

2021 Summary of Advances Nominations

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Question 1: Screening and Diagnosis

Dena Gassner	<p>Barger B, Benevides T, Ritzk S, Rice C, Heiman H, Salmon A, Sanchez-Alvarez S. Race/ethnic inequities in conjoint monitoring and screening for U.S. children 3 and under: Disparities in Monitoring and Screening. <i>Disabil Health J.</i> 2021 Aug 13:101179. doi: 10.1016/j.dhjo.2021.101179. Epub ahead of print. PMID: 34412986.</p> <p>Non-White children with developmental disabilities are frequently identified later than White children and therefore miss out on opportunities for early intervention (EI). Recent research indicates that conjoint monitoring and screening is more strongly associated with EI receipt than monitoring or screening alone.</p>
Alycia Halladay	<p>Kaat AJ, Shui AM, Ghods SS, Farmer CA, Esler AN, Thurm A, Georgiades S, Kanne SM, Lord C, Kim YS, Bishop SL. Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis. <i>J Child Psychol Psychiatry.</i> 2021 Jan;62(1):97-106. doi: 10.1111/jcpp.13242. Epub 2020 Apr 20. PMID: 32314393; PMCID: PMC8115212.</p> <p>Concerns have been raised that scores on standard measures of autism spectrum disorder (ASD) symptoms may differ as a function of sex. However, these findings are hindered by small female samples studied thus far. The current study evaluated if, after accounting for age, IQ, and language level, sex affects ASD severity estimates from diagnostic measures among children with ASD.</p>

Question 2: Biology

Question 3: Risk Factors

Question 4: Treatments and Interventions

Question 5: Services

HUD	<p>Schott W, Nonnemacher S, Shea L. Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services. <i>J Autism Dev Disord.</i> 2021 Apr;51(4):1188-1200. doi: 10.1007/s10803-020-04593-2. [PMID: 32671666]</p> <p>There are typically long waitlists for autistic adults in need of long-term services and supports through Medicaid. This study used data from a large statewide survey to examine the service needs reported by autistic individuals and their caregivers on a waiting list for Home and Community-Based Services (HCBS) in Pennsylvania. The authors found that the majority of those on the waitlist have unmet needs for functional skills services (63.6%), employment or vocational services (62.1%), and mental and behavioral health services (52.8%). These results highlight the needs of the autistic population waiting for services and help policymakers to plan how best to serve these individuals.</p>
CDC	<p>Zuvekas SH, Grosse SD, Lavelle TA, Maenner MJ, Dietz P, Ji X. Healthcare Costs of Pediatric Autism Spectrum Disorder in the United States, 2003-2015. <i>J Autism Dev Disord.</i> 2021 Aug;51(8):2950-2958. doi: 10.1007/s10803-020-04704-z. PMID: 33113106; PMCID: PMC8079509.</p>

Published healthcare cost estimates for children with ASD vary widely. This study suggests that costs are less than estimated elsewhere and provides a grounded evidence-based estimate that can inform policy. Results found that the incremental annual per-child cost of ASD relative to no ASD diagnosis was \$3930 (2018 US dollars) using ASD case status from the National Health Interview Survey (NHIS) Child Core and \$5621 using current-year ASD case status from Medical Expenditure Panel Survey (MEPS). Both estimates are lower than some published estimates but still represent substantial costs to the US healthcare system.

Question 6: Lifespan Issues

Alycia Halladay	<p>White LC, Law JK, Daniels AM, Toroney J, Vernoia B, Xiao S; SPARK Consortium, Feliciano P, Chung WK. Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort. <i>J Autism Dev Disord</i>. 2021 Jan 2:1–8. doi: 10.1007/s10803-020-04816-6. Epub ahead of print. PMID: 33387233; PMCID: PMC7775834.</p> <p>The impact of the 2019 coronavirus pandemic (COVID-19) in the United States is unprecedented, with unknown implications for the autism community. We surveyed 3502 parents/caregivers of individuals with an autism spectrum disorder (ASD) enrolled in Simons Powering Autism Research for Knowledge (SPARK) and found that most individuals with ASD experienced significant, ongoing disruptions to therapies. While some services were adapted to telehealth format, most participants were not receiving such services at follow-up, and those who were reported minimal benefit. Children under age five had the most severely disrupted services and lowest reported benefit of telehealth adaptation. Caregivers also reported worsening ASD symptoms and moderate family distress. Strategies to support the ASD community should be immediately developed and implemented.</p>
ACL	<p>Wong J, Coster WJ, Cohn ES, Orsmond GI. Identifying School-Based Factors that Predict Employment Outcomes for Transition-Age Youth with Autism Spectrum Disorder. <i>J Autism Dev Disord</i>. 2021 Jan;51(1):60-74. doi: 10.1007/s10803-020-04515-2. PMID: 32356081.</p> <p>Limited research has investigated what aspects of support should be prioritized when preparing youth with ASD for employment. By conducting structural equation modeling using a nationally representative dataset on high school students receiving special education services (NLTS-2), this study examined the malleable predictors of employment during the transition and developed a model to examine the relationships between predictors and employment outcomes. The findings suggested two pathways for youth with ASD. For youth with higher daily functioning skills (DFS), academic performance mediated the relationship between parent participation and employment. For youth with lower DFS, school-based transition supports were the key mediator.</p>

Question 7: Infrastructure and Surveillance