

Meeting of the Interagency Autism Coordinating Committee

January 19, 2022; 10:00 a.m. - 5:00 p.m. ET



Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health
(NIMH) and Chair, IACC

Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

IACC Membership Updates



Welcoming:

- Taryn Williams, M.A., Assistant Secretary in the Office of Disability Employment Policy, U.S. Department of Labor
- Lawrence Tabak, D.D.S., Ph.D, Acting Director, National Institutes of Health

Thank you/Farewell to:

- Francis Collins, M.D., Ph.D., Former Director, National Institutes of Health
- Valerie Paradiz, Ph.D., Autism Speaks (retired)
- Jennifer Sheehy, Ph.D., Deputy Assistant Secretary in the Office of Disability Employment Policy, U.S. Department of Labor

The Social Security Administration and the Autism Spectrum: Disability Insurance, Supplemental Security Income, and Work



Jeff Hemmeter, Ph.D.

Acting Deputy Associate Commissioner
Office of Research, Demonstration, and Employment Support
Office of Retirement and Disability Policy
Social Security Administration

SSA and Autism: Supplemental Security Income, Disability Insurance, and Work

Jeffrey Hemmeter, Ph.D.

Acting Deputy Associate Commissioner

Office of Research, Demonstration, and Employment Support

Social Security Administration

January 19, 2022

SSA as an organization

- Independent Federal agency
- ~60,000 employees: 90% provide direct service
- Over 1,500 field offices
- Disability Determination Services: ~15,000 state employees

SSA Programs

Social Security (OASDI)

- Old Age, Survivors Insurance (OASI)
- Disability Insurance (DI)
 - DI—\$144 billion outlays
 - Disabled Workers, Disabled Adult Children, Disabled Widow(er)s

Supplemental Security Income (SSI)

- SSI—\$56 billion outlays
- Children (<18); Adults (18-64); Elderly (65+)

Selected SSA FY 2021 workloads

- ~2.5 million initial disability claims (DI and SSI)
 - 171-day average processing time
- ~400-500k hearings
 - 310-day average processing time
- 36 million National 800 Number calls handled
- ~1.6 million continuing disability reviews (CDRs)
 - ~500k full medical CDRs
- 2.36 million SSI non-medical redeterminations
- Many other workloads: OASI claims, enumerations, statements, earnings, etc.

Social Security Disability Insurance

Payments come from Social Security trust funds and are based on a person's earnings.

Insurance that workers earn by paying Social Security taxes on their wages.

Pays benefits to disabled individuals who are unable to work, regardless of their income and resources.

Pays benefits for workers and for adults disabled since childhood. Must meet insured status requirements.

Supplemental Security Income

Payments come from the general treasury fund, NOT the Social Security trust funds. SSI payments are not based on a person's earnings.

Needs-based public assistance program that does not require a person to have a work history.

Pays disabled individuals who are unable to work AND have limited income and resources; pays aged individuals 65 and older with limited income and resources.

Benefits for children and adults in financial need. Must have limited income and limited resources.

Disability Determination

Children

1. Earnings above SGA
2. Severe impairment
3. a. Meets or equals medical Listings*
- b. Functionally equals level of severity of Listing*

* Step that can lead to an allowance

Adults

1. Earnings above SGA
2. Severe impairment
3. Meets or equals medical Listings*
4. Capacity for past relevant work
5. Capacity for any work*

Definition of Disability

20 CFR § 404.1505. Basic definition of disability. (DI; § 416.905 for SSI)

- (a) The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

20 CFR § 416.906. Basic definition of disability for children. (SSI)

- If you are under age 18, we will consider you disabled if you have a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months.

Disability Evaluation Under Social Security (a.k.a., the Blue Book)

- Provides physicians and other health professionals with an understanding of the disability programs administered by SSA
- Explains how each program works, and provides information to help health professionals make sound and prompt determinations and decisions on disability claims
- Lists specific criteria under which claimants who suffer from a disabling condition can more easily qualify for disability benefits.

ASD Listing Summary

A. Medical documentation of both of the following:

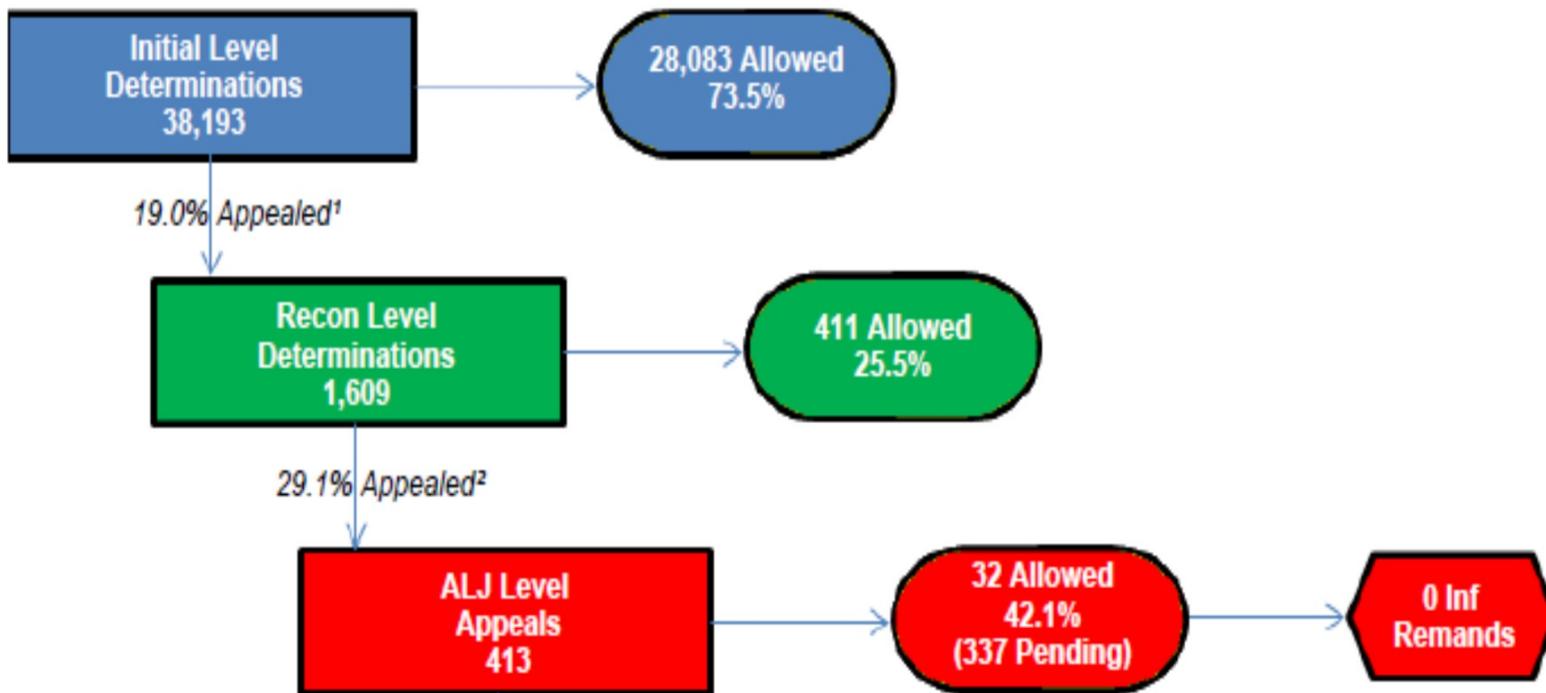
1. Qualitative deficits in verbal communication, nonverbal communication, and social interaction; and
2. Significantly restricted, repetitive patterns of behavior, interests, or activities.

AND

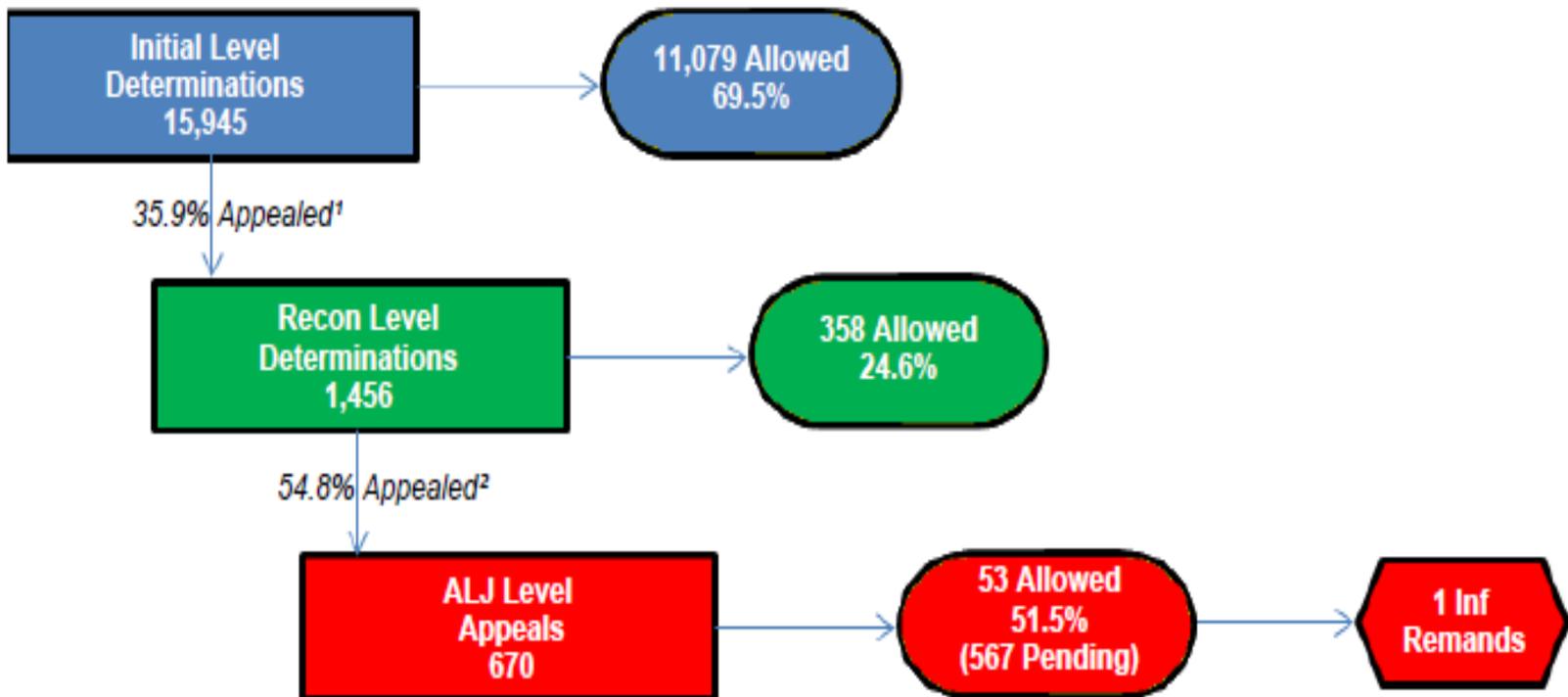
B. Extreme limitation of one, or marked limitation of two, of the following areas of mental functioning:

1. Understand, remember, or apply information.
2. Interact with others.
3. Concentrate, persist, or maintain pace.
4. Adapt or manage oneself.

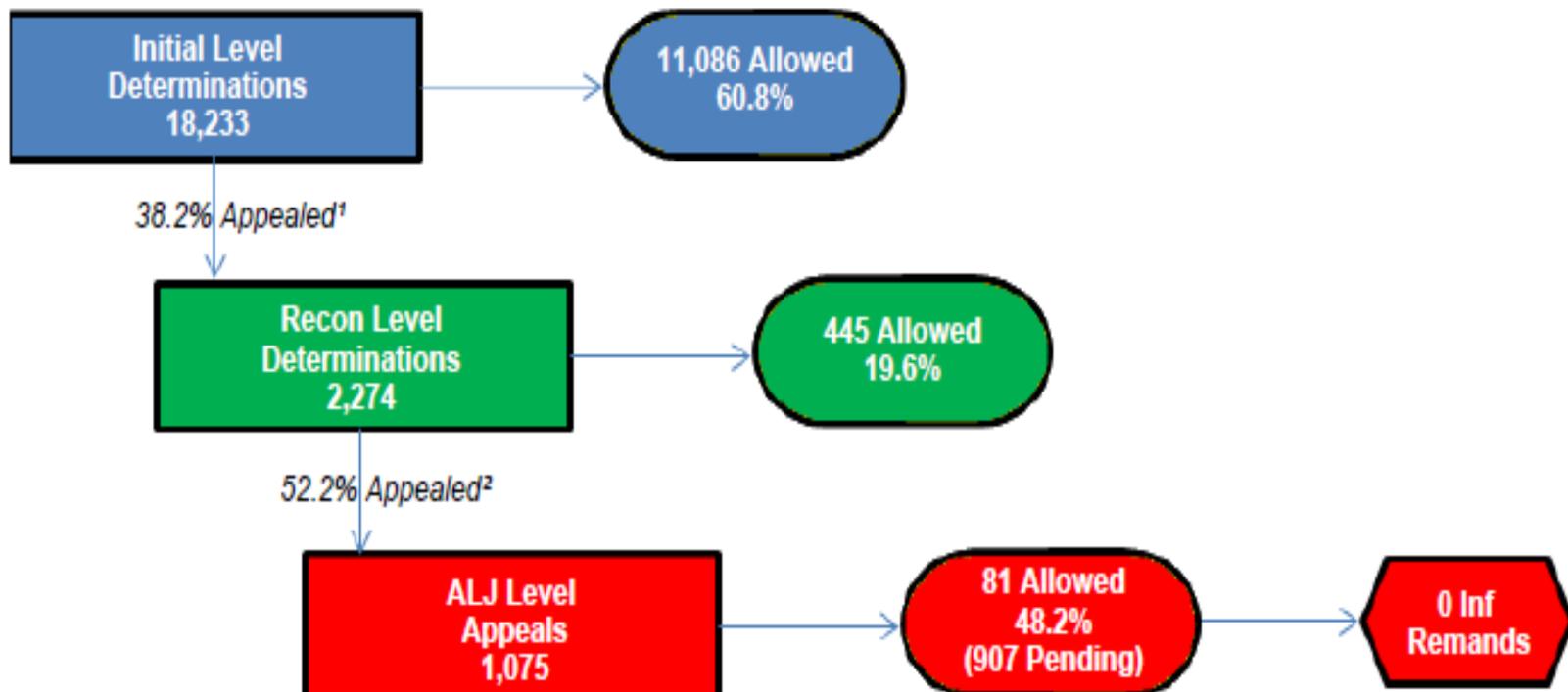
2019 Child SSI Autism Claims Outcomes (including FO Technical Denials)



2019 DI Autism Claims Outcomes (including FO Technical Denials)



2019 Adult SSI Autism Claims Outcomes (including FO Technical Denials)



SSI Payment Rules

- Maximum monthly Federal Benefit Rate: \$841 individual/\$1,261 couple (in 2022)
 - Reduced by \$1 for every \$2 of countable earned above \$65
 - Reduced by \$1 for every \$1 of countable unearned income above \$20
- Asset limits: \$2,000 individual/\$3,000 couple
- Deeming from spouses/parents
- States can supplement

DI Payment Rules

- Primary Insurance Amount
 - Family Maximum
- Full benefit regardless of earnings during Trial Work Period (TWP)
 - 9 months in rolling 60-month period
 - Earnings > \$970 (in 2022)
- After TWP, benefits suspended if performing substantial gainful activity (SGA)
 - \$1,350 non-blind, \$2,260 blind (in 2022)
- If still working above SGA after 36 months, benefits terminated

ASD in each program

- SSI

- Children: 215,174 (19.4% of children)
- Adults: 190,106 (4% of adults)
- About 80% male
- Average payments: \$653.42 (above average)

- DI

- 102,248 (1.1%) of beneficiaries (\$853.79) (below average)
- Workers: 28,622 (0.4%) (\$762.45) (below average)
- Widow(er)s: 33 (<.05%) (\$695.02) (below average)
- Adult Children: 73,603 (6.4%) (\$889.38) (above average)

Working While Receiving Benefits

- Yes, DI beneficiaries and SSI recipients can work!
- There are several employment support programs and provisions commonly referred to as work incentives.
- These are summarized in the Red Book—A Summary Guide to Employment Supports
 - SSA's one-stop publication on work incentives
 - Expands on what is on the following slides

Selected Work Incentives (1)

- Continued Payment under VR or similar program (Section 301)
 - If found ineligible as the result of a medical CDR or an age-18 redetermination (NOT an initial claim), benefits may continue if the individual is participating in an appropriate program of vocational rehabilitation or similar services
 - Requires a specific application
- Student Earned Income Exclusion (SEIE) (*SSI only*)
 - If under age 22 and regularly attending school, up to \$1,820 of earned income per month and up to \$7,350 per year is excluded from SSI calculations (2022)
 - SEIE is applied *before* the earned income exclusion (\$65) and general income exclusion (\$20)

Selected Work Incentives (2)

- Impairment-Related Work Expenses
 - Includes items or services needed because of medical condition and needed to work
 - Excluded from SSI monthly payment calculation and SGA
- Expedited Reinstatement (EXR)
 - If eligibility ends because an individual returned to work, payments can start again immediately while the eligibility is being determined
 - Must have the same or related medical impairment, request EXR within 5 years of initial payment end, and meet other conditions

Selected Work Incentives (3)

- Plan to Achieve Self-Support (PASS)
 - A formal plan that allows an individual to set aside non-SSI income and resources for a specific period of time so that the individual can pursue a work goal that will reduce or eliminate SSI or DI benefits
 - PASS can help *establish* eligibility as well as *maintain* eligibility
- Section 1619(b) (*SSI only*)
 - Even if SSI payments end because of work, Medicaid can continue if all other SSI rules are met and Medicaid is required for working
 - Each state has a different earnings thresholds
 - Individualized thresholds can apply if medical expenses are above state threshold

Selected Work Incentives (4)

- Unsuccessful Work Attempt
 - If stopped working or reduced work to below SGA after a short time (6 months or less) because of impairment or the removal of special conditions necessary for work, that is taken into consideration during the *initial* claim
- Subsidies and special conditions
 - SSA only counts earnings that represent the real value of the work performed when deciding if work is at the SGA level
- Achieving a Better Life Experience (ABLE) Accounts (*SSI only*)
 - Contributions to, earnings of, and distributions from ABLE accounts are excluded from income calculations for SSI
 - Up to \$100,000 of the balance in an ABLE account is excluded from resource calculations for SSI

Other SSA Work Resources (1)

- Work Incentives Planning and Assistance (WIPA) providers
 - WIPA programs provide, individualized counseling to Social Security beneficiaries who are working or about to work
 - Counseling includes accurate information about work incentives and work supports that will assist beneficiaries to meet their financial and employment goals
- Protection and Advocacy for Beneficiaries of Social Security (PABSS)
 - Agencies serve beneficiaries with disabilities who want to work, by helping to remove barriers to employment
 - PABSS staff, consisting of attorneys and advocates assist beneficiaries with understanding and securing employment protections

Other SSA Work Resources (2)

- Ticket-to-Work
 - Provide employment services to beneficiaries
 - Only eligible if over 18 and have an adult determination of eligibility
 - SSA pays employment service providers (Employment Networks) for successful employment outcomes (milestones and outcomes)
- Vocational Rehabilitation Cost Reimbursement
 - SSA reimburses state Vocational Rehabilitation agencies for costs associated with beneficiaries who achieve 9 months at SGA

ASD and SSI Research

- Supplemental Security Income Program Entry at Age 18 and Entrants' Subsequent Earnings
 - <https://www.ssa.gov/policy/docs/ssb/v75n3/v75n3p35.html>
 - Third-largest spike in applications at age 18
 - 10.9% of applications within 2 months
 - Over 91% awarded SSI
- Trends in Supplemental Security Income Payments to Adults With Autism | Psychiatric Services
 - <https://ps.psychiatryonline.org/doi/10.1176/appi.ps.201900265>
 - Increasing proportion of first-time adult awards have ASD as the primary or secondary impairment
 - 1.5% of awards in 2005; 5% of awards in 2015

ASD and SSI Research

- National and State Trends in autistic Adult Supplemental Security Income Awardees: 2005–2019
 - <https://link.springer.com/article/10.1007/s10803-021-05215-1>
 - Substantial variation in new adult SSI awards across states
 - Most ASD awards are between ages 18-25
- Changing Stays? Duration of Supplemental Security Income Participation by First-Time Child Awardees and the Role of Continuing Disability Reviews
 - <https://www.ssa.gov/policy/docs/ssb/v81n2/v81n2p17.html>
 - Increasing proportion of first-time child awards
 - 3.5% of awards in 1997; 16.1% of awards in 2017
 - 10-year cumulative SSI \$64,539 (2007 ASD awards)

ASD and SSI Research

- Promoting Readiness of Minors with Autism Spectrum Disorder: Evidence from a Randomized Controlled Trial
 - <https://www.mathematica.org/publications/promoting-readiness-of-minors-with-autism-spectrum-disorder-evidence-from-a-randomized-controlled>
 - Most participating youth with ASD received some transitions services.
 - Early impacts for youth with ASD were similar to those for youth without ASD.
 - Increases in job-related training, paid employment, earnings, and receipt of various transition related services (case management, employment promoting services, benefits counseling, financial education, and vocational rehabilitation services)

How to Apply

- Apply Online—start the process this way
 - DI and adult SSI claims
 - <https://secure.ssa.gov/iClaim/dib>
 - Children under 18 years old cannot complete application
 - <https://www.ssa.gov/benefits/disability/apply-child.html>
- Call or make an appointment
 - 1-800-772-1213
 - TTY 1-800-325-0778
- Information for People Helping Others
 - <https://www.ssa.gov/thirdparty/>

Work Resources

- Red Book on Work Incentives: A Summary Guide to Social Security and Supplemental Security Income Work Incentives for People with Disabilities
 - <https://www.ssa.gov/redbook/>
- Ticket to Work
 - <https://choosework.ssa.gov/>
- Working While Disabled: How We Can Help
 - www.ssa.gov/pubs/EN-05-10095.pdf
- Youth Portal
 - www.ssa.gov/youth

Disability Determination Resources

- Disability Evaluation Under Social Security
 - <https://www.ssa.gov/disability/professionals/bluebook/index.htm>
- Fact Sheet for Mental Health Care Professionals: Supporting Individuals' Social Security Disability Claims
 - <https://www.ssa.gov/disability/professionals/mentalhealthproffacts.htm>
- Childhood Disability Under the Social Security Administration's Supplemental Security Income: A Guide for Physicians and Other Health Professionals
 - <https://www.ssa.gov/disability/professionals/childhoodssi-pub048.htm>
- Childhood Disability Under the Social Security Administration's Supplemental Security Income: A Guide for School Professionals
 - <https://www.ssa.gov/disability/professionals/childhoodssi-pub049.htm>

Understanding SSI and DI

- Benefits for People with Disabilities
 - <https://www.ssa.gov/disability/>
- Supplemental Security Income Payments
 - <https://www.ssa.gov/benefits/ssi/>
- Understanding SSI - SSI for Children
 - <https://www.ssa.gov/ssi/text-child-ussi.htm>
- SSI Benefits for Adults
 - <https://www.ssa.gov/benefits/ssi/adults.html>
- Benefit Eligibility Screening Tool
 - <https://ssabest.benefits.gov/>

Thank you

National Autism Coordinator Update

IACC Full Committee Meeting
January 19, 2022

Susan Daniels, Ph.D.

Acting HHS National Autism Coordinator

Office of the NIMH Director

National Institute of Mental Health



National Autism Coordinator Update

- 2021 HHS Report to Congress on Health and Well-Being
- Federal Entity and Workgroup Updates & Non-Governmental Updates

2021 HHS Report to Congress on Health and Well-Being



- Required by the Autism CARES Act of 2019:
“Not later than 2 years after September 30, 2019, the Secretary shall prepare and submit, to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives, **a report concerning the health and well-being of individuals with autism spectrum disorder.**”
- NAC and OARC coordinated on behalf of HHS the completion of the *Report* with contributions from multiple federal departments and agencies
- The *Report* was submitted to Congress in Fall 2021.
- The full *Report* is now available on the IACC website: <https://iacc.hhs.gov/publications/report-to-congress/2021/>

2021 HHS Report to Congress on Health and Well-Being

For the purposes of this Report, “health and well-being” was defined as:

- Physical and mental health outcomes
- Access to autism-related services and supports (healthcare, Social Security, home and community-based services, etc.)
- Access to and inclusion in the community (employment, education, housing, transportation, safety, social inclusion, etc.)

2021 Report to Congress: Report Elements

- 1) Information describing **demographic factors** associated with the health and well-being of individuals on the autism spectrum.
- 2) An overview of current federal **policies and programs** relevant to the health and well-being of individuals on the autism spectrum.
- 3) Information on current federal **comprehensive approaches** to improving health outcomes and well-being for individuals on the autism spectrum.
- 4) Department/agency **recommendations** on improving health outcomes and ensuring coordination between relevant agencies and service providers

2021 Report to Congress: Departments/agencies included

Information from 22 Federal departments and agencies was included:

- Department of Health and Human Services (HHS)
 - Administration for Children and Families (ACF)
 - Administration for Community Living (ACL)
 - Agency for Healthcare Research and Quality (AHRQ)
 - Office of the Assistant Secretary for Planning and Evaluation (ASPE)
 - Centers for Disease Control and Prevention (CDC)
 - Centers for Medicare & Medicaid Services (CMS)
 - Health Resources and Services Administration (HRSA)
 - Indian Health Service (IHS)
 - National Institutes of Health (NIH)
 - Office of Disease Prevention and Health Promotion (ODPHP)
 - Substance Abuse and Mental Health Services Administration (SAMHSA)

2021 Report to Congress: Departments/agencies included

Information from 22 Federal departments and agencies was included:

- Department of Defense (DoD)
 - Army
 - Military Health System (MHS)/TRICARE)
- Department of Education (ED)
- Environmental Protection Agency (EPA)
- Department of Housing and Urban Development (HUD)
- Department of Justice (DOJ)
- Department of Labor (DOL)
- National Science Foundation (NSF)
- Social Security Administration (SSA)
- Department of Transportation (DOT)
- Department of Veterans Affairs (VA)

2021 Report to Congress: Recommendations

- 23 recommendations for activities related to health and well-being were developed by FIWA member agencies across 7 categories set by Congress:
 - 1) Interdisciplinary coordination of federal resources
 - 2) Screening and diagnosis of autism in children and adults
 - 3) Behavioral and other therapeutic interventions
 - 4) Primary, preventative, and emergency/acute care
 - 5) Treatment and understanding of co-occurring physical, behavioral, and mental health conditions
 - 6) Caregiver mental health and supports
 - 7) Quality of life factors

Report recommendations: Interdisciplinary coordination of Federal resources

1. Review current federal policies and **develop best practice guidelines for interdisciplinary coordination and collaboration of service providers** receiving federal funding, emphasizing person- and family-centered approaches and use of evidence-based practices.
2. Promote **increased understanding of and access to systems that provide services and supports** to people with ASD across the lifespan and increase awareness of the rights and entitlements of individuals with ASD to receive these services.
 - Systems should include, but are not limited to, education, health care, employment/vocational supports, community participation/inclusion services, housing, transportation, justice systems, public safety, and legal assistance.

Report recommendations: Interdisciplinary coordination of Federal resources

3. Support state and local efforts to create **coordinated systems of mental health supports** for individuals with ASD across the lifespan.
- Encourage state and local school systems to incorporate existing programs into coordinated systems of supports for mental health and social-emotional well-being.
 - Support state and local efforts to create coordinated mental health systems for adults with ASD.
 - Support workplace initiatives that ensure full access to mental health supports for workers on the autism spectrum and training on autism for employee assistance programs.

Report recommendations: Interdisciplinary coordination of Federal resources

4. Support the **development of interstate/intrastate health care information exchanges** to encourage interdisciplinary coordination among service providers.
5. **Track, collaborate with, and learn from the efforts of national and international organizations** that are developing recommendations, guidelines, and/or best practices to address health and well-being issues relevant to the ASD community.
6. Engage state and local organizations that receive federal and/or state funding to **enhance delivery of community-based services**, including services that support independent living, job training, and career development.

Report recommendations:

Screening and diagnosis of ASD in children and adults

7. Support research to **develop effective approaches and tools for the identification of autism in children and adults**, as well as decreasing the time between identification of autism and referral for/access to services and interventions.

- Assess trends in the age at first ASD diagnosis using recent population-based data to better identify disparities in the early detection of ASD in children.
- Analyze the health and quality of life outcomes across the lifespan of individuals who have been diagnosed with ASD in differing life stages, including early childhood, adolescence, or adulthood.
- Develop new diagnostic tools or improve existing tools to better identify autism among people whose backgrounds reflect diversity of gender, gender identity, race, ethnicity, nationality, culture, and language use.
- Ensure that diagnostic tools used with youth and adults fully consider compensatory strategies, coping systems, communication differences, and secondary conditions that may mask or occlude key traits of autism.

Report recommendations: Behavioral and other therapeutic interventions

8. Develop and implement **behavioral interventions and mental health supports in educational settings** that will promote academic achievement for students with ASD at all levels.
9. Support research to **develop and validate measures of social and behavioral functioning** that can be used to evaluate the effectiveness of interventions, services, and supports for individuals with ASD across the lifespan, including measures that are sensitive enough to detect clinically or functionally meaningful changes in outcomes.

Report recommendations: Behavioral and other therapeutic interventions

10. Support the development of **professional training programs for educators, health care workers, and service professionals** working with individuals with ASD.

- Programs should address the needs of professionals across different disciplines and settings, encourage interdisciplinary collaboration, and/or increase professionals' knowledge and implementation of evidence-based practices.
- Standards and guidelines for professional development and training on autism should be developed for health care practitioners, particularly for inpatient settings in which autistic children, youth, and adults face high vulnerability for harm because of lack of sufficient training and standards on delivering appropriate care.

Report recommendations: Behavioral and other therapeutic interventions

11. Support **research on the communication needs** of individuals with ASD and **improve access to tools for communication**, including:

- Research to identify factors that indicate potential for enhanced verbal or non-verbal/assisted communication ability or responsiveness to appropriate communication intervention;
- Development of effective and diverse communication approaches and assistive technologies; and
- Projects to increase access to, knowledge of, and training on augmentative and alternative communication (AAC) tools to facilitate different modes of communication for individuals with ASD and explore physical and mental health and wellness among AAC users on the autism spectrum.

Report recommendations: Primary, preventative, and emergency/acute care

12. Support the **development and dissemination of health literacy resources** that empower autistic individuals and their families to make informed health care decisions, including resources on supported decision making, peer support, mentoring models, and patient navigation.
13. Engage state agencies to **increase awareness of existing federal Medicaid and Medicare services and support programs**, including federal policies, regulations, and existing flexibilities within the law that can be used to improve the health and well-being of individuals with autism.

Report recommendations: Primary, preventative, and emergency/acute care

14. Support **development of best practices to reduce gaps in primary care and mental health services**, thereby reducing the need for emergency room visits and acute care hospitalization.

15. **Address health care disparities** in individuals with ASD, including those in underserved groups (e.g., racial/ethnic minorities and rural populations) and those who have secondary conditions such as ID.

- Reduce barriers to healthcare access by increasing outreach to underserved populations as well as enhancing training and resources for medical providers.
- Increase use of telehealth and telemedicine approaches to better reach underserved populations.

Report recommendations:

Primary, preventative, and emergency/acute care

16. Increase **provider awareness, tools, and training** for autism and its co-occurring physical, behavioral, and mental health conditions, including symptoms and potential treatments and interventions.

- Address sensory-related needs, healthy aging, age-appropriate health issues across the lifespan for autistic individuals, and long-term health impacts of medication on autistic individuals.
- Develop tools and training for health care providers to enhance the quality of care for autistic patients, including for:
 - Primary care providers, to enhance the effectiveness of primary and preventative care visits for autistic patients and reduce the impact of gaps in access to specialist care;
 - Specialty care providers, to enhance the effectiveness of visits with autistic patients; and
 - Providers in acute care settings, to improve interactions with and treatment of autistic individuals.

Report recommendations:

Treatment and understanding of co-occurring physical, behavioral, and mental health conditions

17. Engage in research that will **increase understanding of the underlying mechanisms of co-occurring physical, behavioral, and mental health conditions** in ASD across the lifespan and support the **development of tailored supports and services, treatments, and interventions** to address these conditions and improve quality of life.

18. Support the **development and improvement of behavioral, mental health, and pharmacological interventions for individuals who experience major challenges** in communication, social interaction, sensory processing, and executive functioning that impact health and wellness.

Report recommendations:

Treatment and understanding of co-occurring physical, behavioral, and mental health conditions

19. Gather and disseminate information on **best practices related to person-centered approaches that prevent wandering** of individuals with ASD, including current tracking technology, to improve the response to wandering in the public safety and public health communities.

- Provide resources and technical assistance for teachers, public safety officers, and other community members to develop plans to address wandering of individuals with ASD.
- Conduct research on factors that may cause autistic individuals to wander, such as fixation on specific locations, sensory overload, anxiety, emotional or physical distress or discomfort, and leaving harmful situations.
- Develop interventions that protect health and wellness for persons inclined to wander.

Report recommendations: Caregiver mental health and supports

20. Enhance **supports and services for the caregivers** of individuals with ASD to improve quality of life.

- Support research on the needs of caregivers across the lifespan of autistic individuals.
- Develop and increase awareness of community services that support the caregivers of autistic children and adults, including family-centered support models.
- Increase/enhance use of telehealth/telemedicine and other forms of virtual support to caregivers, particularly populations that have been historically harder to reach and/or engage.
- Increase providers' (e.g. physicians, school counselors, related services providers) awareness of the potential mental health needs of caregivers and the availability of mental health services and supports for caregivers.

Report recommendations: Quality of life factors

21. Support **activities, research, and resources that contribute to improving the overall well-being** of individuals on the autism spectrum, including:

- Activities focused on competitive integrated employment, healthy living in the community, independent or supported living options, and other factors that play direct and indirect roles in improving health and well-being;
- Research on social determinants of health for individuals on the autism spectrum;
- Research and resources related to assessing the abilities of people with ASD to perform real-life complex activities that may inform support or interventions to improve function and participation; and
- Research and resources on resilience factors that support and promote positive mental health and well-being.

Report recommendations: Quality of life factors

22. Support research identifying effective **strategies to prepare adolescents and adults on the autism spectrum for gainful employment and foster access to career pathways** for adults on the autism spectrum across the life course.

23. Gather additional population-based data to **better understand, prevent, and reduce causes of premature mortality** in individuals with ASD.

2021 HHS Report to Congress on Health and Well-Being



<https://iacc.hhs.gov/publications/report-to-congress/2021/>

Federal Activities

- White House
- Defense Advanced Research Projects Agency (DARPA)
- National Science Foundation (NSF)
- National Council on Disability (NCD)
- Federal Partners in Transition (FPT)
- Interagency Committee for Disability Research (ICDR)
- RAISE Family Caregiving Advisory Council (FCAC)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- Federal Communication Commission Disability Advisory Committee (DAC)

White House

- On October 28, 2021, President Biden [appointed Sara Minkara](#) to be the U.S. Special Advisor on International Disability Rights – reinstating a role critical to ensuring that U.S. diplomacy and foreign assistance promote and protect the human rights of persons with disabilities around the world.
- On December 2, 2021, President Biden issued a [Proclamation on the International Day of Persons with Disabilities](#) affirming the human rights of people with disabilities.

Defense Advanced Research Projects Agency (DARPA)

- A project funded under the DARPA Physics of Artificial Intelligence (PAI) program addressed autism. The researchers at University of Chicago set out to investigate, develop, and implement tools that augment current machine learning tools and capabilities. They identified a need for tools that help identify children with ASD as early as possible.
- One [study](#), published in the open-access journal *Science Advances* in October 2021, developed a machine learning approach to identify autism based on patterns of co-occurring conditions using information from electronic health records (EHRs). This tool has the potential to complement current screening methods and reduce the number of false positives. The method worked consistently across various racial groups tested, suggesting it could contribute to reduction in disparities.

National Science Foundation ([NSF](#))

- In 2022, the NSF [Convergence Accelerator](#) Program had “**Enhancing Opportunities for Persons with Disabilities**” selected as a research topic for this year. This theme includes communication and assistive technologies, workforce accommodations, and robotics. Announcement can be [found here](#).
- NSF also is calling for proposals for their [National Artificial Intelligence Research Institutes](#). This program solicitation expands upon the nationwide network established by the first 18 AI Research Institutes to pursue transformational advances in a range of economic sectors, and science and engineering fields.
 - Six new themes have been identified for the new solicitation. Theme #6, AI-Augmented Learning to Expand Education Opportunities and Improve Outcomes focuses on AI technology to enhance education and outcomes, **including those for people with disabilities.**

National Council on Disability (NCD)

- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- In October, NCD released the [2021 Progress Report: The Impact of COVID-19 on People with Disabilities](#). The report provides recommendations in areas such as healthcare, education, employment, and communication access for people with disabilities.
- In December, NCD [sent a letter](#) to the leaders of the National Institute on Minority Health and Health Disparities (NIMHD) at NIH, as well as the Agency for Healthcare Research and Quality (AHRQ), supporting **designating people with disabilities as a health disparity population.**

Federal Partners in Transition (FPT)

Managed by the U.S. Department of Labor

- All-federal workgroup formed in 2005 to facilitate exchange of information between federal agencies on transition-related issues for youth with disabilities.
- Members are continuing to work on developing a new Strategic Plan and updating the mission/vision statement for FPT.

Interagency Committee on Disability Research (ICDR)

Managed by the Administration for Community Living

- All-federal committee established to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
 - Publication of the [*Health Care Access and Quality for People with Disabilities Toolkit*](#).
 - ICDR has identified three new themes for future activities: equity and disability, COVID-19 and disability, and disability statistics.
 - Recent Lunch & Learn Webinars have covered workplace disability and inclusion ([August 2021](#)) and how national health surveys can be used to better understand HUD-assisted adults living with disabilities ([September 2021](#)).

RAISE Family Caregiving Advisory Council (FCAC)

Managed by the Administration for Community Living

- Federal advisory committee charged with providing recommendations to the HHS Secretary on effective models of family caregiving and support to family caregivers.
- Recent activities include:
 - The RAISE Family Caregiving Advisory Council and the [Advisory Council to Support Grandparents Raising Grandchildren](#) will hold their first joint meeting on January 25, 2022, from 12:30 pm to 4:30 pm ET, to begin the development of the National Family Caregiving Strategy.

Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)

**Managed by the Substance Abuse and Mental Health Services
Administration**

- Federal advisory committee charged with addressing issues related to serious mental illness (SMI) and serious emotional disturbance (SED).
- The ISMICC recently met on December 16, 2021. The Committee discussed the 2021 ISMICC Report to Congress and held an overall planning session. The full agenda of that meeting is available [here](#).

Disability Advisory Committee (DAC)

Managed by the Federal Communications Commission

- Federal advisory committee that provides advice and recommendations to the Federal Communications Commission on a wide array of disability issues, including communications and video programming access.
- Recently produced a set of recommendations from their Pandemic Communication Access Working Group titled [*Concerns and Lessons Learned Regarding Communication Access for People with Disabilities During the Pandemic.*](#)

Non-Governmental Activities

- American Academy of Pediatrics (AAP)
- Patient-Centered Outcomes Research Institute (PCORI)
- National Academies of Science, Engineering and Medicine (NASEM)

Patient-Centered Outcomes Research Institute (PCORI)

- As part of the 2019 legislation that reauthorized PCORI's funding for 10 years, Congress included research on intellectual and developmental disabilities as a priority topic for PCORI.
- Recent activities include:
 - In October 2021, PCORI hosted a [workshop](#), during which a panel of clinical and research professionals discussed the topics of IDD and co-occurring mental health conditions.
 - In November 2021, PCORI hosted a [stakeholder webinar](#) on diagnosis and treatment for attention deficit hyperactivity disorder in children and adolescents.
 - Current funding opportunity announcement: [Comparative Effectiveness of Interventions Targeting Mental Health Conditions in Individuals with Intellectual and Developmental Disabilities -- Cycle 1 2022](#)
 - PCORI is inviting [Public Comments](#) on its [Proposed Research Agenda](#) until January 31, 2022.

American Academy of Pediatrics (AAP)

- AAP published a new report [Promoting the Participation of Children and Adolescents With Disabilities in Sports, Recreation, and Physical Activity](#) in the journal *Pediatrics* in December 2021.
- The report encourages pediatricians to include children with disabilities in the physical activities of their peers, instead of focusing solely on the child's disability as a barrier. The report also discusses how families should talk about fitness goals, likes, and dislikes in order to develop a movement plan to help with social inclusion and physical wellness.

National Academies of Sciences, Engineering, and Medicine

- The National Academies recently hosted a [workshop](#) exploring the **Challenges and opportunities for creating an optimal care system for individuals with intellectual and developmental disabilities (IDD)**.
 - It explored questions related to three areas of focus: models of care that deliver holistic, tailored, and coordinated care; the development of a competent workforce; effective financing and payment approaches.
 - The workshop was sponsored by the Lucille Packard Foundation for Children's Health.



Break

IACC Committee Business

IACC Full Committee Meeting,
January 19, 2021



Susan A. Daniels, Ph.D.

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

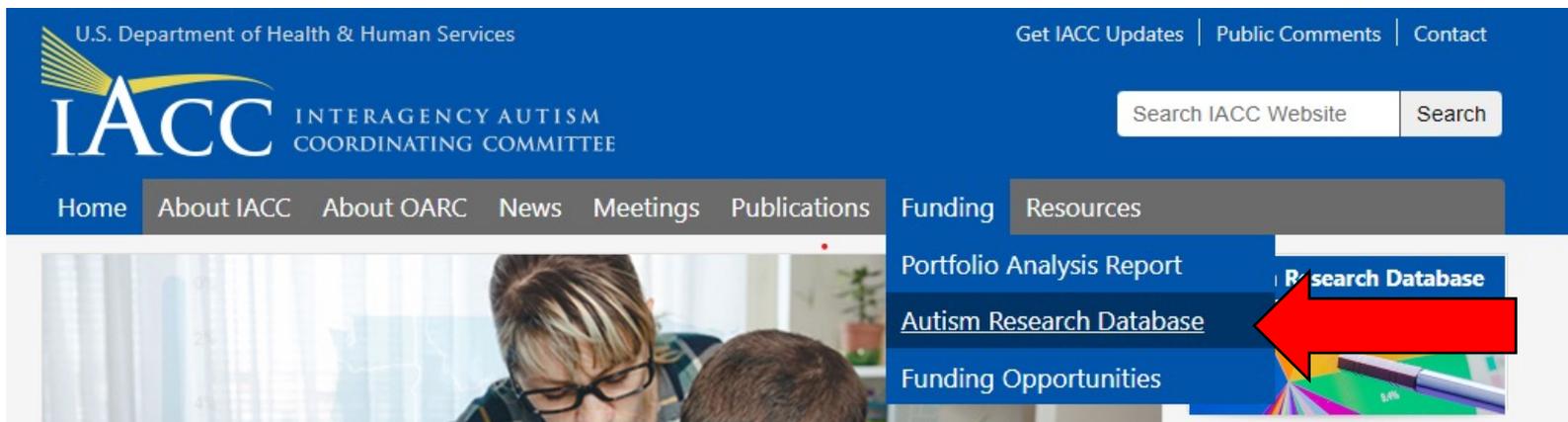


1. **Intro to the Autism Research Database**
2. ***IACC Strategic Plan Update***
 - a. **Overview of Responses to the Public Request for Information**
 - b. ***ACTION ITEM:* Budget Recommendation**
3. ***IACC Summary of Advances***
 - a. ***ACTION ITEM:* Refine list of 2020 nominations**
 - b. **Overview of *2021 Summary of Advances* Process**

Intro to the Autism Research Database



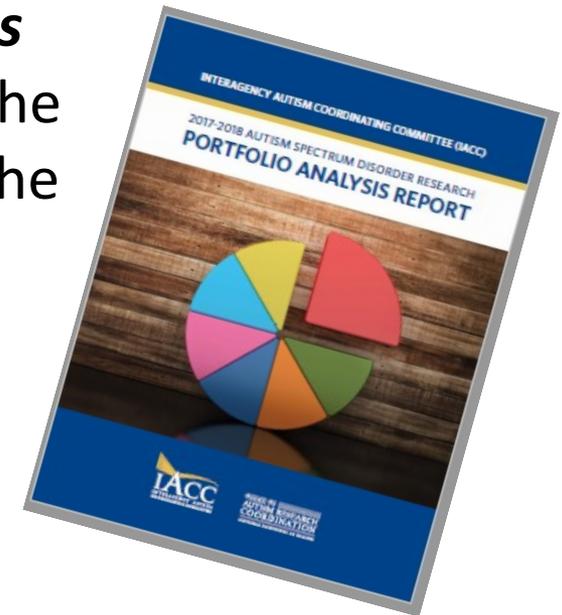
- The **Autism Research Database (ARD)** is a publicly available resource that provides comprehensive information about the status of autism research funding among federal agencies and private research organizations.
- It is a tool that the IACC can use as they are thinking about research and priority areas to highlight in the upcoming ***Strategic Plan Update***.
- The **ARD** is available at: <https://iacc.hhs.gov/funding/data/>
- From the IACC homepage, you can find it under the **Funding** tab:



Intro to the Autism Research Database



- When each release of the ***IACC Autism Spectrum Disorder Research Portfolio Analysis Report***, the complete dataset is uploaded to the ARD. For each project included in the report, the following are listed in the ARD:
 - Funding amount
 - Funder
 - Principal Investigator
 - Project Description
 - Institution and Location
 - Strategic Plan Question, Objective, and Subcategory



The ARD: What it Contains

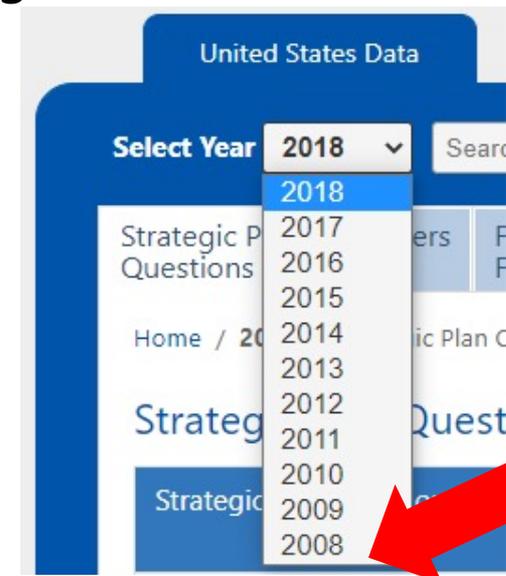


Project Title	A Drug-Screening Platform for Autism Spectrum Disorders Using Human Neurons and Astrocytes
Principal Investigator	Ferrer-Alegre, Marc
Description	This project aims to utilize high throughput screening to rescue the ASD-derived astrocytes cytokine signature. During this period, the collaborative team utilized the previously optimized high-throughput screening assay to screen a focused library, and a number of candidate compounds were identified that reduced toxic IL-6/8 levels. These candidates were advanced for testing in brain organoids and in vivo experiments using heterozygous Setd5 knockout mice, subjected to a battery of autism-related behavioral tests, to observe if they can rescue the disease phenotype. The mechanisms of action of these hits are currently being validated, and their activity profiles are being characterized in follow-up assays, such as glutamate uptake, neuron-astrocyte co-cultures and testing in brain organoids in dose response.
Funder	National Institutes of Health
Funding Country	United States
Fiscal Year Funding	\$127,680
Current Award Period	2018
Strategic Plan Question	Question 4: Which Treatments and Interventions Will Help?
Strategic Plan Objective	Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in ASD.
Subcategory	Model Systems/Therapeutic Targets
Funder's Project Link	NIH RePORTER Project Page
Institution	National Institute of Health - Intramural
Institute Location	Maryland
Project Number	1ZIATR000073-03
Federal or Private	Federal

The ARD: What it Contains



- The amount of data included in each **Portfolio Analysis Report** is substantial. For the year 2018, this reflected data:
 - from 23 federal agencies and private organizations
 - totaling \$394.2 million and 1,543 projects
 - covering all Objective areas in the *Strategic Plan*
- The **ARD** is a user-friendly and interactive way to view and understand these data, going back over a decade's worth of research.
 - The following slides introduce a few key features and useful tools.



*2019 and 2020 data are currently being analyzed and will be uploaded in 2022.

The ARD: What it Contains

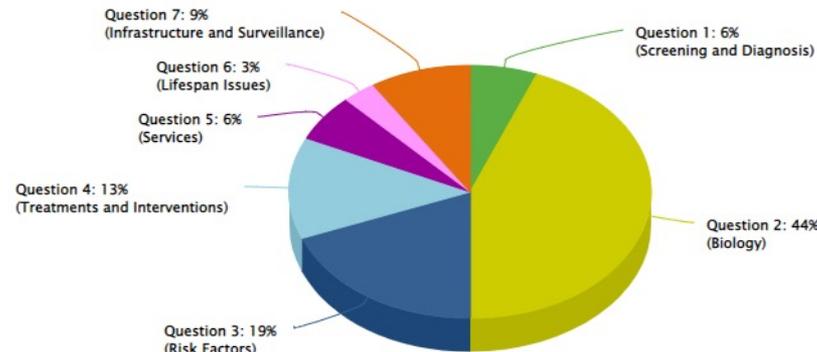


- The **ARD** aligns projects with **Objectives in the IACC Strategic Plan**, providing an account of how much funding has supported projects, and **highlighting trends** over the years.
- This has been used to help the IACC in their efforts to monitor ASD research and track funding progress made each year.
- In the tab for **Strategic Plan Questions**, you can see the proportion of funding aligned with each Question area.

Strategic Plan Questions	Funders	Federal vs Private Funding	Strategic Plan Multiyear Funding	Strategic Plan Objectives	Subcategories	Geography
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ASD Research Funding by Strategic Plan Questions, 2018
Total Funding: \$394,212,761.00



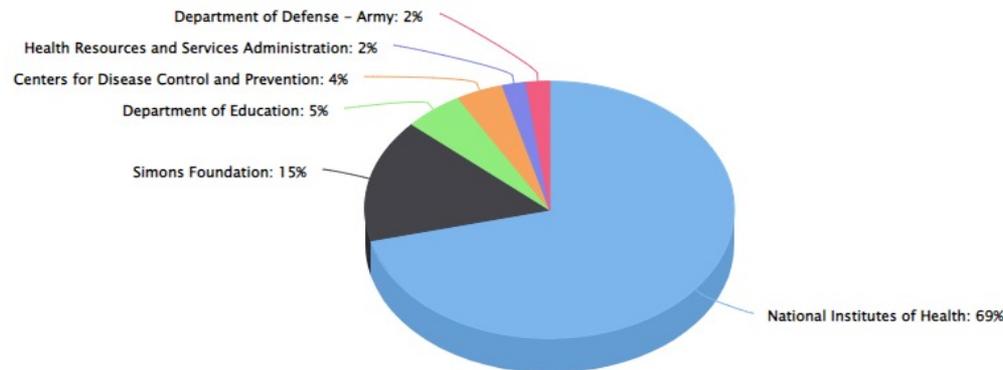
The ARD: What it Contains



- The **ARD** provides data broken down by **Funder**.
- In the tab for **Funders**, you can see:
 - total amount and distribution of each funder's portfolio across the Strategic Plan Question Areas.
 - The proportion of each funder's contribution to total ASD research funding.



ASD Research Funding by Organization, 2018 *
Total Funding: \$394,212,761.00

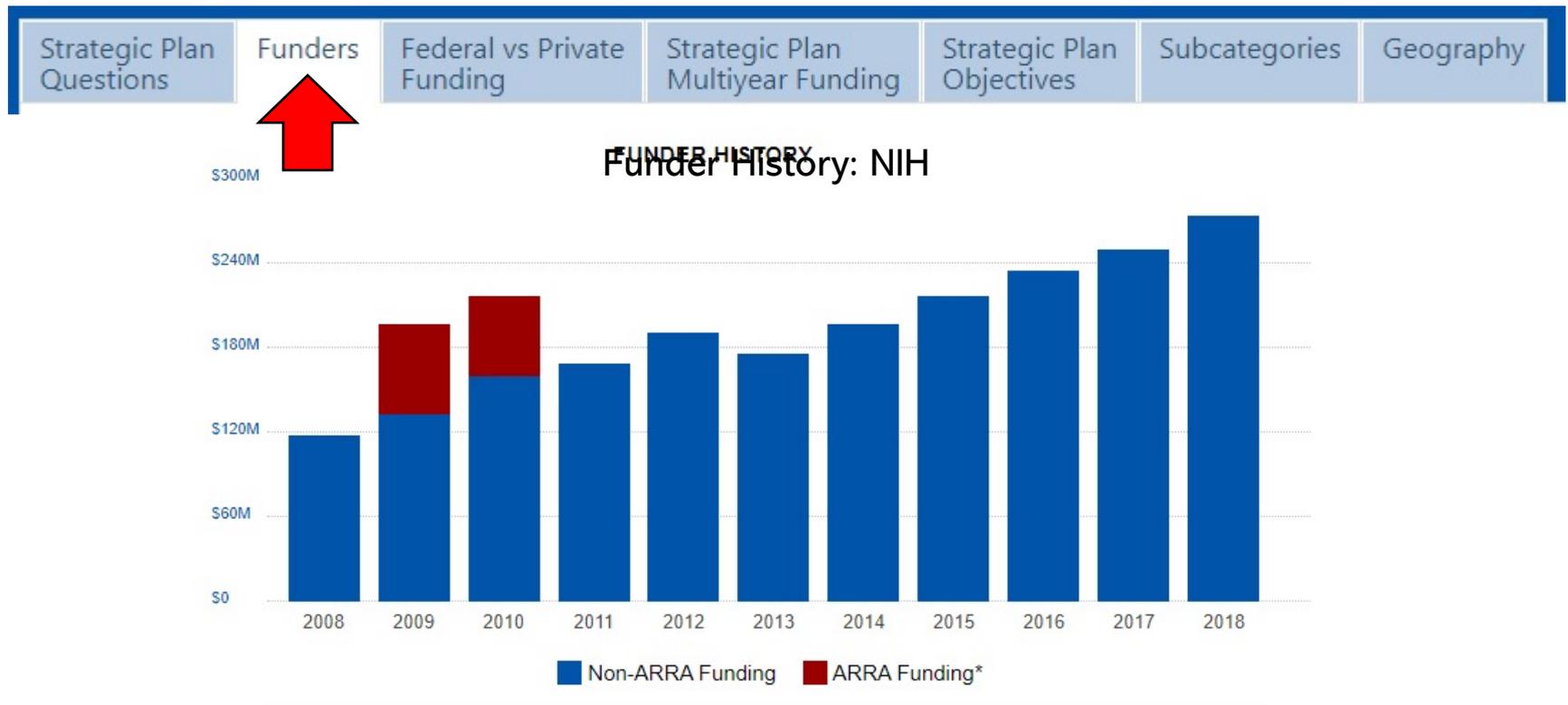


* In order to ensure that the ARD represents a comprehensive view of the ASD research landscape, new funders are added when they are identified and if they are willing to participate.

The ARD: What it Contains



- You can also see historical data for funding over time, going back to 2008.



*The American Recovery and Reinvestment Act (ARRA) provided additional funding in 2009 and 2010 that was used to support autism research projects, creating a temporary increase in autism research funding levels during those years.

The ARD: What it Contains

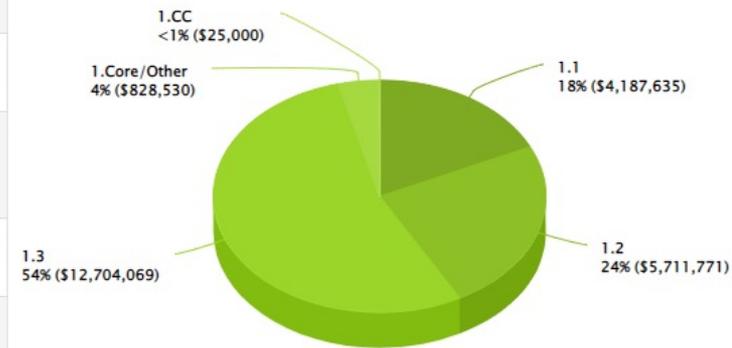


- In the tab for **Strategic Plan Objectives**, you can see the Number of Projects, Funding, and % of Total Funding for the Objectives within each Question area.



Question 1: How Can I Recognize the Signs of ASD, and Why is Early Detection So Important?

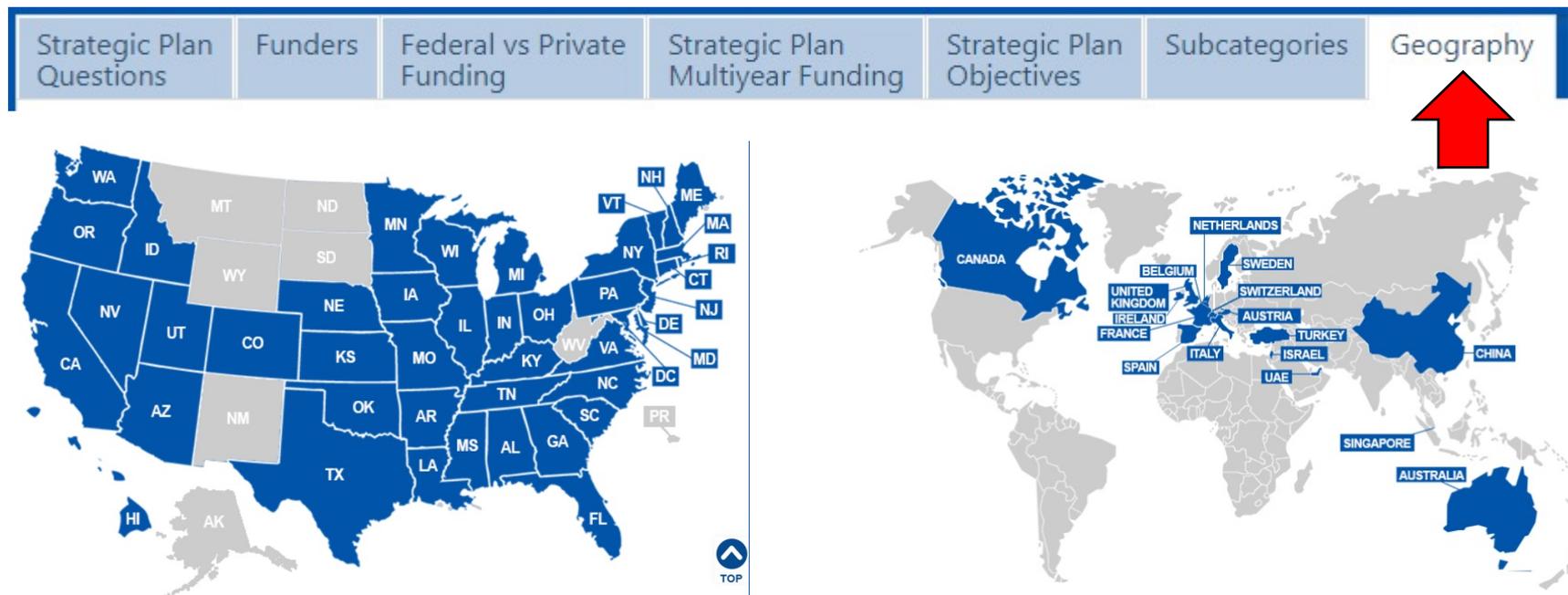
IACC Strategic Plan Objectives	Number of Projects	Funding	% of Total Funding
1.1: Strengthen the evidence base for the benefits of early detection of ASD.	11 projects (13%)	\$4,187,635 (18%)	1%
1.2: Reduce disparities in early detection and access to services	15 projects (17%)	\$5,711,771 (24%)	1%
1.3: Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.	57 projects (66%)	\$12,704,069 (54%)	3%
1.Core/Other: Not specific to Question 1 objectives	3 projects (3%)	\$828,530 (4%)	<1%
1.CC: Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.	1 projects (1%)	\$25,000 (0%)	<1%
Total Funding for Question 1	87 projects	\$23,457,005	6%



The ARD: What it Contains



- The **ARD** provides data broken down by the **Geographic Location**.
 - Can see how many projects are taking place within each country/state, and the total funding for each.
 - In addition to research investments made in the U.S., we also have some funding that goes to support international research.



The ARD: What it Contains



- You can search each funding year by **Keyword** to see all the projects on that topic. Results can be exported to Excel or PDF.

Select Year: 2018

Search Projects by Keyword: Search

Strategic Plan Questions | Funders | Federal vs Private Funding | Strategic Plan Multiyear Funding | Strategic Plan Objectives | Subcategories | Geography

Home / 2018 / Search Results

Search Results for "epilepsy"

Projects Found: 36

Display 10 Records

Funder	Project Title	Funding	Institution	Principal Investigator
National Institutes of Health	Exploring Novel Epilepsy Pathways	\$50,430	University of Iowa	Bassuk, Alexander G
National Institutes of Health	Signaling Mechanisms Underlying Epilepsy and Autism Comorbidity	\$415,500	Baylor College of Medicine	Lugo, Joaquin N
National Institutes of Health	Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex	\$1,496,413	University of Alabama at Birmingham	Bebin, Martina

36 records

Pages 1 of 4 Next

Export options: Excel | PDF

The ARD: What it Contains



- You can also view data organized by **Principal Investigator** by clicking on their name. This will give you a list of all their projects conducted in a given year.

Select Year **2018** Search Projects by Keyword Search

Strategic Plan Questions Funders Federal vs Private Funding Strategic Plan Multiyear Funding Strategic Plan Objectives Subcategories Geography

Home / 2018 / Piven, Joseph

Piven, Joseph

Projects Found: 3 Total Funding: \$2,422,092

Funder	Project Title	Funding	Strategic Plan Objective	Institution
National Institutes of Health	Brain and Behavior Study of Autism from Infancy Through School Age	\$2,212,492	2.3	Univ of North Carolina Chapel Hill
Simons Foundation	Carolina SPARK: Carolina Site for the SFARI National Autism Cohort	\$200,000	3.1	Univ of North Carolina, Chapel Hill
Simons Foundation	SPARK Incentive Award	\$9,600	3.1	Univ of North Carolina, Chapel Hill

3 records

Export options: Excel | PDF

The ARD: What it Contains



- In 2016, the IACC released a report on **International ASD Research**. These data are available in the **International Tab**.
 - Countries included: United States, the United Kingdom, Canada, and Australia.



United States Data | **International Data**

Select Year: 2016 | Search Projects by Keyword | Search

Strategic Plan Questions | Funders | Government vs Private Funding | **Countries**

Home / 2016 / Strategic Plan Questions

International data, which includes funding of ASD research within other countries, is currently only available for 2016.

Strategic Plan Questions | Download all 2016 projects

Strategic Plan Questions	Number of Projects	Total Funding	% of Total Funding
Question 1: How Can I Recognize the Signs of ASD, and Why is Early Detection So Important? (Screening and Diagnosis)	123 projects	\$30,505,682	8%
Question 2: What is the Biology Underlying ASD? (Biology)	558 projects	\$142,124,912	36%
Question 3: What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted? (Risk Factors)	256 projects	\$89,525,283	23%

*We aim to publish another International Report in the future, with additional countries represented.

Conclusion



- Please note that this is just a brief intro to all the information that you can find in the **ARD**.
- **Upcoming in 2022:** Publication of the **2019-2020 Portfolio Analysis Report**, data will be uploaded to the ARD.

If you have any questions about the **ARD** or the **Portfolio Analysis Report**, please email us at:
IACCPublicInquiries@mail.nih.gov



Topics for Discussion:

1. Public Request for Information (RFI) Discussion
2. **ACTION ITEM:** Budget Recommendation
3. *Strategic Plan* Process

REMINDER to IACC Members: If you have not done so already, please submit your written input on the Strategic Plan update via Survey Monkey. Participation of all IACC members will ensure that a variety of perspectives and experiences are reflected in the new *Strategic Plan*.

IACC Request for Public Comments



- The 2021 IACC RFI was open for public comments for two months, from October 1 through November 30.
- **403** individuals and organizations responded to the RFI, including two responses via the Spanish version of the RFI.
- To assist the IACC, OARC reviewed all responses and identified major themes and topics within each Question area.
- Each response was assigned one or more themes:
https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/january19/responses_themes.pdf
- Full text responses to the RFI are available on the IACC website:
<https://iacc.hhs.gov/meetings/public-comments/requests-for-information/2021/>

Cross-Cutting Themes of RFI Responses



- The following cross-cutting themes were identified across all Question areas:
 - **Accessibility** to services and treatments and interventions
 - **Disparities** in detection/diagnosis and service access and utilization
 - **Acceptance** of autistic people
 - **Inclusion** of autistic voices and underserved groups in research and services
 - **Lifespan issues** that affect adults on the autism spectrum from childhood through older adulthood, including aging
 - **Personalized approaches** that include all autistics, including those with high support needs

Question 1: Diagnosis and Screening



Question 1 Themes	
Acceptance	NEW Education and Stigma
Accessibility	Subgroups
Co-occurring Conditions	Training
Diagnostic Criteria	Current Priorities Still Relevant
Disparities	Question Area Not a Priority
Early Screening	Miscellaneous

Major themes in Question 1 included reducing **Disparities** in early detection for girls and women, ethnic and racial minorities, other underserved communities, and adults; need for more practitioner **Training** to ensure timely and accurate diagnoses; and **Access** to diagnosis and screening services.

Question 2: Biology



Question 2 Themes	
Acceptance	NEW Inclusion
Cognitive and Behavioral Biology	Molecular Biology and Neurobiology
Co-occurring Conditions	Sensory
Gender	Current Priorities Still Relevant
Genetics	Question Area Not a Priority
Immune System and Metabolism	Miscellaneous

Major themes in Question 2 included the need for more research on several areas, including **Co-occurring Conditions** that can contribute to quality of life for people on the autism spectrum, and **Inclusion** of autistic individuals in the research process.

Question 3: Risk Factors



Question 3 Themes	
Acceptance	Pregnancy and Birth
Environment	<i>NEW</i> Social Determinants of Health
Gene-Environment	Current Priorities Still Relevant
Genetics	Question Area Not a Priority
GI and Microbiome	Miscellaneous

Major themes for Question 3 reflected that some members of the community value research on genetic and environmental causes of autism while others do not feel this is a priority. Some comments advocated for research on how **Social Factors and Determinants** shape the autistic experience.

Question 4: Treatments and Interventions



Question 4 Themes	
Acceptance	NEW Inclusion of Full Spectrum
Accessibility	Lifespan
Behavioral Approaches	Medical
Communication	Current Priorities Still Relevant
Complementary Approaches	Question Area Not a Priority
Education	Miscellaneous
NEW Reducing Negative Effects	

Major themes for Question 4 included providing personalized/targeted interventions for those with a variety of needs, including improved **Communication** supports, **Reducing Potential Negative Effects**/experiences associated with some interventions, and improving **Access** to interventions.

Question 5: Services



Question 5 Themes	
Acceptance	High Support Needs
NEW Accessibility	Housing and Employment
Adults	Inclusion
Caregivers	Mental Health
Community	Current Priorities Still Relevant
Education	Miscellaneous

Major themes for Question 5 included increasing **Community Acceptance**, development of services that meet the needs of **Underserved Groups** such as girls/women and minorities, **Access** to services, services that promote **Community** integration, and services for **Adults**.

Question 6: Lifespan Issues



Question 6 Themes	
Acceptance	High Support Needs
Accessibility	Housing
Community	Inclusion
Coordination	NEW Lifespan (including older adulthood)
Education	Current Priorities Still Relevant
Employment	Question Area Not a Priority
Health	Miscellaneous

Major themes for Question 6 included **Employment** for autistic people, ensuring services and research continue across the entire **Lifespan** of people on the autism spectrum through aging, services for people with **High Support Needs**, and adult services for **Community** integration.

Question 7: Infrastructure and Surveillance



Question 7 Themes	
NEW Acceptance	Standardization
Collaboration	Workforce
Funding	Current Priorities Still Relevant
NEW Inclusion	Question Area Not a Priority
Research	Miscellaneous

Major themes for Question 7 were most concerned with **Inclusion** of autistic voices in research and services, developing a strong **Workforce** for needed research and services for people on the autism spectrum, and promoting **Collaboration** across agencies and organizations.

NEW

Supplemental Question 1: COVID-19 Pandemic



Supplemental Question 1 Themes	
Accommodations	Regression
Benefits	Routine
COVID-19	Services Disruption
Disparities	Question Area Not a Priority
Mental Health	Miscellaneous
Misinformation	

Major themes related to COVID-19 and its impact on the autism community included **Services Disruption** during the pandemic, ensuring that **Benefits** such as remote options and other accommodations will continue to be available after the pandemic, and the **Mental Health** impacts of the pandemic, including isolation and loneliness.

Supplemental Question 2: Disparities and Underserved Communities



Supplemental Question 2 Themes	
Accessibility	Internet
Cultural Competency	Outreach
Disparities	Rural Communities
Gender and Sexuality	Training
High Support Needs as Underserved Group	Miscellaneous
Inclusion	

Major themes related to Disparities and Underserved Communities included **Access** to services and supports for underserved communities; reducing **Disparities** in service access and health outcomes for underserved communities; and **Inclusion** of autistic people of diverse genders, racial and ethnic minority groups, and other underserved communities in research, services, and policy for autism.



Conclusion:

The RFI yielded valuable input on community priorities that can be incorporated into the new Strategic Plan.

Thank you to all who contributed!

Questions for Consideration:



Would the committee like to see a section of the plan devoted to COVID-19 Response?



Would the committee like to consider a second Cross-Cutting Objective to track activities relate to disparities and underserved communities?

Public RFI Discussion: Poll Results

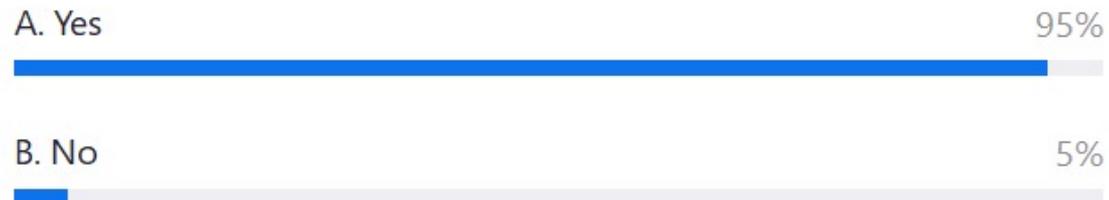


1. Would the Committee like to see a section of the plan devoted to the COVID-19 Response? (Multiple Choice) *



You did not answer this question

2. Would the Committee like to consider a second Cross-Cutting Objective to track activities related to disparities and underserved communities? (Multiple Choice) *

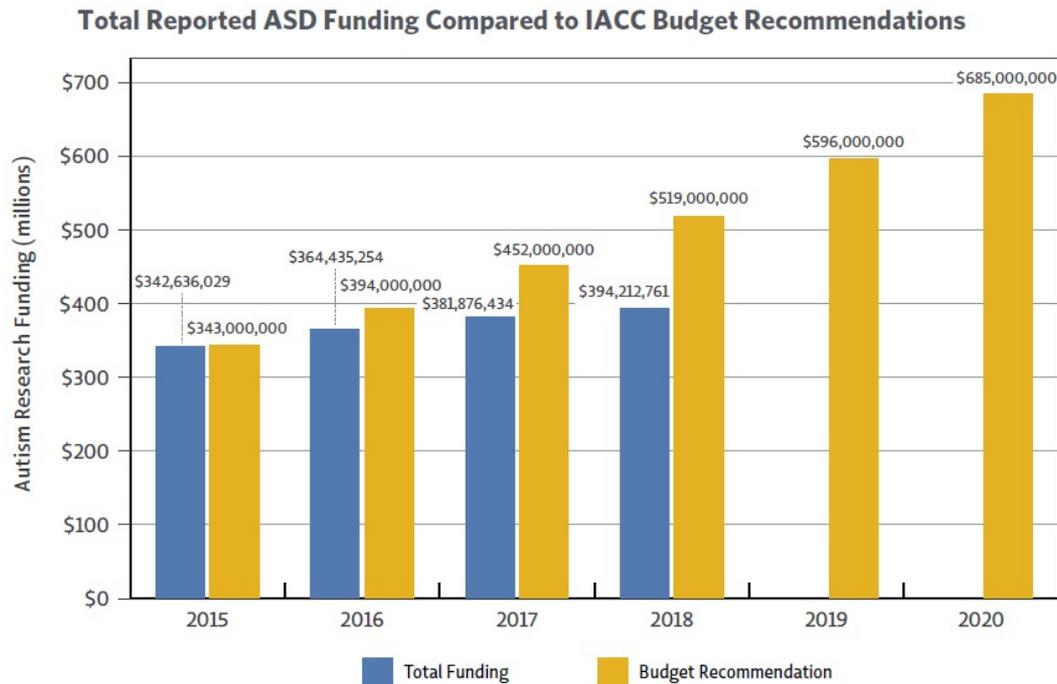


Results based on responses of IACC members and alternates

Budget Recommendation



The 2016-2017 IACC Strategic Plan calls for a doubling of the 2015 ASD research budget to \$685 million by 2020. To accomplish this goal, the IACC recommended a nearly 15% annual increase in ASD research funding across combined federal and private funders. The Committee recognized that this was an ambitious goal, but it believed that such an increase could also have a significant impact if achieved.



Note: This graph illustrates funding amounts from the earlier editions of the IACC ASD Research Portfolio Analysis Report; 2019 and 2020 funding will be published in the upcoming report.

ACTION ITEM: Budget Recommendation



How should the budget recommendation be updated in the upcoming *Strategic Plan*?

Option #1:

Extend the timeline on the current recommendation by 5 years: The ASD research budget should reach **\$685 million** (doubling of 2015 spend) by 2025.

Option #2:

Recommend doubling the research funding amount for 2020 (approx. \$430 million): The ASD research budget should reach **~\$860 million*** by 2025.

Option #3: Other (neither #1 nor #2)

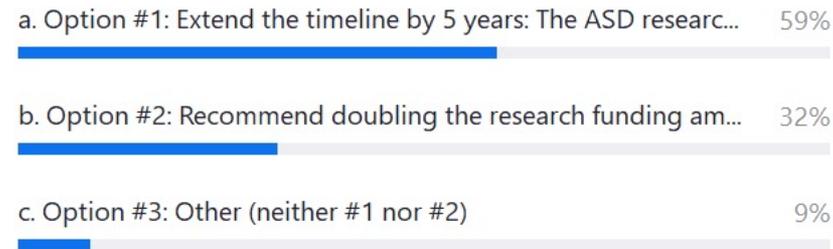
* Based on current estimate for 2019 ASD research funding. 2020 data is currently being analyzed but will be available before publication of the updated *Strategic Plan*.

Budget Recommendation: Poll Results



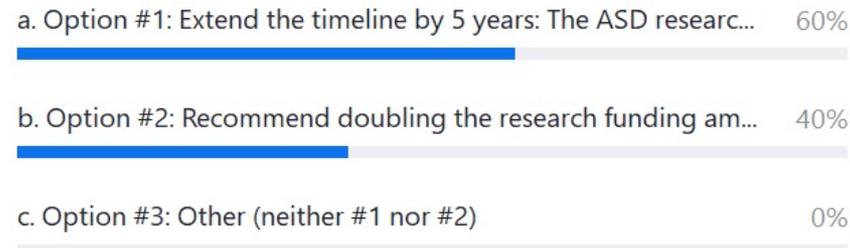
Before Discussion

1. How should the budget recommendation be updated in the upcoming Strategic Plan? (Single Choice) *



After Discussion

1. How should the budget recommendation be updated in the upcoming Strategic Plan? (Single Choice) *



Results based on responses of IACC members and alternates

ACTION ITEM: Budget Recommendation



**Changes to priority areas for budget:
Should any of the previous priority areas be removed?**

Previous Priority Areas:

**Treatments and Interventions
Evidence-Based Services
Lifespan Issues**

Option #1: Yes

Option #2: No

ACTION ITEM: Budget Recommendation



Should research and services on **disparities and underserved communities** be added as a priority area that needs more focus and attention?

Option #1: Yes

Option #2: No

IACC 2021-2022 Strategic Plan Update Process



- **Next:** To assist the IACC, OARC will begin drafting the *Strategic Plan Update* based on input shared at this and past IACC meetings, the responses obtained from the public RFI, and written input from the Committee.
- **April Committee Meeting: Review of** IACC written input and discussion of any areas where further input is needed to reach consensus on key issues.
- **July Working Group Meeting:** OARC will present a draft of the *Strategic Plan* at a Working Group meeting open to all IACC members. (*Tentative date – July 13-14, 2022*)
- **September via e-mail:** Committee will review the revised draft Plan.
- **October Committee Meeting:** The *Strategic Plan* draft will be presented to the IACC for final decisions and approval.



Lunch Break

Public Comment Session



Susan A. Daniels, Ph.D.

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

Summary of Written Public Comments



Written public comments were submitted on the topics below by the following individuals:

- ***Addressing the Needs of Autistic Individuals with High Support Needs/Profound Autism***
 - Lori Kay
 - Nate Watkins
 - John Saito
 - Lori and Alex Kay
 - Jane McCready
 - Anthony J. Thompson
 - Cynthia Reed
 - Jill Escher, National Council on Severe Autism
- ***Concern about Medical Practices and Potential Causes of Autism***
 - Eileen Nicole Simon, Ph.D., R.N.
 - Parrish Hirasaki
 - Tal Purk
 - Anonymous
 - Lori Frome M.Ed.
- ***The Role of the IACC and the Federal Government***
 - Eileen Nicole Simon, Ph.D., R.N.

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/january19/public_comments.pdf

Summary of Written Public Comments



Written public comments were submitted on the topics below by the following individuals:

- ***Research and Service Needs, Resources, and Policy Implications***
 - Zolfa Valiani-Merchant, M.D.
 - Rosalind Kaplan
 - Karen Barrett
 - Gene Bensinger
 - Melvin R. Rodgers, D.Min ACPE
 - Musu Sesay
 - Matthew K. Belmonte
- ***Comments for the IACC Strategic Plan update***
 - Greg Robinson, M.P.H., Autistic Self Advocacy Network
- ***Services and Supports for Adults with Autism***
 - Daina Krumins
 - Rick Grossman
 - Nicole LeBlanc
 - Tal Purk
 - Matthew Zeidman
- ***Safety, Elopement, and Interactions with Law Enforcement***
 - Nicole Corrado
 - Edrick LaTrone Linston-Jones

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/january19/public_comments.pdf

Findings and Update from the Autism and Developmental Disabilities Monitoring Network



Matthew Maenner, Ph.D.

Surveillance Team Lead, Child Development and Disability Branch
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention



Findings and Update from the Autism and Developmental Disabilities Monitoring (ADDM) Network

Matthew Maenner, PhD

Surveillance Team Lead, Child Development and Disability Branch

Division of Human Development and Disability

National Center on Birth Defects and Developmental Disabilities

New ADDM Reports – 3 December 2021

Centers for Disease Control and Prevention

MMWR

Morbidity and Mortality Weekly Report

Surveillance Summaries / Vol. 70 / No. 11

December 3, 2021

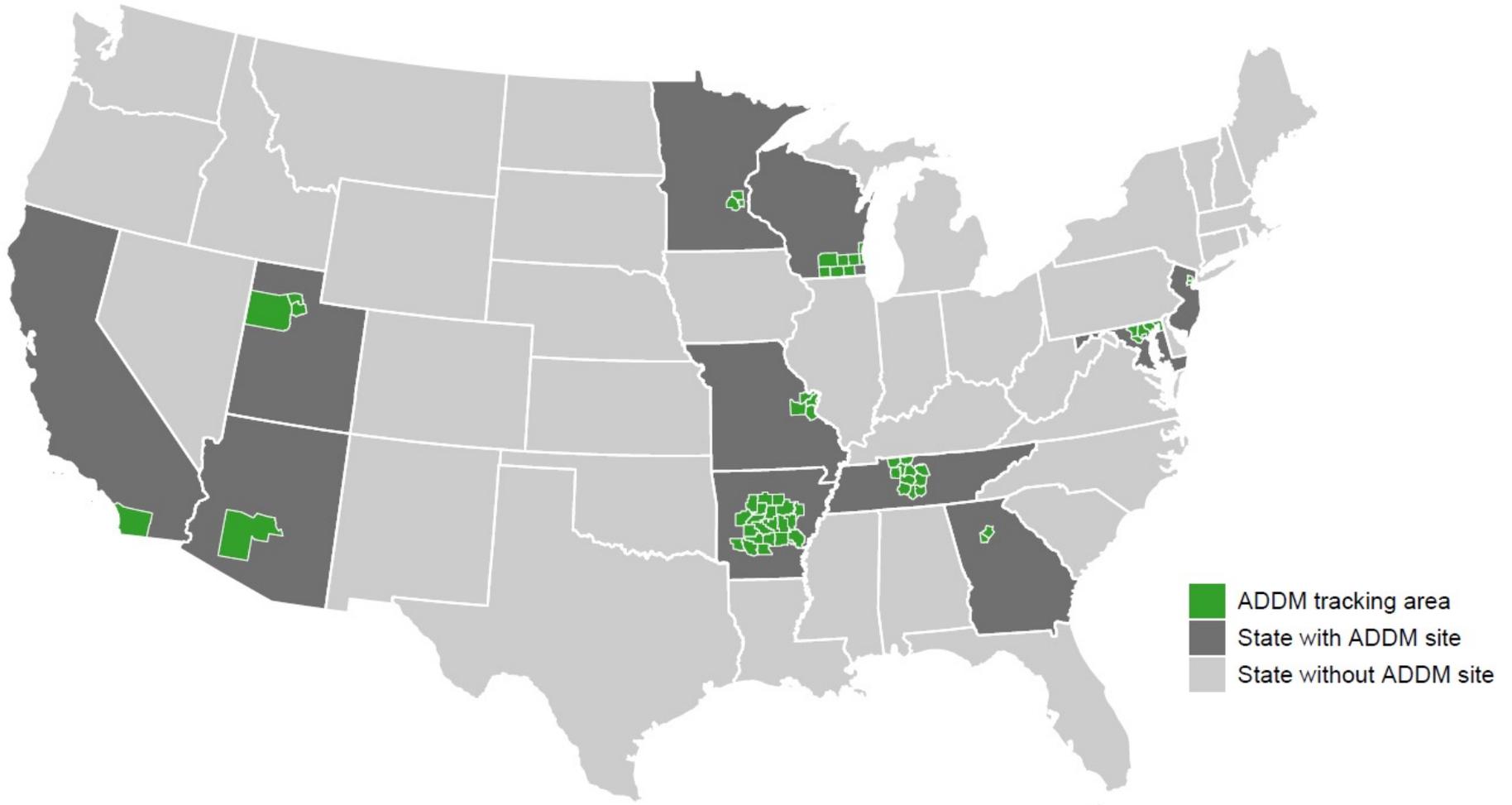
**Prevalence and Characteristics of
Autism Spectrum Disorder Among Children
Aged 8 Years — Autism and Developmental
Disabilities Monitoring Network,
11 Sites, United States, 2018**

**Early Identification of Autism Spectrum Disorder
Among Children Aged 4 Years —
Autism and Developmental Disabilities Monitoring
Network, 11 Sites, United States, 2018**

<https://www.cdc.gov/mmwr/volumes/70/ss/ss7010a1.htm>

<https://www.cdc.gov/mmwr/volumes/70/ss/ss7011a1.htm>

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



Expanded activities for 2018

	Tracking Year 2016	Tracking Year 2018
Date funded	January 2015	January 2019
No. of sites funded	10 (plus MADDSP, the ADDM Network site administered by CDC)	10 (plus MADDSP)
No. of sites tracking 4-year-olds	6 (partial sites)	11 (full sites)
No. of sites tracking 8-year-olds	11	11
No. of sites following up 16-year-olds	N/A	5

ADDM Ascertainment and ASD Case Definition

ASD case definition	Suspected ASD case definition
<p>Child has documentation of ever receiving:</p> <ol style="list-style-type: none">1) a written ASD diagnosis by a qualified professional,2) a special education classification of autism, OR3) an ASD ICD code obtained from administrative or billing information	<p>(4-year-old only)</p> <p>Child does not meet criteria of full case definition but there is a qualified examiner's diagnostic statement that the child is suspected of having ASD</p>

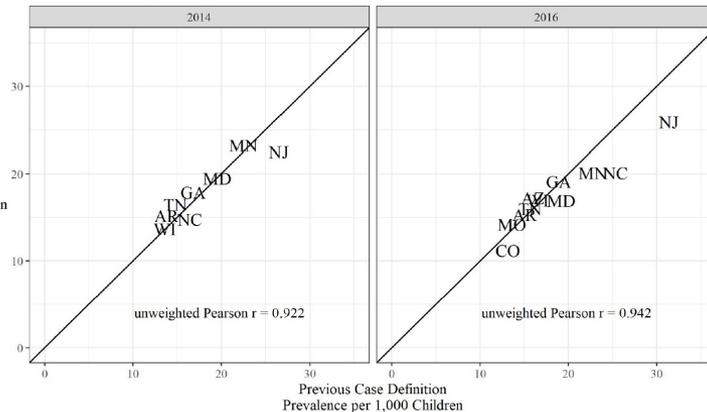
Evaluation of the new approach



Practice of Epidemiology

Comparison of 2 Case Definitions for Ascertaining the Prevalence of Autism Spectrum Disorder Among 8-Year-Old Children

ASD prevalence estimates based on previous versus new case definitions among children aged 8 years--
Autism and Developmental Disabilities Monitoring Network, 11 sites, 2014 and 2016



Prevalence and other indicators are **very similar overall.**

Improved Efficiency

- ~50% reduction in data collection
- Simplified process
- (allowed faster dissemination, ability to fund more sites than possible w/ previous methods, more robust to data access issues due to pandemic)

Better reflects community practice

- More transparently reports ASD identification and services
- Able to utilize new data sources (e.g., Medicaid)

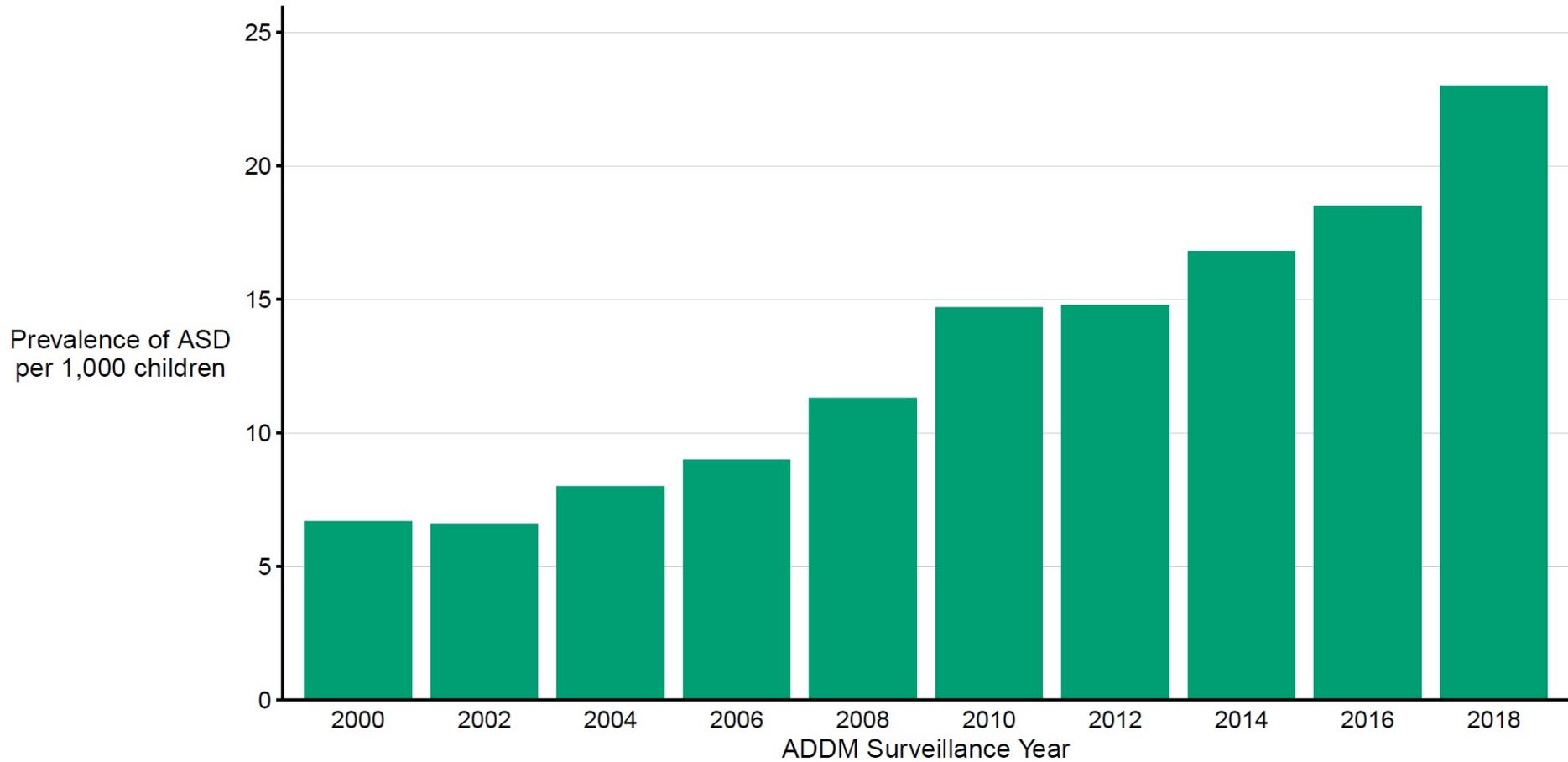
2018

**Prevalence of Autism Spectrum Disorder
Among Children Aged 8 Years**

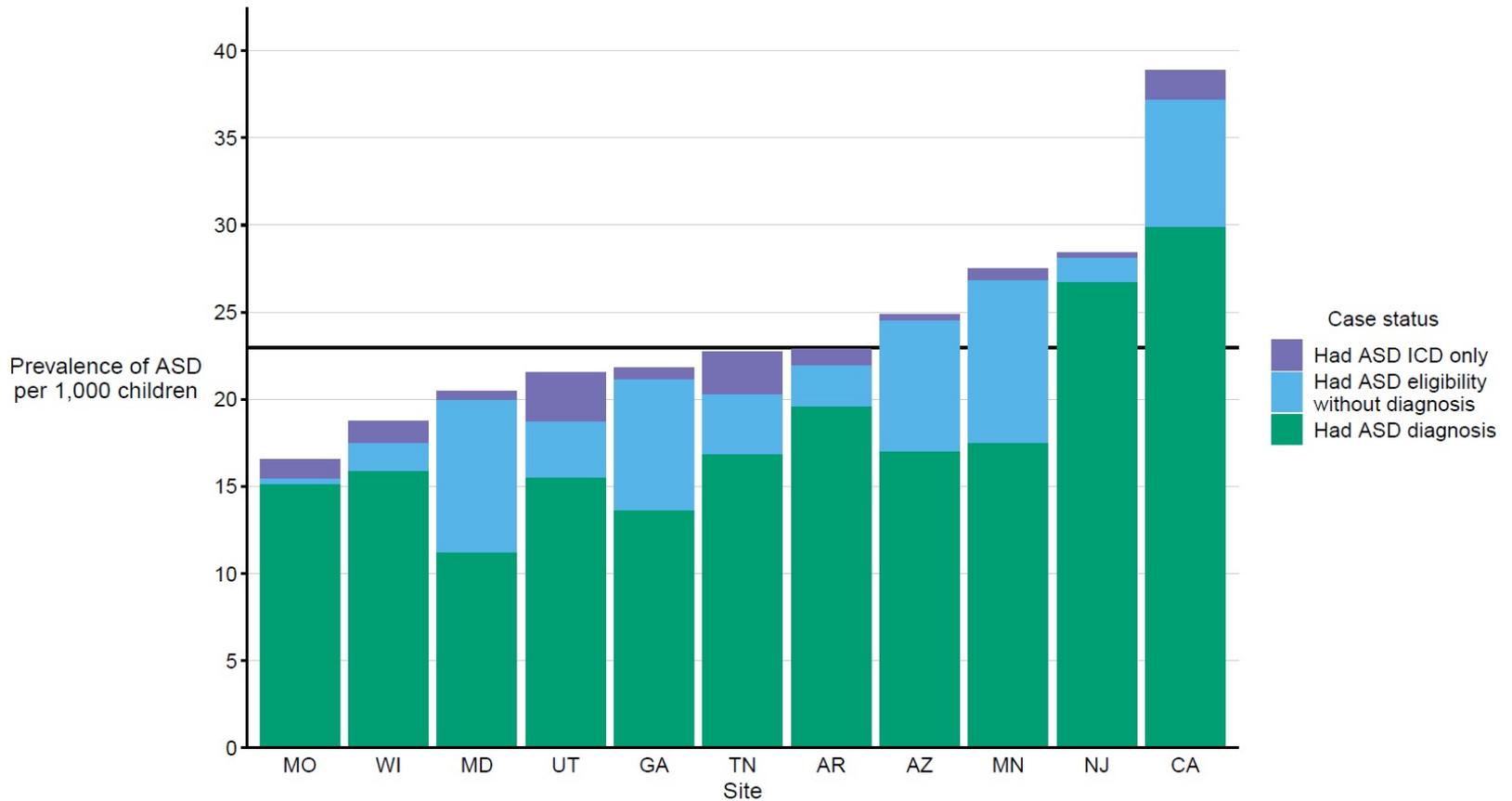
Autism and Developmental Disabilities Monitoring Network
11 Sites, United States

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

Autism and Developmental Disabilities Monitoring Network, 2000–2018



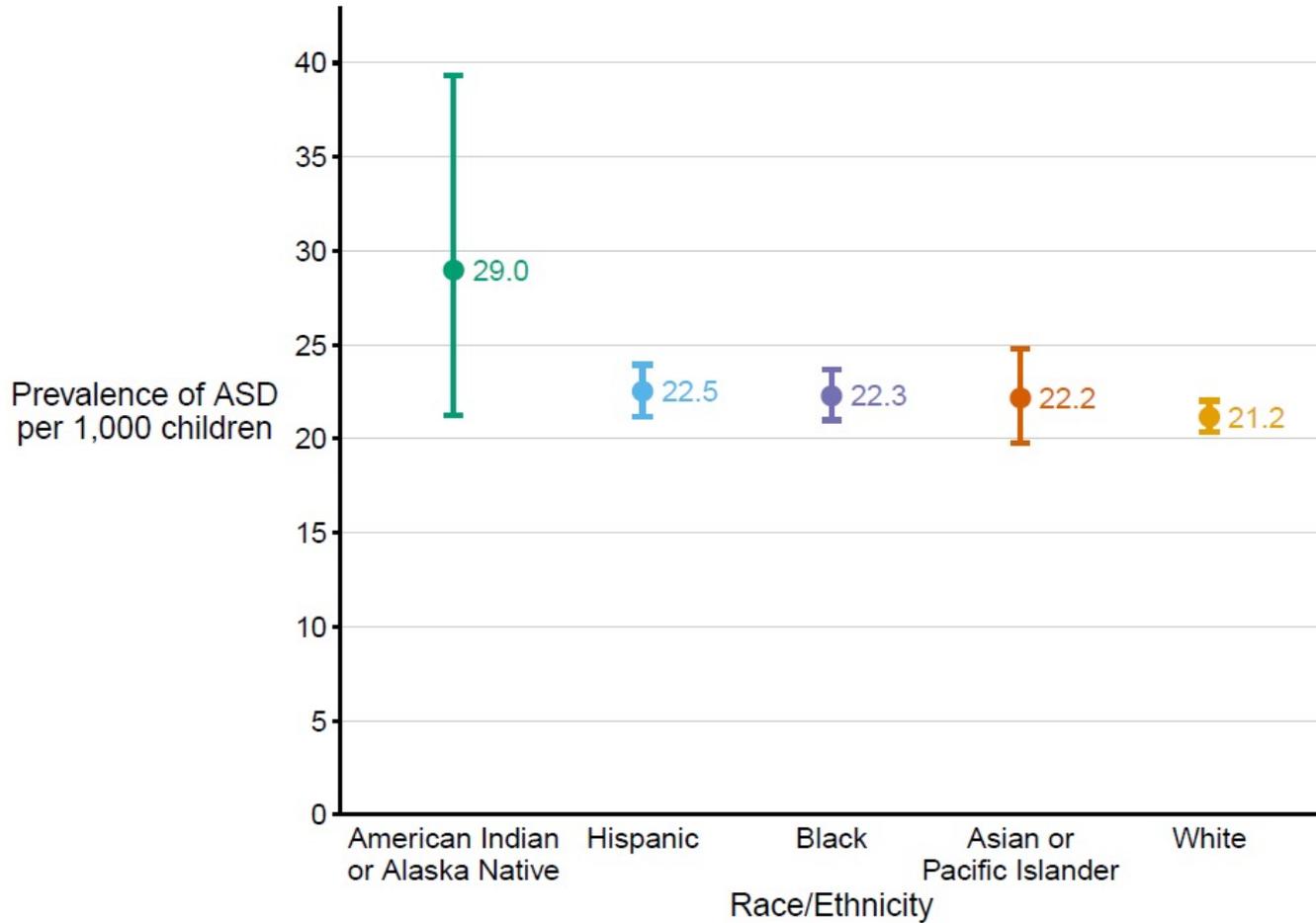
Prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by identification type and site
 Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



* Horizontal line is the overall Autism and Developmental Disabilities Monitoring Network prevalence of 23.0 per 1,000 children aged 8 years. Children with documented ASD statements could also have ASD classifications in special education or ASD ICD codes.

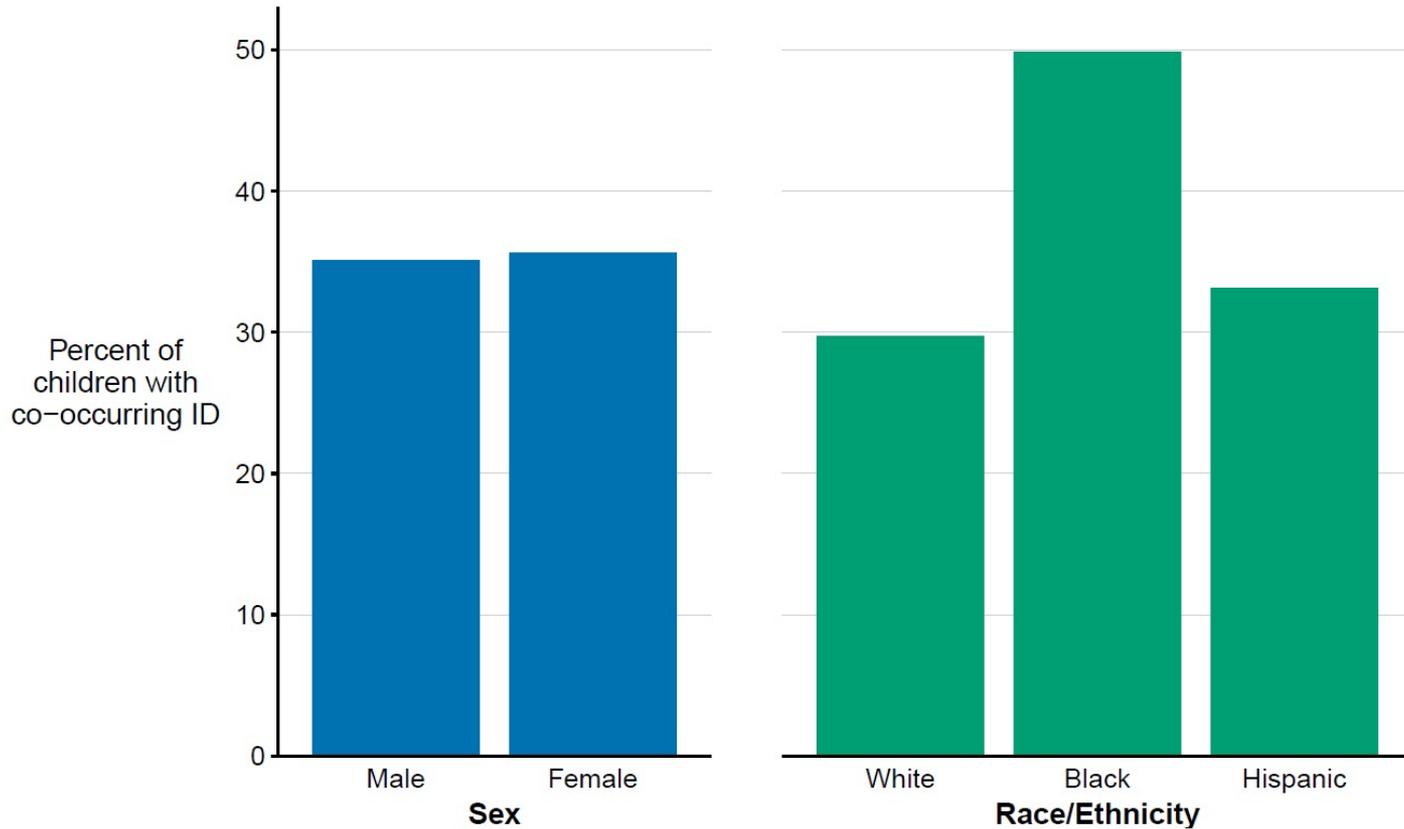
Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by race/ethnicity

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



**Percent of children aged 8 years with autism spectrum disorder
with co-occurring intellectual disability*, by sex and race/ethnicity**

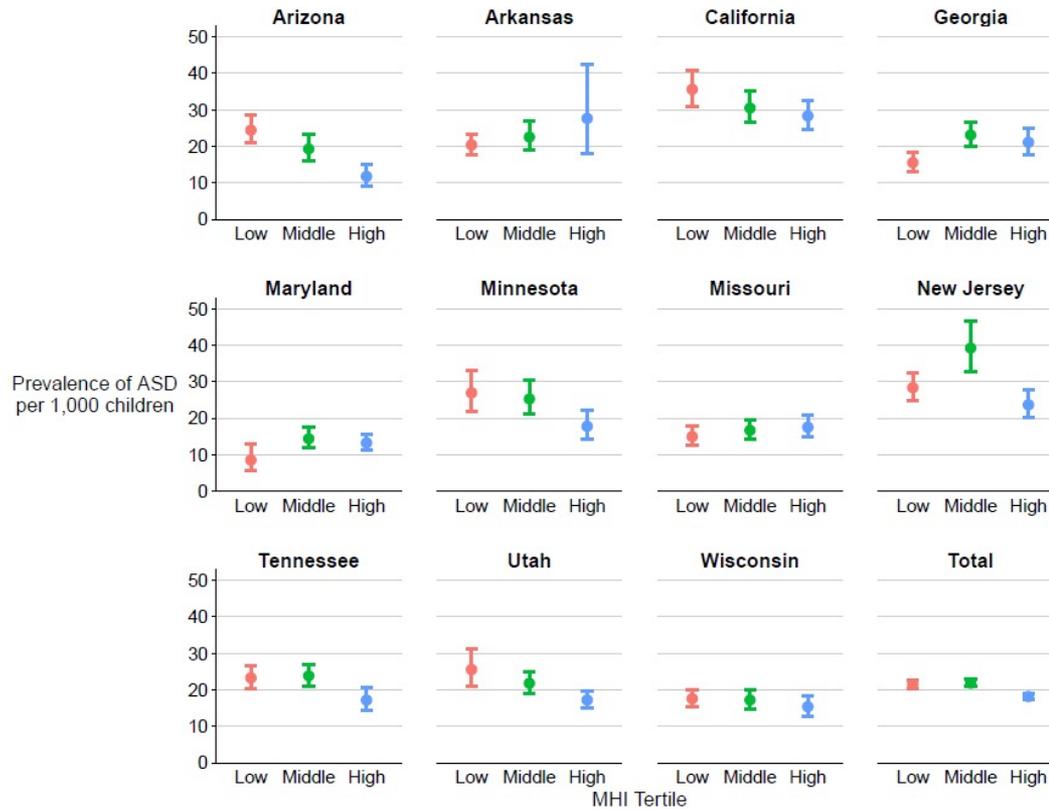
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



* IQ score ≤ 70 or examiner statement of intellectual disability in a comprehensive evaluation

Prevalence* of autism spectrum disorder per 1,000 children aged 8 years, by median household income tertile and site†

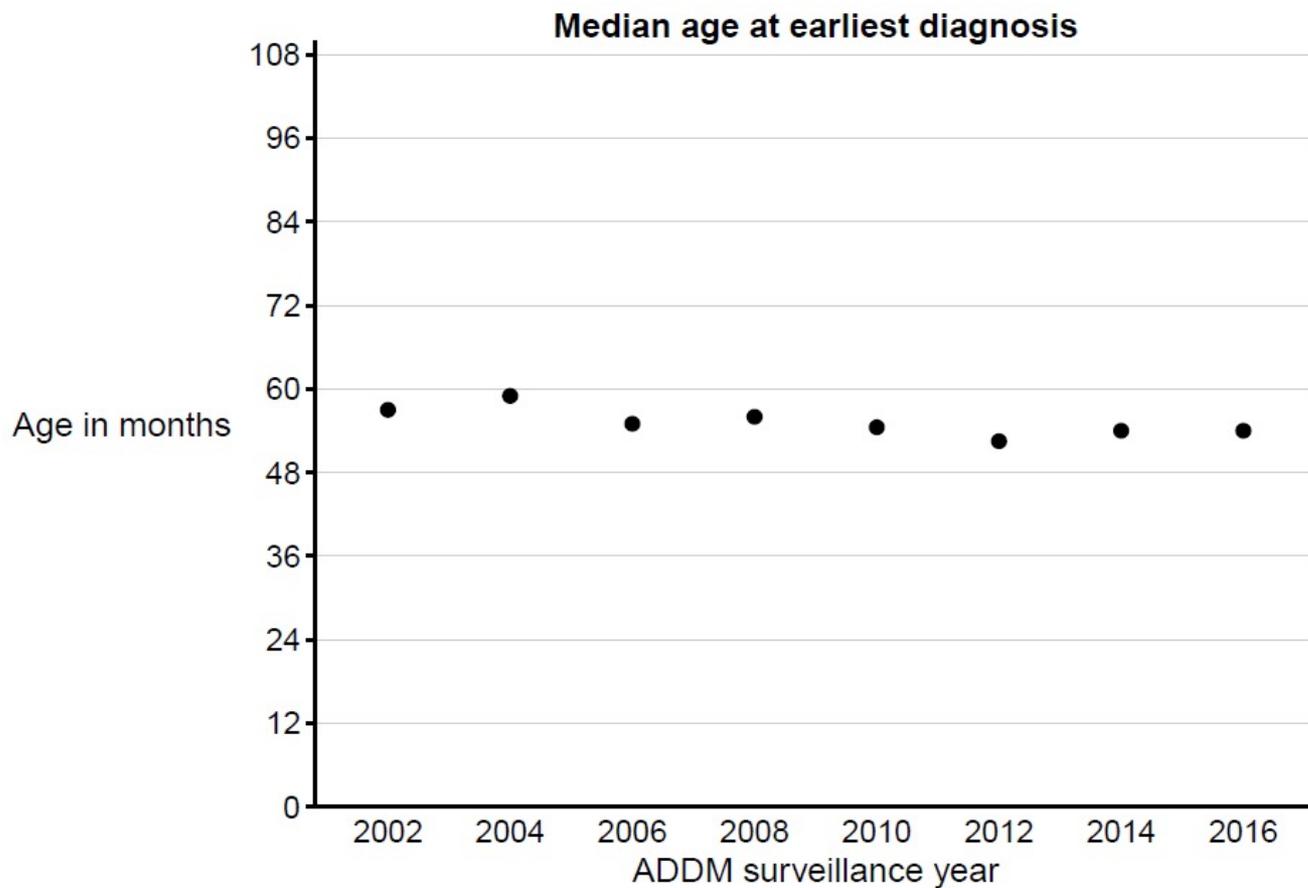
Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2018



* Dots are the point estimates and horizontal lines are the 95% confidence intervals.

† Cochran Armitage test of trend results for association between socioeconomic status tertile and ASD prevalence, by site and overall: Arizona ($p < 0.001$), Arkansas ($p = 0.17$), California ($p = 0.03$), Georgia ($p = 0.01$), Maryland ($p = 0.21$), Minnesota ($p = 0.01$), Missouri ($p = 0.21$), New Jersey ($p = 0.15$), Tennessee ($p = 0.02$), Utah ($p < 0.001$), and Wisconsin ($p = 0.27$); all sites ($p < 0.001$).

(Previous) measures of progress in early ASD identification (2002-2016 ADDM Data)



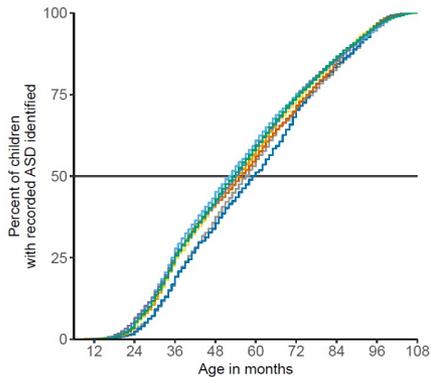
Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016

Kelly A. Shaw, PhD , Dedria McArthur, MPH , Michelle M. Hughes, PhD ,
Amanda V. Bakian, PhD , Li-Ching Lee, PhD, Sydney Pettygrove, PhD ,
Matthew J. Maenner, PhD 

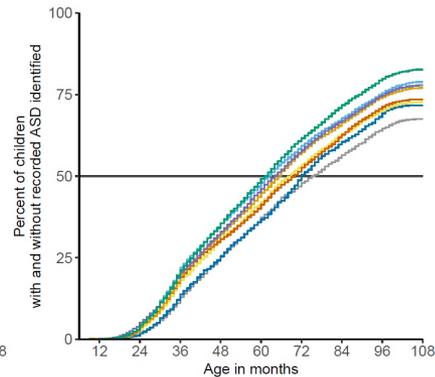
EDITORIAL

Editorial: Evaluating the Success of Early Detection of Autism: It's Time to Move Beyond the Median

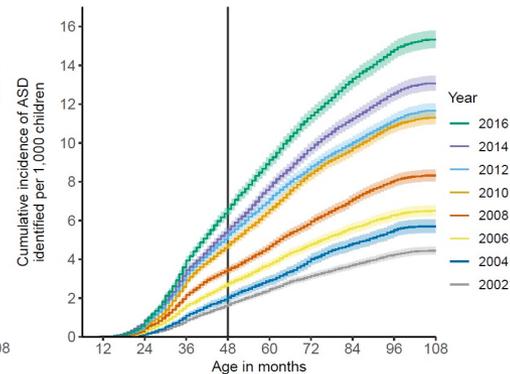
R. Christopher Sheldrick, PhD 



Median age of diagnosis (historical standard) – no progress



Median age of diagnosis (with censoring for unidentified cases) – some progress



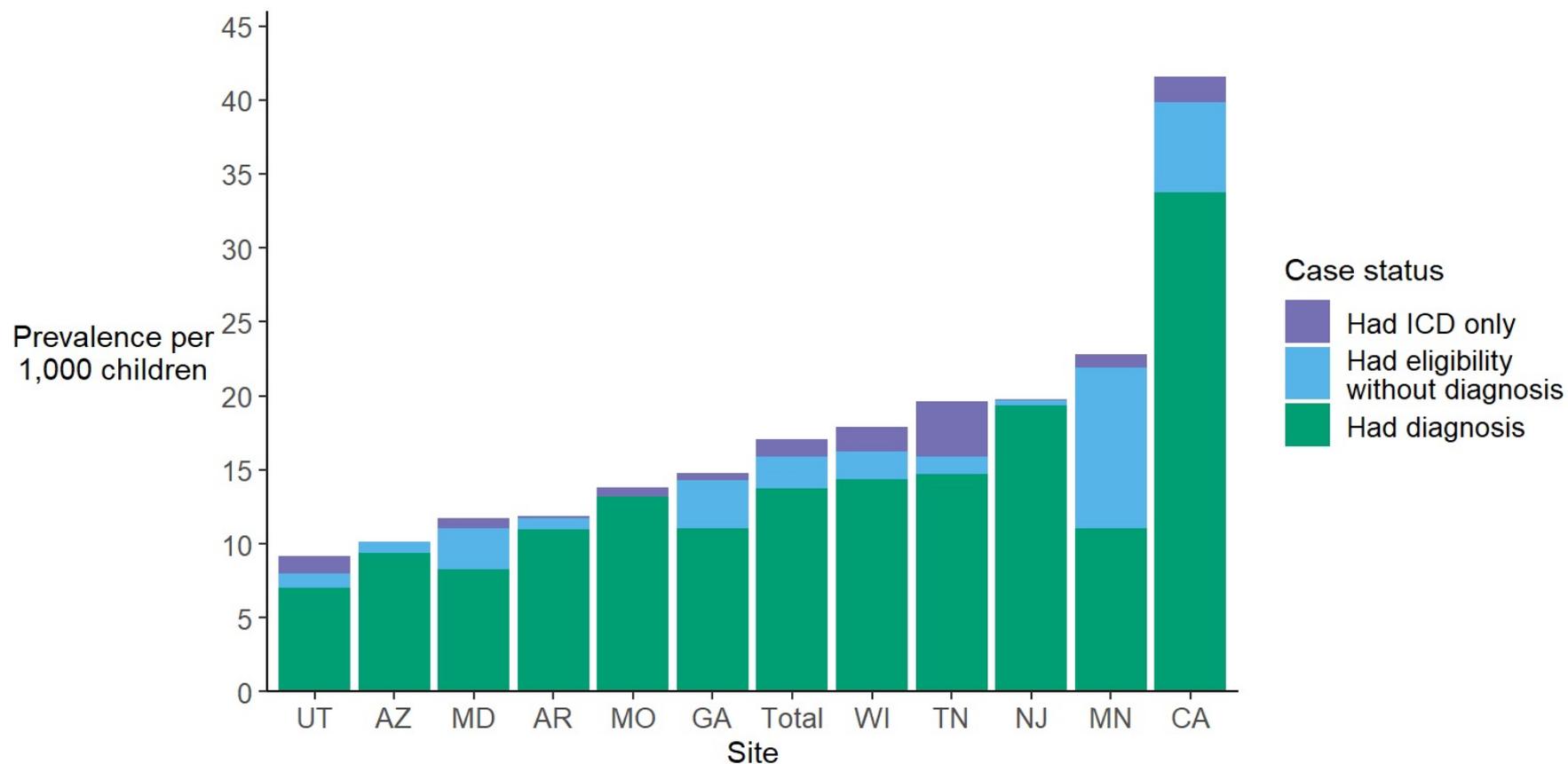
Cumulative incidence of identification – 4x higher at 48 months in 2016 versus 2002

2018

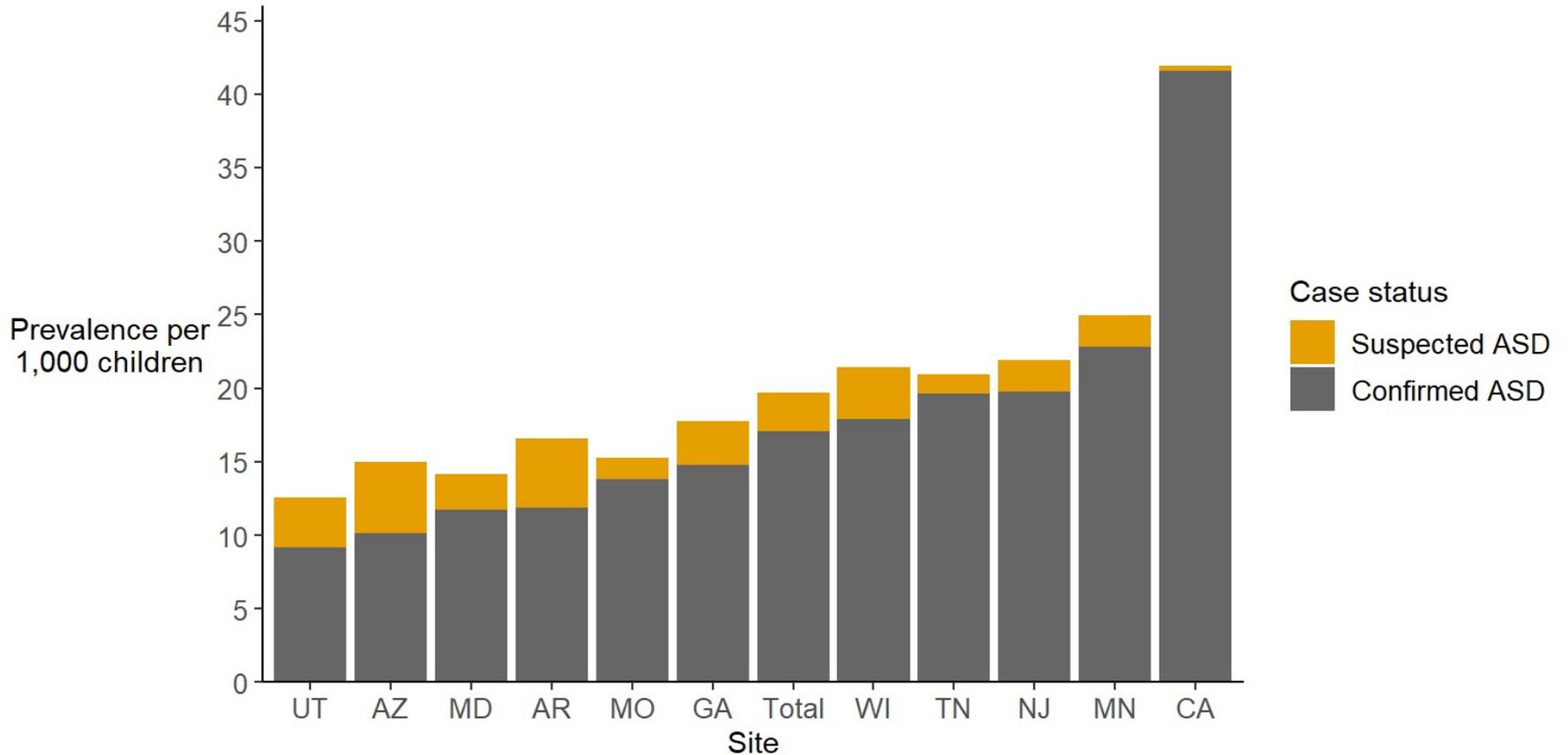
**Early Identification of Autism Spectrum
Disorder Among Children Aged 4 Years**

Autism and Developmental Disabilities Monitoring Network
11 Sites, United States

Overall prevalence was 17 per 1,000 4-year-olds, but varies greatly across sites.



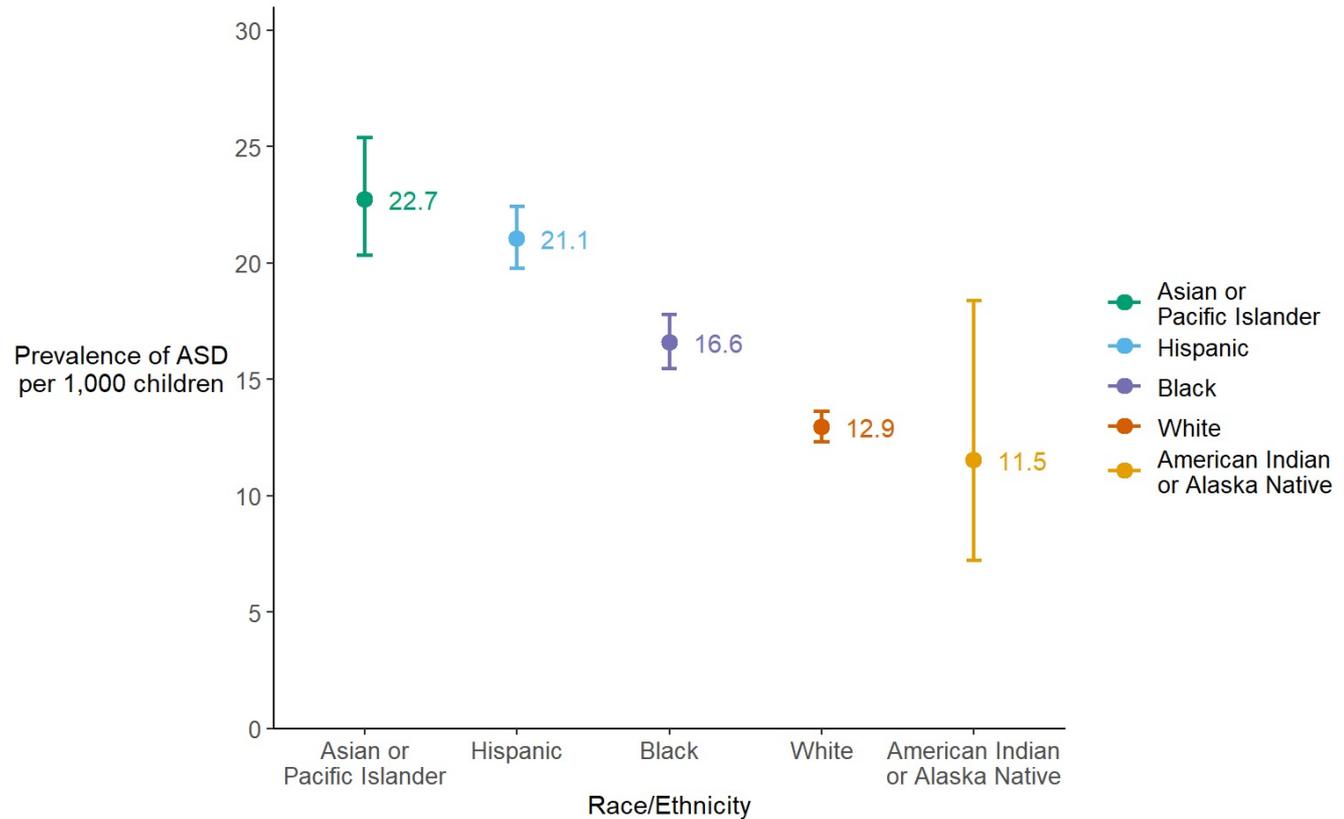
It appears relatively few children are only **suspected** of having autism but this also varies across sites



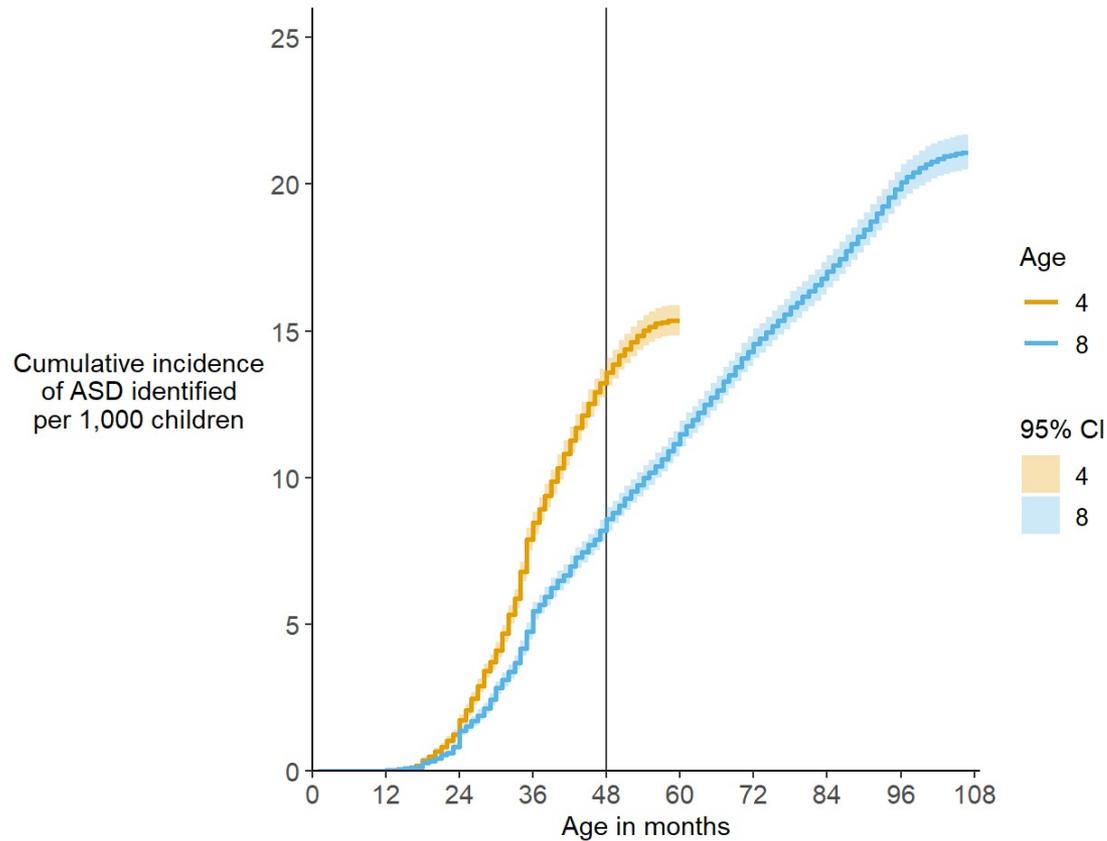
Prevalence was highest among **Asian/Pacific Islander** and **Hispanic** children.

Compared to both those groups and **Black** children, **White** children had significantly lower prevalence of ASD.

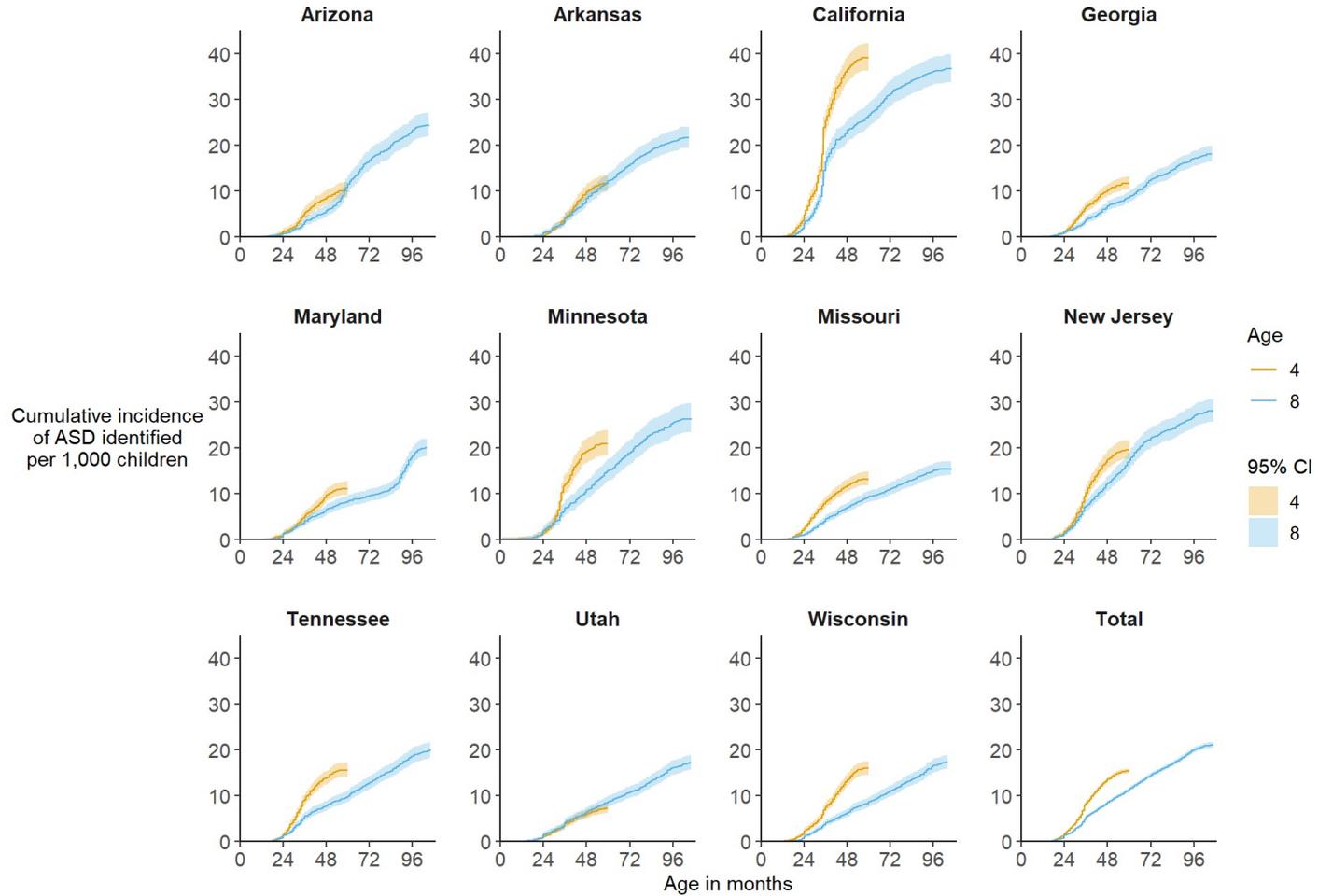
We report prevalence among **American Indian or Alaska Native** children for the first time.



Comparing **children born in 2014 (age 4)** to **children born in 2010 (age 8)**, there was more early identification in the younger group.



This pattern looks different across sites.



Upcoming ADDM Activities

- Follow-up of children at age 16 years in 2018 (aged 8 years in 2010)
- "Profound" autism prevalence estimation
- Pilot for statewide ASD surveillance via record linkages
- 2020 Surveillance Year

2018 ADDM Surveillance Summary Citations and Links

Maenner MJ, Shaw KA, Bakian AV, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. [MMWR Surveill Summ 2021, 70 \(No. SS-11\): 1-16.](#)

Shaw KA, Maenner MJ, Bakian AV, et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. [MMWR Surveill Summ 2021, 70 \(No. SS-10\): 1-14.](#)

Other ADDM Network publications

Shaw KA, McArthur D, Hughes MM, et al. Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016 [published online ahead of print, 2021 Nov 24]. *J Am Acad Child Adolesc Psychiatry.* 2021;S0890-8567(21)02000-1. doi:10.1016/j.jaac.2021.11.019 <https://pubmed.ncbi.nlm.nih.gov/34838692/>

Maenner MJ, Graves SJ, Peacock G, Honein MA, Boyle CA, Dietz PM. Comparison of 2 Case Definitions for Ascertaining the Prevalence of Autism Spectrum Disorder Among 8-Year-Old Children. *Am J Epidemiol.* 2021;190(10):2198-2207. doi:10.1093/aje/kwab106 <https://pubmed.ncbi.nlm.nih.gov/33847734/>

Data and Resources

- 2021 Community Report: <https://www.cdc.gov/ncbddd/autism/addm-community-report/index.html>
 - Spanish translation on web
- Slides with visualizations: <https://www.cdc.gov/ncbddd/autism/data.html>
- Easy-read summaries:
<https://www.cdc.gov/ncbddd/autism/features/autism-among-4-year-old-8-year-old-children-an-easy-read-summary.html>
- Data visualization tool:
<https://www.cdc.gov/ncbddd/autism/data/index.html>
- ADDM Website: <https://www.cdc.gov/ncbddd/autism/addm.html>

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2018 ADDM Investigators and Co-authors

Akilah Ali (CDC)	Jennifer Andrews (AZ)	Andrea Grzybowski (CA)	Karen Pierce (CA)
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Dedria McArthur (CDC)	John Constantino (MO)	Allison Hudson (AR)	Josephine Shenouda (NJ)
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Susan Williams (CDC)	Sarah Furnier (WI)	Sydney Pettygrove (AZ)	Walter Zahorodny (NJ)

And many record abstractors, data managers, communications specialists, and project staff.

Contact: addm@cdc.gov

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

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





Break

The *Lancet Commission*: An International Multi-Disciplinary Group's Perspective on the Future of Healthcare and Clinical Research in Autism



Catherine Lord, Ph.D.

George Tarjan Distinguished Professor of Child and Adolescent Psychiatry

UCLA David Geffen School of Medicine

Semel Institute of Neuroscience and Human Behavior



**An international perspective on the future of care and clinical research in autism:
The Lancet Commission's December 2021 report**

Catherine Lord, Ph.,D.

Tony Charman, co-chair; Alexandra Havdahl, Paul Carbone, Evdokia Angnastou, Brian Boyd, Gauri Divan, Christine Freitag, Marina Gotelli, Connie Kasari, Martin Knapp, Peter Mundy, Alex Plank, Lawrence Scahill, Chiara Serveli, Paul Shattuck, Emily Simonoff, Alison Singer, Vicki Slonims, Paul Wang, Cecilica Ysraelit, Rachael Jellett, Andrew Pickles, James Cusack, Patricia Howlin, Alison Holbrook, Christina Toolan, and James McCauley



- Three in person meetings including two conferences about international approaches to autism.
- Committees outlined sections and presented outlines and possible recommendations at second meeting.
- Revisions and reviews by committee members and full committee.
- Draft formally reviewed by three reviewers outside the committee.



- More revisions and reviews.
- Two rounds of Lancet edits.
- Final “launch” and publication in December, 2021.
- Funding provided by autism advocacy organizations, not for profit family foundations and UCLA. No author was paid.
- Hard copies will be available in spring.
- A “plain language version” will be available in spring as well.



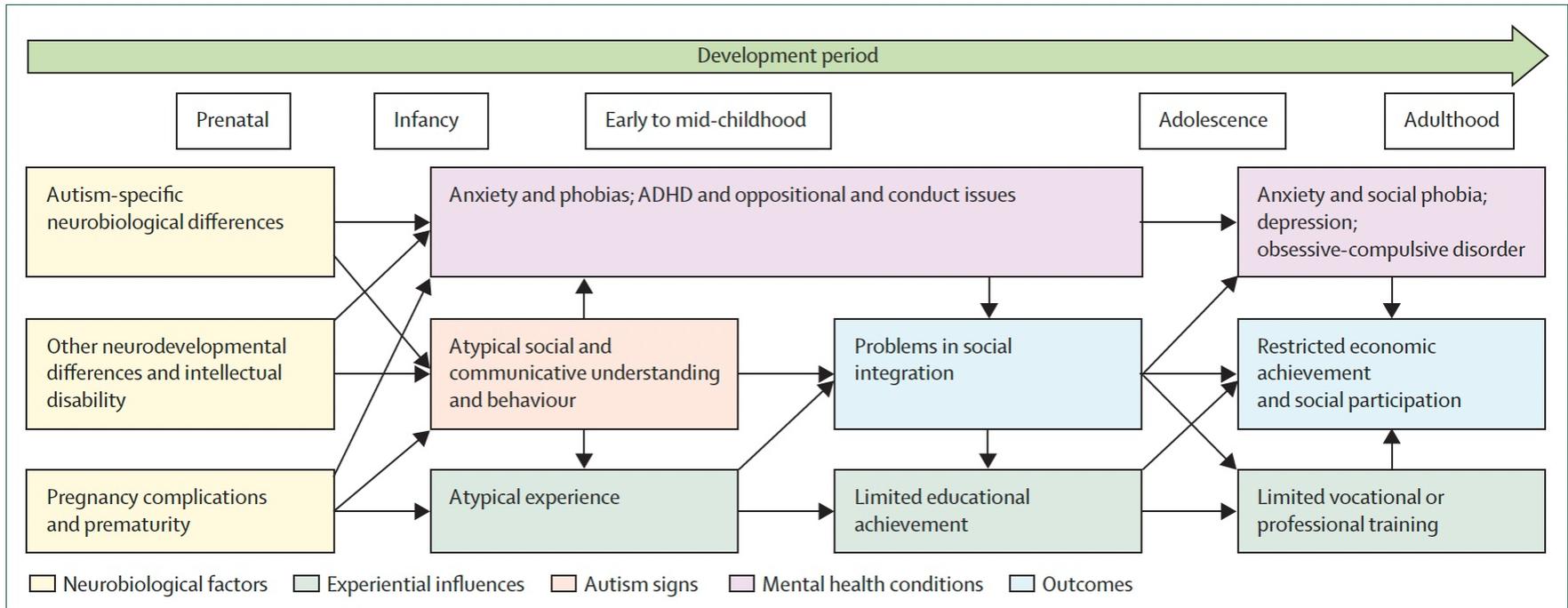
- Our commission comes to you from six continents, thirteen disciplines and thirty-two people, including autistic people and parents of autistic people
- Our first point is urgency: It is time to directly address ways of improving the lives of the 78 million autistic people in the world and their families
- There is much evidence and scientific data known about autism that is ready to be used...
- Particularly if we can determine what strategies and interventions and support systems benefit whom, when and with what intensity (as well as how)

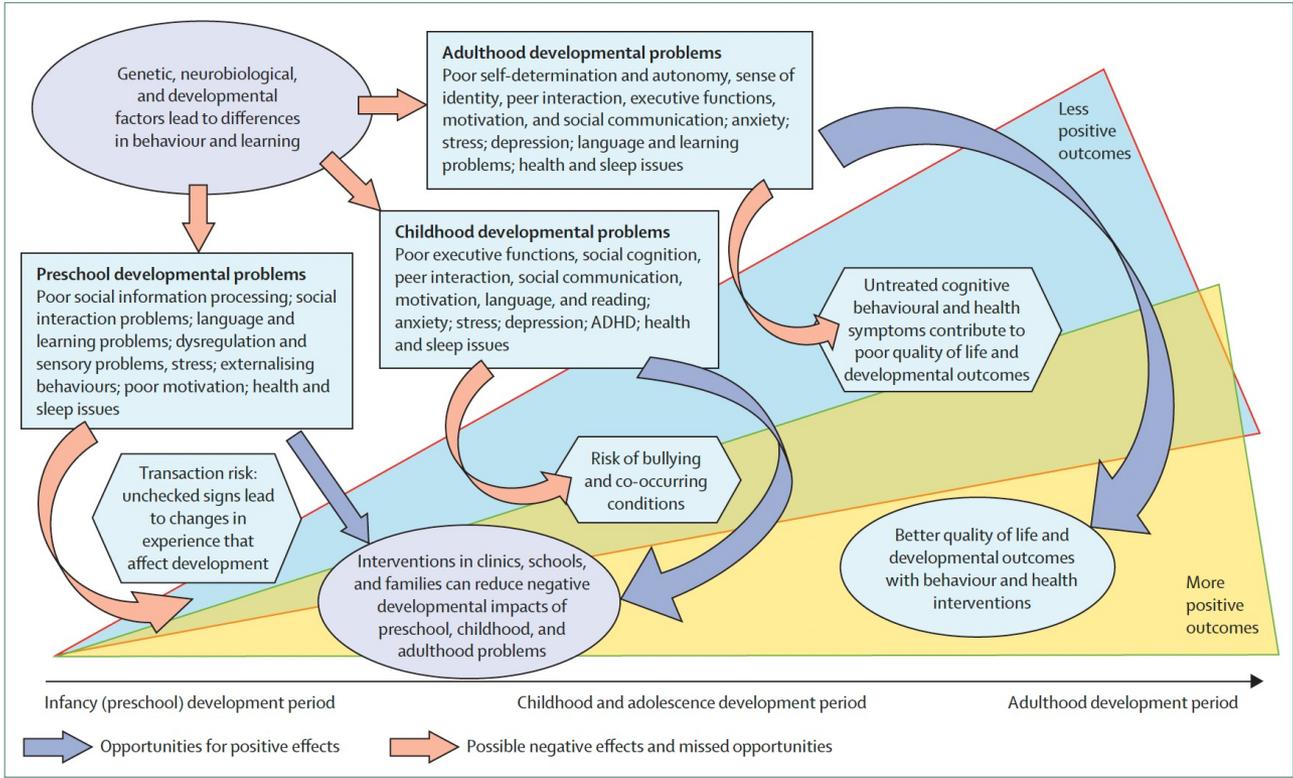


- Autism is a neurobiological condition
 - Basic and translational science efforts are important (and well funded)
 - The clinical challenges autism raises for society and for autistic people are not ones likely to be solved by biomedical solutions for most people in the near future
- We have focused on recommendations that can be put into effect in the next 5 years
 - Targeted research can change lives now by improving mental and physical health and strengthening support systems
 - To have immediate and long-term effects on the quality of life for autistic people and their families
- Research that will result in immediate improvements in the lives of autistic people and their families should be prioritised by governments and funding agencies worldwide



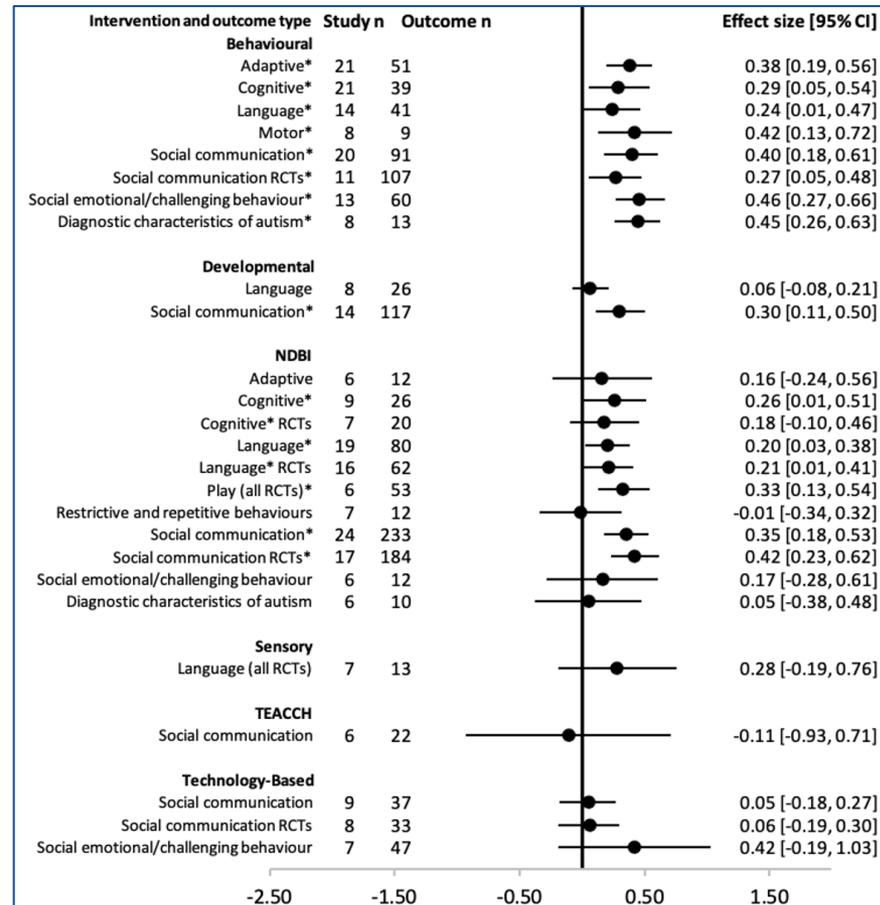
- Autism manifests differently *between* individuals
 - Some autistic people can live independent lives; others need support every day throughout their lives; and many others fall in between
- Autism also manifests differently *within* individual across the lifespan
 - It is a developmental condition
 - Autistic people will require different intervention and supports at different points in their lives
- We have proposed the term ‘profound autism’ to highlight the needs of autistic children and adults with severe intellectual and communication disabilities who cannot speak for themselves and will need extensive care throughout their lives
- Many autistic people have strengths that contribute to their family, community and society
- Valuing autism and neurodiversity benefits society as a whole







- Evidence-based psychosocial interventions exist for young, autistic children
- Naturalistic interventions to promote positive parent-child interactions have been successfully implemented in LMICs
- There is some general agreement about helpful intervention strategies (e.g., visual supports) even when lacking “traditional” empirical support
- Psychopharmacological treatments for co-occurring conditions become more common in later childhood or adolescence





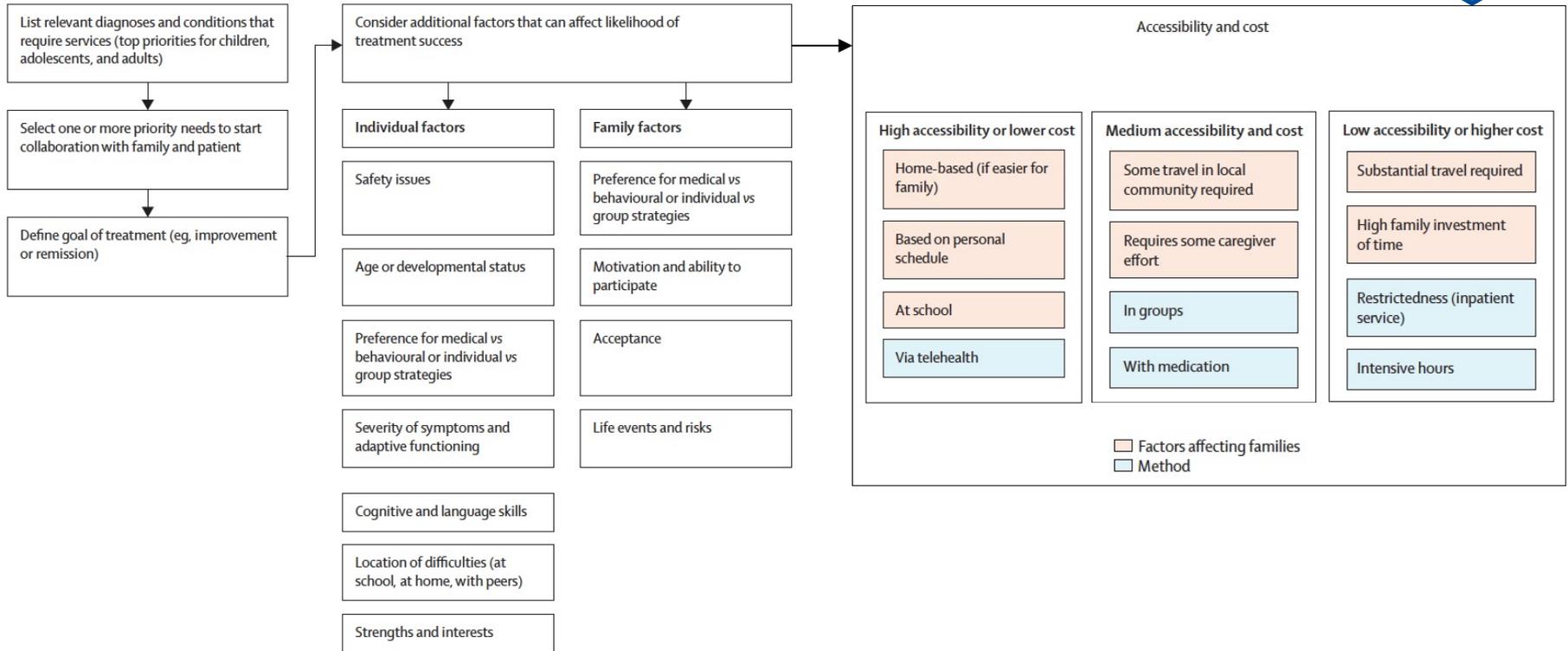
- However, this will require different research on a much larger scale and coordination across arms of government and services to find results that are meaningful on an individual level.
- Such information can also provide the beginnings for culturally appropriate adaptations across the globe using the strengths and addressing the needs of different communities.
- Much of this information, and other research, also has the potential for direct bearing to approaches to other developmental disorders and mental health conditions.

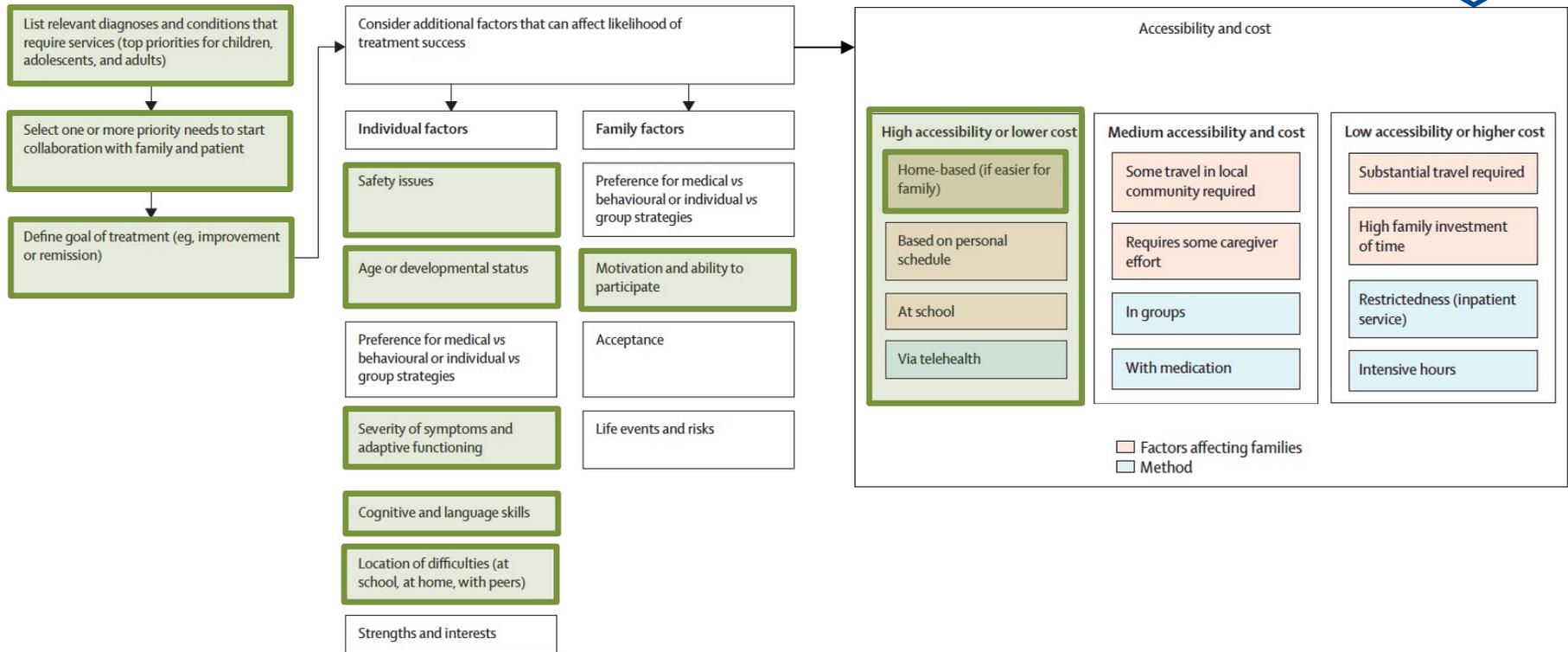


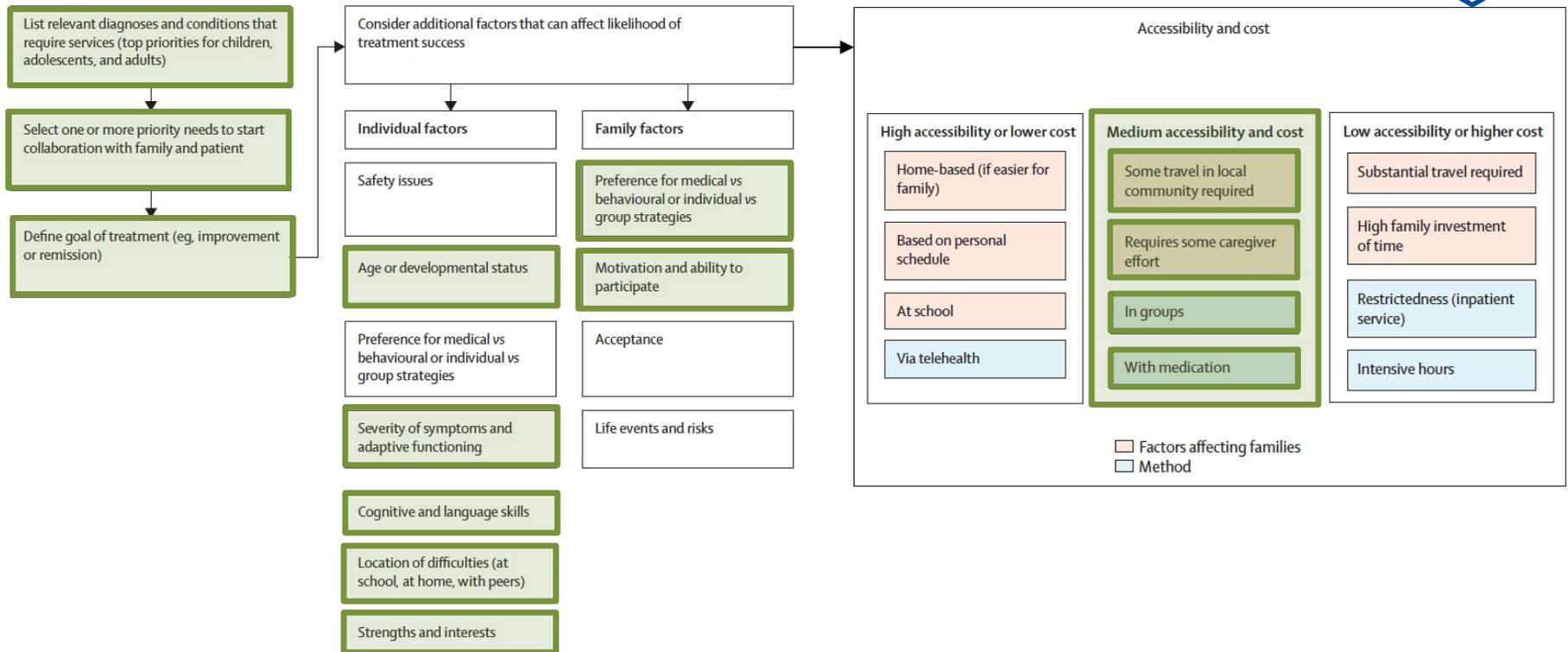
- Acknowledging the heterogeneity of autism both within individuals across the lifespan and between individuals, we propose a new consideration of how to apply a stepped care, personalized health approach to autism
- Often such models have primarily considered financial and practical considerations of service systems (e.g., such as medical systems) with personalization proposed, not for the individual patient, but for their “disease” or “tumor”
- Autism is not a disease but a condition that can cause impairment in daily living, but to what degree and in what way depends on the individual profile of the autistic child, adolescent or adult and also their family resources, their community and their geographical region.



- We propose to shift the traditional stepped care perspective and propose steps that take into account the costs, burden and preferences of individuals or families (rather than just to the health system) and personalization on the basis of the autistic individual and families' needs, strengths and challenges.
- This means that information needs to be gathered about the skills and needs of each autistic person and their family, beyond a diagnosis to include other factors and preferences....
- This is more than “person-centered.”
- And updated as needed because it will change as children become adults and as adults grow older.









- If we are going to do this, we need to know more than that there are evidence-based treatments that are effective for some people.
- We need to know which interventions are effective for whom, when, with what intensity and for how long (and ideally why, but the we don't need to wait for the “why”). This requires personalised knowledge about the family and possible resources in order to determine appropriate steps.
- Example of recent CMS mandate and response from healthcare systems.
- It is critical that we figure out financially feasible ways of working within and across systems to support research that will give us answers to practical questions and then to use this research to implement changes that make a difference in the lives of autistic people and their families.



Schools

Challenge:

- In some HICs, public schools cannot legally exclude students with disabilities. Schools may be underfunded or experience personnel shortages and turnover
- In some LMICs, schools may not provide specialized supports for students with disabilities or only provide segregated services

There is a need for:

- Ensuring autistic children across the globe receive a high-quality education in schools
- Funding for school-based research and service delivery

Building Workforce Capacity

Challenge:

- Often those without professional training are involved in the delivery of care to autistic individuals
- Reimbursement or funding models for service delivery may be a delimiting factor

There is a need for:

- Task sharing between professional and non-professional groups



- Existing service systems may not be designed to meet the specific needs of autistic individuals or are underfunded
 - Service deserts exist for many groups, especially those living in LMICs or impoverished neighborhoods in HICs
- Service user is a lifelong social role for many autistic individuals

95% of children
under age 5 with
developmental
disabilities live in
LMICs



There is a need for:

Service systems that are more responsive and strive for continuous quality improvement, including schools, healthcare and social services

Service systems that integrate evidence-based interventions into their care models

High quality research conducted in LMICs to address the science to services gap in those countries

Ensuring equitable access to high quality services for underserved and minoritized groups in both LMICs and HICs



- Formal documentation through governmental health-care, education, and social care systems.
- Governments and health-care systems must recognise the need for integration across systems.
- Focused research strategies should be prioritised with an emphasis on clinical practice that can increase the understanding of what interventions work, for whom, when, how, with what general outcomes, and at what cost.
- Equity in access and use of services by underserved and under-represented groups (those with profound autism, girls and women, minority ethnic groups, those from socially disadvantaged backgrounds, or with severe co-occurring condition) should be monitored.



- To highlight the needs of autistic people with severe intellectual and communication disabilities with profound needs for care and support
 - Those who cannot speak for themselves and need extensive care throughout their lives
 - Require 24-hour access to an adult who can care for them if concerns arise
 - Not be able to take care of basic adaptive daily needs
- Individuals with substantial intellectual disability or very limited language (or both)
 - Most have complex co-occurring difficulties e.g., self-injury, epilepsy, aggression
 - Appropriate to identify from mid-childhood or later when future needs are clear
- New analysis of data from 3 cohorts – 2 population (MoBA, SNAP), 1 clinical (EDX)
 - Proportion meeting criteria for profound autism ranged from 18% to 48%
- Intended to spur the clinical and research communities to prioritise the needs of this vulnerable and underserved group of autistic individuals



There is a need for:

Personalised and developmentally targeted interventions over the life course

Implementation science and community-based effectiveness trials

Cost-effectiveness research to support decision making

*Engagement of stakeholders in intervention development and deployment

*Culturally-adapted and tailored intervention approaches

Use of more advanced research designs to help answer complex questions

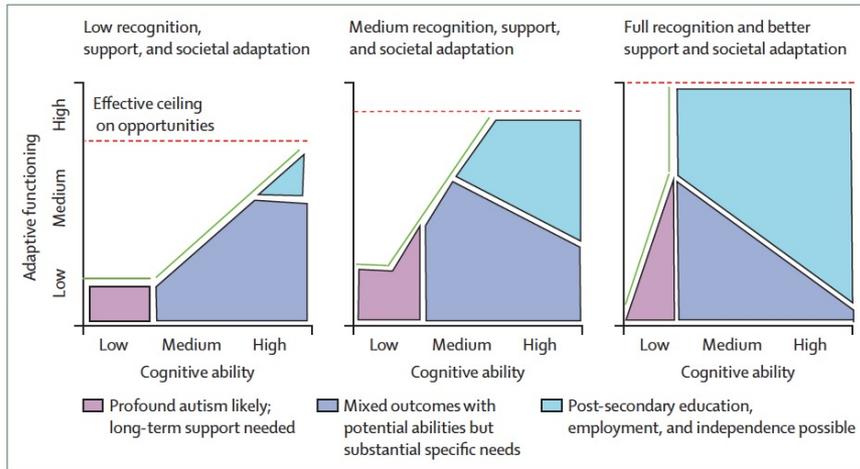


Figure 4: Societal response and services can optimise outcomes for all people with autism
The green line indicates the hypothetical degree to which the environment supports the adaptive potential of autistic people with different cognitive abilities.

- In the end, this is a message of hope.
- We know much about what autism is, how it differs across individuals and how we can support development in autistic people – though we have not put this information to practice as much as we need to.
- We know about the potential for change and ways to make this happen.
- We can also extend much of what we have learned and will learn to other developmental disorders and mental health conditions.
- Let's work together and do this now.

IACC Committee Business (continued)

IACC Full Committee Meeting
January 19, 2022



Susan A. Daniels, Ph.D.

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

2020 IACC Summary of Advances - Process



- Solicit Nominations from IACC members ✓
- Next step: Refine list of nominations – **TODAY**

After Meeting:

- OARC creates the ballot and asks IACC members to vote on the articles (via email)

February-April 2022:

- OARC will develop summaries of the top 20 articles selected by the IACC and prepares the report

ACTION ITEM: Finalize 2020 Nomination List



Question 1: Screening and Diagnosis

PEDIATRICS[®]

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Apr 2020

Trends in Pediatricians' Developmental Screening: 2002-2016.

Lipkin PH, Macias MM, Baer Chen B, Coury D, Gottschlich EA, Hyman SL, Sisk B, Wolfe A, Levy SE.



Not ASD-specific enough?

Neurology[®]

Mar 2020

Validation of the NIH Toolbox Cognitive Battery in intellectual disability

Shields RH, Kaat AJ, McKenzie FJ, Drayton A, Sansone SM, Coleman J, Michalak C, Riley K, Berry-Kravis E, Gershon RC, Widaman KF, Hessl D.



Not ASD-specific enough?

Question 1: Poll Results



1. Should the Lipkin et al. Pediatrics article be included in the list of nominations for the 2020 Summary of Advances? (Single Choice) *

A. Yes 30%

A horizontal bar chart for the 'A. Yes' response. The bar is blue and extends to the 30% mark on a light gray background that represents the total 100% of possible responses.

B. No 70%

A horizontal bar chart for the 'B. No' response. The bar is blue and extends to the 70% mark on a light gray background that represents the total 100% of possible responses.

You did not answer this question

2. Should the Shields et al. Neurology article be included in the list of nominations for the 2020 Summary of Advances? (Single Choice)

A. Yes 42%

A horizontal bar chart for the 'A. Yes' response. The bar is blue and extends to the 42% mark on a light gray background that represents the total 100% of possible responses.

B. No 58%

A horizontal bar chart for the 'B. No' response. The bar is blue and extends to the 58% mark on a light gray background that represents the total 100% of possible responses.

Results based on responses of IACC members and alternates

ACTION ITEM: Finalize 2020 Nomination List



Question 4: Treatments and Interventions

The International Journal of Research and Practice Volume 21 Number 5 July 2017

autism

Aug 2020

Interventions to address health outcomes among autistic adults: A systematic review

Benevides TW, Shore SM, Andresen ML, Caplan R, Cook B, Gassner DL, Erves JM, Hazlewood TM, King MC, Morgan L, Murphy LE, Purkis Y, Rankowski B, Rutledge SM, Welch SP, Wittig K.



Literature review; have not typically included these in the past

Psychological
Bulletin

Jan 2020

Project AIM: Autism intervention meta-analysis for studies of young children.

Sandbank M, Bottema-Beutel K, Crowley S, Cassidy M, Dunham K, Feldman JI, Crank J, Albarran SA, Raj S, Mahbub P, Woynaroski TG.



Meta-analysis; occasionally included these in the past

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Question 4: Poll Results



1. Should the Benevides et al. Autism article be included in the list of nominations for the 2020 Summary of Advances? (Single Choice)

*

A. Yes 24%



B. No 76%



2. Should the Sandbank et al. Psychological Bulletin article be included in the list of nominations for the 2020 Summary of Advances? (Single Choice) *

A. Yes 79%



B. No 21%



Results based on responses of IACC members and alternates

ACTION ITEM: Finalize 2020 Nomination List



Question 4: Treatments and Interventions

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Apr 2020

Weight Management in Primary Care for Children With Autism: Expert Recommendations.

Curtin C, Hyman SL, Boas DD, Hassink S, Broder-Fingert S, Ptomey LT, Gillette MD, Fleming RK, Must A, Bandini LG.



Provider recommendations; have not typically included these in the past

ACTION ITEM: Finalize 2020 Nomination List



Question 5: Services

International Journal of
**Developmental
Disabilities**

Nov 2020

Undocumented Mexican Mothers of Children with Autism: Navigating the Health Care and Educational Service Systems.

Luelmo , P, Sandoval, Y, Kasari, C.



Small sample size (N = 6); findings not yet appropriate for inclusion in the *Summary of Advances*?

Question 5: Poll Results



1. Should the Luelmo et al. International Journal of Developmental Disabilities article be included in the list of nominations for the 2020 Summary of Advances? (Single Choice) *



Results based on responses of IACC members and alternates

ACTION ITEM: Finalize 2020 Nomination List



Question 6: Lifespan Issues

The International Journal of Research and Practice Volume 21 Number 5 July 2017

autism

May 2020

Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project.

Benevides TW, Shore SM, Palmer K, Duncan P, Plank A, Andresen ML, Caplan R, Cook B, Gassner D, Hector BL, Morgan L, Nebeker L, Purkis Y, Rankowski B, Wittig K, Coughlin SS.



Priority-setting, information-gathering activity; have not typically included these in the past

JIDR

Journal of Intellectual Disability Research

Published on behalf of mencap and in association with IASSIDD

Apr 2020

Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions.

Jeste S, Hyde C, Distefano C, Halladay A, Ray S, Porath M, Wilson RB, Thurm A.



Not ASD-specific enough?

Question 6: Poll Results



1. Should the Benevides et al. Autism article be included in the list of nominations for the 2020 Summary of Advances (Single Choice) *

A. Yes 34%

A horizontal bar chart showing the percentage of responses for "A. Yes" at 34%. The bar is blue and extends approximately one-third of the way across the width of the chart area.

B. No 66%

A horizontal bar chart showing the percentage of responses for "B. No" at 66%. The bar is blue and extends approximately two-thirds of the way across the width of the chart area.

You did not answer this question

2. Should the Jeste et al. Journal of Intellectual Disability Research article be included in the list of nominations for the 2020 Summary of Advances? (Single Choice) *

A. Yes 41%

A horizontal bar chart showing the percentage of responses for "A. Yes" at 41%. The bar is blue and extends approximately 40% of the way across the width of the chart area.

B. No 59%

A horizontal bar chart showing the percentage of responses for "B. No" at 59%. The bar is blue and extends approximately 60% of the way across the width of the chart area.

Results based on responses of IACC members and alternates

2021 IACC Summary of Advances – Next Steps



- Solicited 2021 nominations from IACC members ✓
- IACC will review and let OARC know of any article to be added or removed from the list of nominations within coming months
- OARC will send an electronic ballot for 2021 articles via email following production of *2020 Summary of Advances*
- Tentative goal of a late 2022 release date

Round Robin Updates



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

Thank you to the OARC Staff!



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Next IACC Meeting



April 13-14, 2022
Virtual

Check the IACC Website for meeting information and updates.

<https://iacc.hhs.gov>