adverse Events



Percentage Distribution of Challenges in Managing Child's Healthcare Needs



Percentage Distribution of School Engagement



Access to Healthcare

- Though children with ASD are 3 times more likely to have health insurance, they are 2 times as likely to indicate poorer quality of coverage.
- About half of children with ASD indicated lack of availability of suitable services nearby their home, nearly 70% indicated problem with getting appointment to seek clinical services, and 34% indicated problems with transportation.
- Children with ASD are 4 times more likely to report unmet healthcare needs compared to their peers without disabilities.*
- Social determinants predict unmet healthcare needs more than functional limitations or the co-occurring conditions. (Karpur, Lello, Frazier, Dixon, & Shih, 2018).

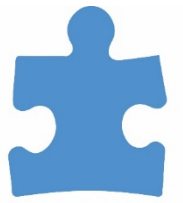
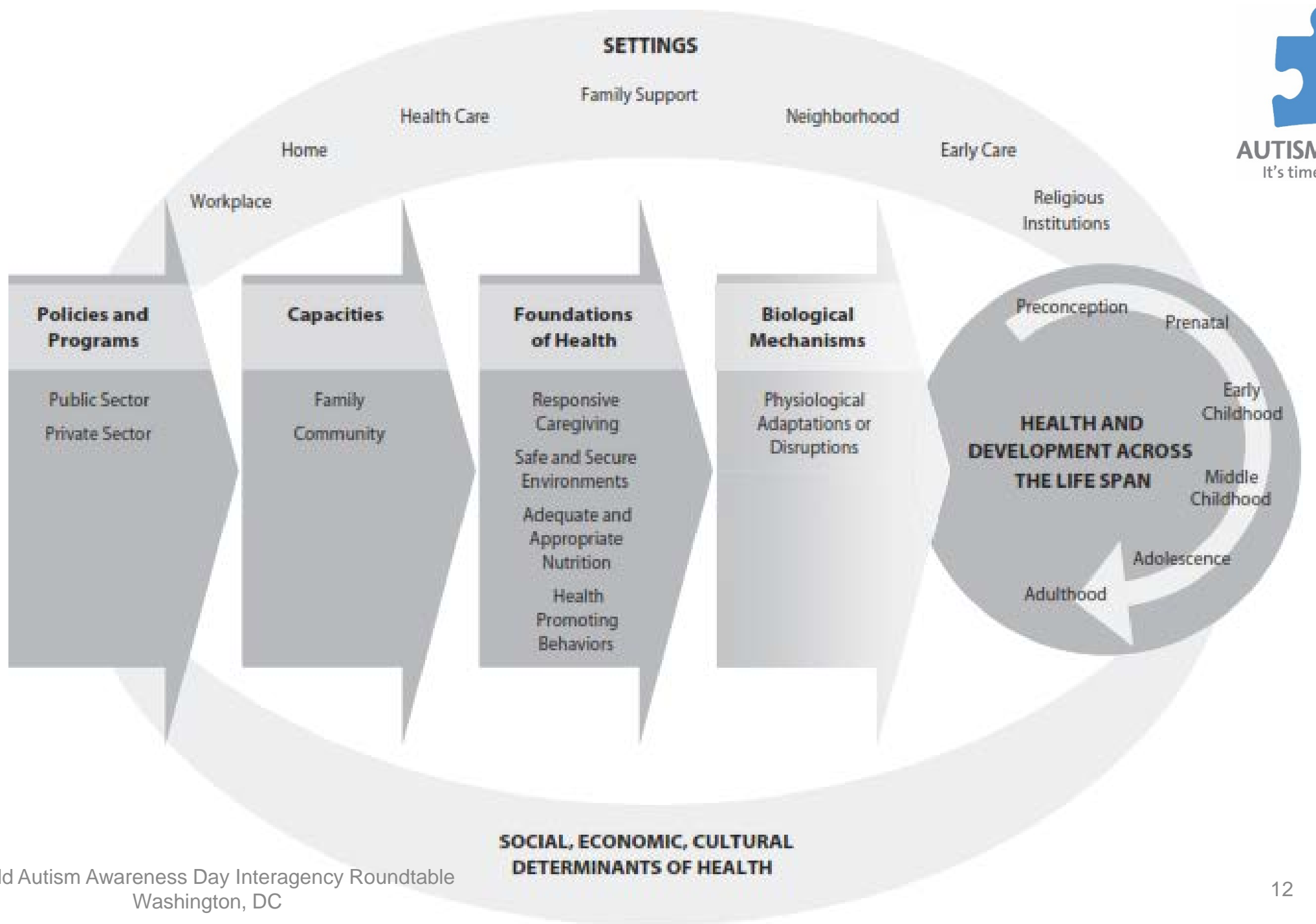
Access to Healthcare (continued)

- Children with ASD continue to have lower quality of life – more often predicted by support needs and cooccurring conditions (Arias et al., 2018).
- Children with ASD, especially from Black and Hispanic families, continue to experience persistent lower quality of services.
- Transition to adulthood continues to pose challenges – where many lose access to public health insurance (Shea et al., 2019).
- As Individuals with ASD grow older, they lose access to needed services that address core functional limitations – a “service cliff” (Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016; Shattuck et al., 2012).

Life-long Learning and Work

- Among individuals with disabilities, young people with ASD are least likely to be engaged in work or community-based opportunities to learn and/or attend post-secondary education (Chen, Sung, & Pi, 2015).
- Individuals belonging to lower socio-economic status and minorities were least likely to be engaged in work and community-based activities.
- Less than one in five youth with ASD receive services from Vocational Rehabilitation to support their life-long learning needs (Rast, Roux, & Shattuck, 2019).

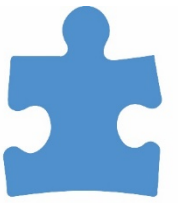
Framework for Response



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Opportunities

- Strengthening access to healthcare through reforms, expanding Medicaid, and access to private insurance.
- Strengthening independent living center programs.
- WIOA provides an unparalleled opportunity to improve access to services to prepare young adults with ASD for careers after high-school.
- HCBS Waiver programs offer opportunities for states to structure services for individuals with ASD to improve access to transportation, housing, and other community-based services to address the “service cliff.”
- Financial and benefits management programs have ability to support families as they support their child with ASD.



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Thank You

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