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The Autistic Self Advocacy Network appreciates the opportunity to submit comments for the July 10, 2024, Interagency Autism Coordinating Committee (IACC) meeting. In our last comments to the IACC, ASAN provided feedback on the 2019-2020 IACC Autism Research Portfolio Analysis Report and the GAO Report titled Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened. Our comment will focus on the Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities FY 2019 - FY 2023 and how agency activities can best meet the needs of the autistic community and the goals of the IACC strategic plan.

## **Required Elements**

### Autism Progress and Expenditures

The section on Autism Progress and Expenditures is the most expansive section on activities related to autism and the provisions within the Autism CARES Act of 2019. To fully and comprehensively highlight every federal activity in these comments would not be productive. We will instead focus primarily on new activities since the FY 2014 - FY 2018 report as well as activities we are concerned about and highlight areas where there is still a need for federal activity.

### *Department of Health and Human Services (HHS)*

Since the last Report to Congress on Activities related to Autism, the Administration for Community Living (ACL) has greatly expanded its activities that impact autistic people by launching three new resource centers and two new technical assistance centers. The resource centers focus on alternatives to guardianship, increasing access to supports for individuals with intellectual and developmental disabilities and mental health support needs, and strengthening the direct care workforce. The technical assistance centers focus on empowering the self-advocacy movement by providing leadership opportunities for people with intellectual and developmental disabilities and assisting ACL grantees that help people with disabilities achieve competitive integrated employment. These activities demonstrate the ACL's commitment to increasing access to supports and services and fostering independence for people with disabilities. These efforts make it possible for more people with disabilities to live in their community, a right affirmed by the *Olmstead* decision that turns twenty-five this month. We hope to see the grants that fund these centers extended in the coming years.



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We would also like to highlight the ACL's expansion of programs to support caregivers in light of this IACC convening's theme of family caregivers. Ensuring family caregivers have proper support is very important. We encourage the IACC to keep in mind that the CDC estimates 33% of caregivers age 45 and older reported having a disability.<sup>1</sup> We would like to see more data collected on the demographics of caregivers, including race, ethnicity, gender, age, and disability status. It is also crucial that the benefits of caregiver supports are all

ASAN has taken an interest in the U.S. Preventive Services Task Force's (USPSTF) final research plan regarding screening for autism in young children. The project seeks to answer important questions about the outcomes of early screening and early intervention as well as what harms they may cause. ASAN has historically raised concern about how early intervention may include harmful approaches such as applied behavioral analysis (ABA) and how early screening can lead to these harmful approaches. We appreciate the Task Force's efforts to assess the outcomes of these interventions and their harms and we eagerly await their results.<sup>2</sup> The USPSTF is convened by the Agency for Healthcare Research and Quality.

The Centers for Medicare and Medicaid Services (CMS) oversight of the nation's healthcare system is essential to the health and wellbeing of autistic people. Rather than going over these programs, ASAN would like to highlight some of the guidance and rules released since the last activities report that have improved the quality of life and care of autistic people. In 2022, CMS issued new guidance to the states to cover behavioral health services under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit and new guidance to strengthen mental health care for children. While we applaud CMS' efforts to expand access to care, we are concerned by some of the treatment options states may include, such as ABA-related interventions. We encourage CMS to release additional guidance around the coverage of habilitative services such as speech and language, occupational, and physical therapy that address core and co-occurring conditions experienced by autistic people. We are grateful for CMS' 2023 guidance on the Medicaid Reentry Section 1115 Demonstration opportunity. This guidance will lead to increased care for incarcerated individuals with disabilities as they prepare to reenter

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<sup>1</sup> CDC. (2018). *Caregiving for Family and Friends – A Public Health Issue*.  
<https://www.cdc.gov/aging/caregiving/caregiver-brief.html>

<sup>2</sup> Autistic Self Advocacy Network. (2021). *For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions*.  
<https://autisticadvocacy.org/wp-content/uploads/2021/12/ACWP-Ethics-of-Intervention.pdf>



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society. According to the Bureau of Justice's 2016 Survey of Prison Inmates, 38% of state and federal prisoners reported a disability. 23% of prisoners reported a cognitive disability.<sup>3</sup> Since the writing of this report, CMS has implemented the final Medicaid Access and Managed Care Access rules.<sup>4,5</sup> The Medicaid Access rule establishes quality reporting and quality improvement standards for home- and community-based services (HCBS) including incident reporting while also establishing a grievance system. The Medicaid Access rule also creates a provision for Direct Support Professionals (DSPs) to receive better pay with the establishment of the 80/20 rule, stipulating in six years, at least 80% of Medicaid payments go toward DSPs and other workers who provide direct care to people with disabilities. The Medicaid Access rule also strengthens opportunities for Medicaid enrollees to share their experiences and feedback with those who make Medicaid policy decisions through the new Beneficiary Advisory Council (BAC). The Managed Care rule takes steps to reduce wait times and improves quality measures. We believe CMS' implementation of these rules will improve the quality and delivery of HCBS.

The Health Resource and Services Administration (HRSA) plays an important role in autism research and training, especially around screening, diagnosis, and intervention. We welcome HRSA's funding of grants in FY 2019 through the Innovations in Care Coordination for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities program. Care coordination is an essential part of improving health outcomes. ASAN encourages HRSA to do more research into communication services, and hopes to see the creation of an Autism Intervention Research Network on Communication or "AIR-C" as part of the Autism CARES Act of 2024. We also encourage HRSA to conduct thorough evaluations of existing behavioral health interventions and investigate new interventions such as trauma-informed approaches as part of the Autism Intervention Research Network on Behavioral Health.

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<sup>3</sup> Maruschak, L. M., Bronson, J., & Alper, M. (2021). Disabilities Reported by Prisoners: Survey of Prison Inmates, 2016. In *Bureau of Justice Statistics* (NCJ 252642). Bureau of Justice Statistics. <https://bjs.ojp.gov/redirect-legacy/content/pub/pdf/drpspi16st.pdf>

<sup>4</sup> Medicaid Program; Ensuring Access to Medicaid Services, 89 F.R. 40542 (published May 10, 2024) (to be codified at 42 C.F.R. § 431, 42 C.F.R. § 438, 42 C.F.R. § 441, 42 C.F.R. § 447). <https://www.federalregister.gov/documents/2024/05/10/2024-08363/medicaid-program-ensuring-access-to-medicaid-services>

<sup>5</sup> Medicaid Program; Medicaid and Children's Health Insurance Program (CHIP) Managed Care Access, Finance, and Quality, 89 F.R. 41002 (published May 10, 2024) (to be codified at 42 C.F.R. § 430, 42 C.F.R. § 438, 42 C.F.R. § 457). <https://www.federalregister.gov/documents/2024/05/10/2024-08085/medicaid-program-medicaid-and-childrens-health-insurance-program-chip-managed-care-access-finance>



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As the home to the IACC and the Office of National Autism Coordination, the National Institutes of Health (NIH) is intrinsic to the strategic plan. With that said, the NIH receives the majority of Autism CARES Act funding and spends the majority of the money on research on the biology and genetics of autism. ASAN encourages the NIH to award more projects focused on the co-occurring conditions with autism and intellectual disability including communication disorders. Please see our April Public Comments on the FY2019-2020 Portfolio Analysis for ASAN's full thoughts on funding allocation.<sup>6</sup> ASAN does take notice and great interest in the NIH's research on ASD Services and Interventions across the lifespan and greatly supports research efforts like those taken by the National Institute of Mental Health (NIMH) to improve independent functioning and social well-being in transition-aged autistic youth and adults.<sup>7,8</sup> We would also like to praise the NIH for designating people with disabilities as a population with health disparities in September 2023, and look forward to seeing more research that takes disability into account as part of equity and disparities analysis.

ASAN is pleased to see HHS' Office of the Assistant Secretary for Planning and Evaluation (ASPE) produce several reports on issues like health insurance coverage, COVID-19 and adolescent mental health, patient-centered outcomes research for people with IDD, and psychotropic medication and psychosocial service use. We hope the reports will inform HHS and administration-wide policy and even legislative efforts. ASAN is interested in ASPE's work on the Integrated Dataset on Intellectual and Developmental Disabilities, but information is limited and we would like to learn more and see the dataset used in policy development.<sup>9</sup>

Autism is not a mental health disability, but it often coincides with them. As a result, many of the efforts of the Substance Abuse and Mental Health Services Administration (SAMHSA) impact autistic people. ASAN is interested in SAMHSA activities like Project

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<sup>6</sup> Poulos, J. (2024, April 17). *Comments for the April 17th IACC Meeting - Autistic Self Advocacy Network*. Autistic Self Advocacy Network.

<https://autisticadvocacy.org/2024/04/comments-for-the-april-17th-iacc-meeting/>

<sup>7</sup> NIH. (2022, June). *A Longitudinal Study of Employment and Educational Instability for Young Adults with Autism Spectrum Disorder*. NIH RePORTER. 5R01MH121438-03.

<https://reporter.nih.gov/project-details/10400892>

<sup>8</sup> NIH. (2023, January). *Measuring Health, Function, and Social Well-being in Adults on the Autism Spectrum*. NIH RePORTER. 5R01MH121407-04. <https://reporter.nih.gov/project-details/10532190>

<sup>9</sup> ASPE. (n.d.). *Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person-Centered Outcomes Research*. Retrieved June 24, 2024, from <https://aspe.hhs.gov/dataset-intellectual-developmental-disabilities-linking-data-enhance-person-centered-outcomes>



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AWARE and Healthy Transitions due to their increased coordination in an individual's support system, but ASAN would like to know more about the supports and services provided in both programs and if they are properly inclusive to an individual's needs. ASAN commends the SAMHSA's efforts as part of the Criminal and Juvenile Justice Programs to help people avoid and reduce the harms of criminal and juvenile justice systems. We encourage behavior health specialists and researchers to look at the National Child Traumatic Stress Network as a model for the importance of trauma-focused interventions for the improvement of behavioral health.

#### *Department of Education*

ASAN follows the research efforts of the Institute of Education Sciences (IES) and the National Center for Special Education Research (NCSER) for its research on autistic people. ASAN appreciates efforts to make the classroom a more inclusive learning environment and has communicated with NCSER on its research efforts before. We would like to see greater coordination to align with the strategic plan and needs of autistic students and students with intellectual disabilities. ASAN commends the joint statement of HHS and Department of Education on the inclusion of children with disabilities in early childhood programs as classroom inclusion is an essential component of improving long-term outcomes.

#### *Department of Labor*

The Department of Labor's Office of Disability Employment Policy (ODEP) worked on several new programs to help people with disabilities achieve competitive integrated employment. The Research Support Services for the Employment of Young Adults on the Autism Spectrum (REYAAS) project began in 2021 in conjunction with Mathematica and produced two deliverables on the programs, models, and strategies to help employ young autistic adults and on the effectiveness of those programs, models, and strategies. This is the most specific and comprehensive project specifically on the employment of autistic people. ASAN would also like to acknowledge a few ODEP projects that have helped expand the knowledge base on disability employment. The Advancing State Policy Integration for Recovery and Employment initiative helps people with mental health needs achieve CIE and get access to healthcare. The Employer Assistance and Resource Network to increase the number of employed neurodivergent people and make the workplace more accessible for neurodiverse people. The Partnership on Inclusive Apprenticeship creates pathways for high-paying, high-skilled jobs for people with disabilities.



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### *Additional Areas of Improvement*

There are several activities that we would like to see created or expanded based on where there is still unmet need. We call on multiple HHS agencies including but not limited to NIH, HRSA, and AHRQ, to expand their activities around communications research for minimally speaking and nonspeaking individuals of all ages to better support and communicate with all autistic people and people with intellectual disabilities. Similarly, we would like to see more research on behaviorally-informed interventions as described in ASAN's Behavior Supports project.<sup>10</sup> On that point, we would like to see the agencies move toward behaviorally informed practices to better service autistic people without causing undue harm. We would also value investment in autism care, support, and services for the Indian Health Service. This would increase access to care and ameliorate disparities. Research into the accessibility of services and supports in housing provided by Section 811, mainstream vouchers, and NED vouchers as well as unmet need for these housing programs would uphold the commitment to services and supports, lifespan issues, and the general health and well-being of autistic people. We would also like to see agencies that operate TA centers to support autistic people and caregivers evaluate the utilization and reach of their centers. We also ask these agencies to take further steps to ensure their efforts actually achieve their goals and make adjustments accordingly by evaluating their effectiveness. Similarly, more effort should be taken to connect parents and caregivers to resources on supports and services for their children as well as transition services. The efficacy of these efforts should be studied. We hope these additional activities will result in positive change in the lives of autistic people.

### *Additional Areas of Concern*

ASAN is concerned about ongoing activities like the Department of Defense's continued support of ABA through the TRICARE program. We appreciate recent opportunities to discuss this issue with DoD.

ASAN also takes issue with the use of artificial intelligence (AI) in several research projects in ways that could lead to failure or harm, including a NCSEER project using AI to identify

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<sup>10</sup> Autistic Self Advocacy Network. (2024). *Beyond Coercion and Institutionalization: People with Intellectual and Developmental Disabilities and the Need for Improved Behavior Support Services*. <https://autisticadvocacy.org/wp-content/uploads/2023/04/BSP-Academic-Full-White-Paper-tagged-2-with-new-attribution.pdf>



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students with Speech and Language needs.<sup>11</sup> This project utilizes two AI products for its intervention, an “AI Screener” and an “AI Orchestrator.” The AI Screener would analyze student data and identify individuals who may need speech-language services or require further evaluation from a speech-language pathologist. The AI Orchestrator would administer interventions, monitor student progress, and recommend modifications to student’s interventions. An AI’s capabilities are only as good as its training data. The study population and the training data need to properly reflect the diversity of the target population, otherwise application will result in disparities in outcomes. For these reasons, it is impossible to evaluate the value of an AI for its intended task without knowing the contents of its training data. That data has not been released for this project, so the quality of its outcomes will be difficult to assess. The use of AI to conduct substantive screening, diagnostic, and intervention tasks are also inherently troubling. Providers may over-rely on this technology and be less likely to challenge the AI when it is incorrect.

A different project funded by the NSF uses AI in an anti-bullying and data theft prevention project.<sup>12</sup> The AI would create a simulated environment populated with agents attempting to bully the participant and steal the participant’s data as well as a personalized AI companion to interpret biometric and socio-emotional factors for the participant and guide them. This concept is disturbing. Many autistic people would benefit from accessible anti-phishing and anti-bullying training. ASAN would support such an effort. However, it is hard to see what benefit participants would derive from interactions simulated through AI as opposed to something like more naturalistic roleplay sessions in a group instruction setting. These attempts to simulate human interaction may be ham-handed, inaccurate, and ultimately confusing to participants.

### *IACC Strategic Plan*

When the sum total of federal activities is considered, the federal government is progressing on the IACC strategic plan. ASAN recognizes the importance of activities that receive Autism CARES Act funding we did not previously highlight, such as the updates made to *Learn the Signs. Act Early* that improve screening and diagnosis. However, activities around the first three, and parts of the fourth, questions of the Strategic Plan have been

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<sup>11</sup> IES. (2023, January). *AI Institute for Transforming Education for Children with Speech and Language Processing Challenges*. IES Funding. 2229873 (NSF).  
<https://ies.ed.gov/funding/grantsearch/details.asp?ID=5840>

<sup>12</sup> NSF. (2021, May). *EAGER: SaTC-EDU: Improving Cybersecurity Education for Adolescents with Autism Through Automated Augmented Self-Monitoring Applications*. NSF Award Search. 2114808 (NSF).  
[https://www.nsf.gov/awardsearch/showAward?AWD\\_ID=2114808&HistoricalAwards=false](https://www.nsf.gov/awardsearch/showAward?AWD_ID=2114808&HistoricalAwards=false)



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historically funded, while activities that address the underfunded questions in the IACC strategic plan do not receive funding from the Autism CARES Act. With the exception of HRSA and the NIH, none of the agencies mentioned above receive funding from the Autism CARES act. While that is not always feasible, and many programs, supports, and services are not exclusive to autism, the current approach overwhelmingly relies on agencies' efforts to address the services and supports and lifespan issues without fully funding them.<sup>13</sup> We would like to see further investment into questions five and six among agencies that received Autism CARES Act funding.

### Autism Surveillance

The following four required elements of the strategic plan all fall under the definition of public health surveillance. Because the majority of autism surveillance efforts are conducted by the Centers for Disease Control and Prevention (CDC), we have chosen to present these elements as one section.

#### *Prevalence of Autism*

The CDC measures the prevalence of autism with the use of the Autism and Developmental Disabilities Monitoring Network (ADDM), a multi-site project tracking 4-year olds and 8-year olds in eleven sites across the country. ASAN has some concerns about differing methodologies at ADDM sites we hope to investigate further in the future. One of our concerns is the persistent racial and gender disparities in prevalence and diagnosis. We are also concerned about the continued prevalence disparities between ADDM sites, despite no evidence supporting living in a specific community should lead to differing prevalence of autism. We are also frustrated that the ADDM's only effort to establish adult prevalence of autism (ages 18-84) is through statistical modeling. It would be useful to conduct an assessment of how many adults are diagnosed with autism compared to the estimated total. The statistical modeling should consider the rise in prevalence due to improved screening and diagnostics.

#### *Average Age of Diagnosis*

The CDC also tracks the average age of autism diagnosis. The resulting racial disparities produce a phenomenon that ASAN would like to further discuss. The surveillance shows that Black and Hispanic children without intellectual disability were 30% less likely to be

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<sup>13</sup> Office of National Autism Coordination, National Institute of Mental Health, & National Institutes of Health. (2024). 2019-2020 Autism Research Portfolio Analysis Report. IACC.  
[https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio\\_analysis\\_2020.pdf?ver=0](https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio_analysis_2020.pdf?ver=0)





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identified with ASD than White children, but Black children were 50% more likely than White children to be identified with ASD and intellectual disability. ASAN would like to learn more about the diagnostic practices at the ADDM sites that lead to these disparities, as there is nothing about race or ethnicity that would be expected to have genetic or biological effects that would produce genuinely different rates of autism across these groups. The study population is also limited to children at the ADDM sites, it would be helpful to track the growth in adult diagnosis of autism as well.

#### *Average Age of Intervention*

As with the average age of diagnosis, the average age of intervention focuses on a child-only study population. We would like to see this information tracked for adults who are diagnosed later in life as well. There is also uncertainty around the definition of intervention as well and how well the Administration for Children and Families (ACF) and the CDC's methodologies align. ACF measures seemingly any service provided before the age of five. The CDC ADDM sites have differing criteria however, with all states covering education services, but only some including services provided by Medicaid and disability. Part of the issue is around data sharing agreements. Some clarity around what constitutes an intervention would be helpful. We also would like to see and encourage better data sharing among the agencies.

#### *Average Time Between Screening, Diagnosis, and Intervention*

Our concerns with the average time between screening, diagnosis, and intervention are similar to our concerns about prevalence. There are wide variances in prevalence across sites but no evidence to suggest that certain communities have higher rates of autism. For this reason, the discrepancies raise questions about the consistency of methodology and practices across the sites. We would like to see an evaluation of the methodology and practices at the ADDM sites and recommendations on how to better improve autism surveillance.

#### Effectiveness and Outcomes of Intervention

ASAN highly values federal activities dedicated to measuring the effectiveness and outcomes of interventions. The results of these efforts are what we can use to improve over time.

*Department of Health and Human Services*



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We applaud the projects at the ACL focused on improving services, the transition to adulthood, and helping people with IDD achieve competitive integrated employment. We also celebrate the launch of the Link Center, a collaboration between ACL and SAMHSA that supports programs for those with both developmental disabilities and behavioral health conditions. ASAN appreciates AHRQ's efforts to examine how to avoid behavioral health crises by exploring behavioral therapies, pharmacological treatments, and barriers to services. The lessons learned might prove useful in preventing self-injurious events, but we caution the AHRQ to only recommend approaches that respect the autonomy of the individual. Interventions that undermine autonomy are often traumatic, making future crises more likely. We would also like to acknowledge AHRQ's project on statewide early intervention care coordination. This project could result in improvements to family caregiver supports and better practices around early intervention, but we similarly caution AHRQ to be mindful of the early interventions being provided and if they are helpful to the child. HRSA's continued work with Autism Intervention Research Networks also helps us better understand existing interventions and the need for new ones, which is why ASAN reiterates the need for HRSA to use AIR-B to evaluate behavioral interventions like ABA and their potential harms and study alternative interventions. We also encourage HRSA to expand its study of communication related interventions.

ASAN appreciates the NIH's intention to improve interventions for autistic people, but we feel there is a common thread among NIH projects, as compared to the research at other agencies, that indicates the NIH is falling behind. Many of the NIH projects continue to use outdated terminology or terminology that reflects a presumed lack of competency. For example there is a subsection of the activities report titled, "Interventions for Pre-verbal and Nonverbal Children with ASD." While ASAN prefers the terms pre-speaking and nonspeaking, the aims of these studies are good, but the fact that NIH is not supporting similar studies on nonspeaking or minimally speaking adults is a problem. The NIH's research on interventions for transition-aged individuals only explores the environment surrounding study participants rather than possibilities that directly enfranchise participants like self-advocacy training. For example, the National Institute of Mental Health has invested in a parent advocacy training program for transition but not



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instruction in self-advocacy for transition-age youth.<sup>14</sup> NIH should prioritize creating such a program.

#### *Department of Defense*

ASAN has long expressed our issues with ABA and the work TRICARE has done regarding ABA interventions. We encourage TRICARE to continue to evaluate ABA interventions and recommend alternative behavioral supports. The Army has also conducted several studies of interest to ASAN. For example, the report speaks of one project where investigators at the Southwest Autism Research and Resource Center tested a multi-faceted behavioral intervention with autistic adults aged (21-70) with the goal of developing and maintaining functional independence. There are also several projects dedicated to novel interventions to treat co-occurring anxiety in autistic people. We hope to see the work of the Army studies continued and expanded.

#### *Department of Education*

ASAN would like to praise NCSE's efforts to improve classroom quality of life, quality of education, and supports for students. We would also like to acknowledge the work RSA has done to track the utilization of and eligibility for vocational rehabilitation by autistic people and people with intellectual disabilities. Both of these efforts are critical for autistic people and people with intellectual disabilities to thrive in society and live as independently as possible.

#### *Additional Thoughts*

We would also like to add that we are disappointed by the use of the term "high-functioning," in a study funded by the ACL and two studies funded by the IES to describe their study populations. The use of this label perpetuates a harmful idea that presumes lack of competence in those who require greater supports, the existence of

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<sup>14</sup> Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial. *Journal of autism and developmental disorders*, 47(3), 846–857. <https://doi.org/10.1007/s10803-016-2994-z>



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those who are inherently “low-functioning.”<sup>15,16,17</sup> This mindset can lead to bias in provision of support and flawed results due to poor study population selection.

### Home- and Community-Based Services

ASAN would like to acknowledge and applaud the report’s specific focus on home- and community-based services. ASAN is proud to see the further improvement and expansion of HCBS as we celebrate the 25<sup>th</sup> anniversary of the *Olmstead* decision that says people with disabilities have the right to live in the community.

The ACL, works closely on HCBS by funding direct supports and services, and being the overseeing federal agency for the protection and advocacy systems (P&As), the state councils on developmental disabilities (SCDDs), the centers for independent living (CILs), independent living services (ILS), and the university centers for excellence in developmental disabilities education, research, and services (UCEDDs). P&As play a vital role in helping people with disabilities navigate the legal system including how to access HCBS and helping individuals find resolution in the face of abuse and neglect. The SCDDs empower people with disabilities to live in their communities independently and become leaders, SCDDs are often involved in advocacy for HCBS. The existence of CILs enables people with disabilities to live in their community by providing ILS like skills training, peer counseling, housing and transportation assistance, and more. CILs are a crucial part of good HCBS for many people with disabilities. The UCEDDs mission is to improve HCBS through interdisciplinary education, research and policy analysis, information dissemination, and community services. Unfortunately, all of these entities are underfunded and are unable to meet demand. We encourage conversations among the agencies and IACC members about how these issues can be addressed including potential policy and legislative solutions developed by ASPE.

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<sup>15</sup> National Institute on Disability, Independent Living, and Rehabilitation Research. (2022, June). *Summer Job Story for Transition Age Youth Who Have Autism Spectrum Disorder and are Considered High Functioning*. National Rehabilitation Information Center. 90BISA0055.  
[https://naric.com/content/cf-pd-adv-srch-record?search\\_type=&officer\\_type=&record\\_id=3924&load\\_source=form\\_search&search\\_id=323837&start\\_rec=0&user\\_name=public.user.264105&load\\_form=](https://naric.com/content/cf-pd-adv-srch-record?search_type=&officer_type=&record_id=3924&load_source=form_search&search_id=323837&start_rec=0&user_name=public.user.264105&load_form=)

<sup>16</sup> IES. (2008, July). *Development of an Intervention to Enhance the Social Competencies of Children with Asperger’s/High Functioning Autism Spectrum Disorders*. IES Funding. R324A080136.  
<https://ies.ed.gov/funding/grantsearch/details.asp?ID=682>

<sup>17</sup> IES. (2013, August). *Efficacy of a Comprehensive School-Based Intervention for Children with High-Functioning Autism Spectrum Disorders (HFASDs)*. IES Funding. R324A130216.  
<https://ies.ed.gov/funding/grantsearch/details.asp?ID=1416>



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Where ACL oversees many of the actors that enable community living, CMS oversees HCBS. CMS has demonstrated its belief in HCBS' continued importance through the HCBS Special Projects, the establishment of the HCBS Quality Measure Set, and the release of Medicaid Access and Managed Care rule. ASAN appreciates CMS dedication. We also applaud CMS' benefits for health homes and the Money Follows the Person program. We ask that CMS continue to innovate and improve HCBS. We call on Congress to provide the necessary funding by extending the ARPA funding with the HCBS relief act and making the Money Follows the Person program permanent.

ASAN appreciates HUD's growing involvement with HCBS through Section 811 project rental assistance which requires the cooperation of state housing and Medicaid agencies to ensure affordable housing is accessible to those with the greatest need. The Housing and Services Partnership Accelerator is an exciting development, and we hope to see quality housing supports and services developed to address risk of homelessness among Medicaid-eligible people with disabilities and older adults. We would also like to draw attention to the recent successes of the Mainstream Voucher program. As of 2024, it is now the most utilized Special Purpose Voucher program, when only a few years ago it was severely underutilized. We ask HUD to collect data on who the mainstream voucher recipients are and to provide clarity on how they are evaluating the program. It is critical that any evaluation includes what share of program beneficiaries are people with disabilities who are at risk of or transitioned out of institutionalization. This success demonstrates the value of interagency coordination and data-driven policy monitoring and we hope to see the IACC facilitate more activities with this in mind.

ASAN appreciates the Department of Labor's growing involvement in supporting HCBS through workforce development programs, supported employment, and career planning services as more states include employment and work readiness supports as eligible HCBS services. The REYAAS report's comprehensive findings on how autistic people experience vocational rehabilitation systems is incredibly valuable for our advocacy.

While the Office of Management and Budget is not part of the IACC we call on it to establish a unique standard occupational classification code for direct support professionals ahead of the standard 2028 review. This would strengthen the direct support workforce by improving data collection and allowing for better billing for care delivered as part of HCBS and long-term services and supports. We also ask all agencies to continue and increase their investments in HCBS and to better educate the public and



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Congress about the benefits of quality HCBS and the improved outcomes for those who receive it. We hope the agencies will continue to provide support and develop innovative policy solutions for care delivery to uphold the individuals' right to live in the community as established in *Olmstead*.

### Implementation of the IACC Strategic Plan

Since the last activities report, the federal government has improved at implementing the IACC's strategic plan. We appreciate that the IACC continues to recognize gaps in lifespan, evidence-based interventions, and disparities in services and the need for more services and supports research.<sup>18</sup> However, activities that covered the whole lifespan of autistic people were lacking (e.g. all the NIH intervention effectiveness and outcomes research across the lifespan had study populations transition-aged or younger). IACC must do more to support investigations of the impacts of aging, how to measure the real prevalence of autistic adults, and the utilization of services. Additionally, while federal activities around supports and services have increased, funding for research on those supports and services have come from outside action and advocacy, not from Autism CARES funding. Congress needs to provide more funding for supports and services and the IACC needs to award more research projects focused on direct supports and services. While the delivery of these supports and services as most are not autism-specific should be external, there should be more dedicated research to their improvement with CARES funding being dedicated to services and supports for autistic people and people with ID. We would also like to reiterate our request from our last public comments for the IACC to produce regular progress reports regarding adherence to strategic plan and project funding with option for comment.<sup>19</sup> This would serve as a key measure for accountability and will allow for faster innovation and improvement in supports, services, interventions for autistic people and their health, well-being, and independence.

### **Concluding Remarks**

ASAN thanks the IACC for inviting interested stakeholders to comment and help the IACC improve the lives of autistic people. For more information on ASAN and our priorities, please visit our website at [www.autisticadvocacy.org](http://www.autisticadvocacy.org).

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<sup>18</sup> Office of National Autism Coordination, National Institute of Mental Health, & National Institutes of Health. (2024). 2019-2020 Autism Research Portfolio Analysis Report. IACC.

[https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio\\_analysis\\_2020.pdf?ver=0](https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio_analysis_2020.pdf?ver=0)

<sup>19</sup> Poulos, J. (2024, April 17). *Comments for the April 17th IACC Meeting - Autistic Self Advocacy Network*. Autistic Self Advocacy Network.

<https://autisticadvocacy.org/2024/04/comments-for-the-april-17th-iacc-meeting/>