



2021 Report to Congress

on the Health and Well-Being of Individuals with Autism Spectrum Disorder (ASD)

Under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019

Prepared by the
Office of Autism Research Coordination
National Institutes of Health

On Behalf of the
Office of the Secretary
Department of Health and Human Services



Cover Design

Medical Arts Branch, Office of Research Services, National Institutes of Health

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Suggested Citation

U.S. Department of Health and Human Services, National Institutes of Health, Office of Autism Research Coordination (on behalf of the Office of the Secretary). *2021 Report to Congress on the Health and Well-Being of Individuals with Autism Spectrum Disorder (ASD), under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019*. September 2021. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <https://iacc.hhs.gov/publications/report-to-congress/2021/>

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September 2021

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BACKGROUND



Introduction

AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a developmental disability (DD) identified in 1 in 54 children¹ and approximately 2% of adults.² Autism causes challenges in areas including social interaction and communication, executive functioning, sensory processing, and motor coordination. These differences can impact social relationships and other aspects of daily living. Each individual on the autism spectrum has a distinct and unique set of strengths and difficulties and may need varying levels of support in different areas. For example, some individuals on the autism spectrum have accompanying language and/or intellectual disabilities (ID) or other co-occurring physical or mental health conditions that may result in additional challenges and require specialized supports across the lifespan. Data from the Centers of Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM) Network indicate that 33% to 53% of children on the autism spectrum have co-occurring ID.^{1,3}

Research using brain imaging techniques suggests that differences in development indicative of ASD may be observed as early as 6 months of age.⁴ However, overt signs and traits of ASD usually emerge between 1 and 2 years of age,⁵ though official diagnosis may be delayed even further until adolescence or adulthood due to missed diagnoses earlier in life, particularly among those without intellectual disabilities, girls, and racial minorities.⁶⁻¹⁰ Because ASD is a lifelong condition, and the combination and degree of characteristics can differ greatly from one individual to another, its associated challenges and support needs can range from modest to very extensive.

Services and supports are available to help maximize health and well-being among children and adults on the autism spectrum, but the needs for earlier identification, improved interventions, and broadly available access to services remain issues to be addressed.

ASD continues to be a top national health priority. Federal agencies, private research and services organizations, advocacy groups, academia, state and local agencies, and other entities engage in collaborative efforts to advance ASD research and improve relevant services and support systems. This Report describes the efforts supported by federal departments and agencies to address research, health, education, and social services that will improve health and well-being among children, adolescents, and adults on the autism spectrum.

HEALTH AND WELL-BEING ISSUES EXPERIENCED BY INDIVIDUALS WITH ASD

Autistic individuals often have many health concerns, both due to the defining characteristics of autism, as well as physical and mental health conditions that often co-occur in this population. An analysis of CDC's 2010 ADDM Network data found that the mean number of co-occurring conditions or symptoms among children on the autism spectrum was 4.9 per child among 8-year-olds and 3.8 per child among 4-year-olds, with 98% and 96% of children, respectively, having at least one co-occurring condition or symptom.¹¹ Additional research has demonstrated that autistic individuals are more likely to experience conditions such as epilepsy, gastrointestinal issues,

Please note: The terms “individuals with autism,” “individuals with ASD,” “autistic individuals,” and “individuals on the autism spectrum” are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The Department of Health and Human Services (HHS) respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the terms “autism” and “autism spectrum disorder (ASD)” are used interchangeably throughout this document unless otherwise noted. In cases where the specific DSM-5 defined diagnosis of autism spectrum disorder (ASD) is discussed, that term is used.

sleep disturbances, depression, anxiety, and other mental health conditions.^{11,12,13} Appropriate treatment for these conditions is critical in order to improve the overall well-being of autistic individuals. Co-occurring physical and mental health conditions have been documented in research^{14,15,16} as an important factor that can reduce quality of life for people on the autism spectrum when not acknowledged, recognized, and properly addressed. These conditions may contribute to the shortened lifespans of individuals on the autism spectrum compared to the general population.¹⁷ (For more information on demographic factors associated with the health and well-being of individuals with ASD, see the **Demographic Factors** section of this Report.)

Additionally, there is a need to address the challenges faced by autistic individuals and their families for adequate health care services and supports (both private and public) and to reduce barriers to access for existing services and supports.¹⁸ In particular, advocates have highlighted the shortage of adequately trained primary care providers, specialists, and acute care providers who are familiar with ASD and its common co-occurring conditions. Many individuals on the autism spectrum also experience difficulties transitioning from pediatric to adult health care, as few adult care physicians and adult mental health professionals are trained to treat autistic patients.^{18,19} Availability of trained personnel who can address health needs across the lifespan and access to health care services continue to present challenges for autistic individuals. There are also racial disparities in ASD diagnosis and access to care. For example, despite recent progress, Black children are typically evaluated for ASD later than White children.¹⁸ Additionally, studies have shown that Black, Asian, and Native American/Pacific Islander children with ASD receive fewer outpatient services compared with White children.²⁰

Advocates have also cited the importance of social determinants of health, including access to social opportunities and inclusion in all aspects of community living, as important contributors to well-being among autistic individuals.^{21,22} **Social determinants of health** describe how the conditions in which people live,

including health care access and quality, education access and quality, social and community context, economic stability, and the surrounding neighborhood and built environment, impact health and well-being. For example, access to special and general education classes, with appropriate accommodations and supports, is vital to ensure that individuals on the autism spectrum are given the opportunity to develop their abilities and potential.²³ Of particular importance is the need to prepare students to transition out of school and into higher education, employment, and/or community living.²⁴ Lack of suitable employment opportunities and necessary accommodations remain commonly experienced obstacles to successful transition and independent living.^{25,26,27} Given the spectrum of abilities of autistic individuals, increased housing options that can provide a wide range of supports are also needed. In addition, characteristics associated with ASD, such as “stimming” or communication difficulties, can potentially lead to negative experiences in interactions with police.^{28,29} Innovative and continued police training programs are necessary to ensure public safety and improve interactions between the autism community and law enforcement. It is necessary to address the social determinants of health,³⁰ which include these and other environmental factors, such as food³¹, economic security for individuals on the autism spectrum and their families, and ensuring access to public transportation,³² in order to improve the overall health and well-being of autistic individuals and their families.

LEGISLATIVE BACKGROUND: THE AUTISM CARES ACT OF 2019

The Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act) of 2019 (**Public Law 116-60**) was signed into law on September 30, 2019. The Autism CARES Act of 2019 reauthorized the ASD-related activities that began in 2006 under the Combating Autism Act (CAA) and continued under the Combating Autism Reauthorization Act (CARA) in 2011 and the Autism CARES Act of 2014, thus continuing support for federal programs related to ASD research and services.

The Autism CARES Act of 2019 authorized \$1.8 billion in federal funds to sustain support for activities related to ASD research and services through 2024. The Autism CARES Act of 2019 also requires the preparation and submission of two Reports to Congress detailing federal activities relevant to ASD, including this Report concerning the health and well-being of individuals with ASD.

PROVISIONS OF THE AUTISM CARES ACT OF 2019

The Autism CARES Act of 2019 includes the following provisions:

- Continues efforts in autism surveillance, research, education/awareness, early detection, and intervention, including efforts to increase cultural competency and provider training across several federal departments/agencies.
- Reauthorizes the Interagency Autism Coordinating Committee (IACC) to coordinate federal agencies in ASD-related efforts, serve as a forum for public input, and provide advice to the Secretary of the Department of Health and Human Services (HHS) on matters pertaining to ASD. Mandates the addition of the U.S. Departments of Housing and Urban Development, Justice, Labor, and Veterans Affairs to the membership of the IACC.
- Requires a Report to Congress on federal activities related to health and well-being in individuals with ASD.
- Requires a Report to Congress on activities related to autism spectrum disorder, including progress made in implementing the provisions of the Autism CARES Act of 2019.
- Authorizes \$1.8 billion in appropriations for federal ASD-related efforts through September 30, 2024.
- The role of National Autism Coordinator (NAC), originally mandated by the Autism CARES Act of 2014, continues within HHS to “oversee, in consultation with the Secretaries of Defense and Education, national autism spectrum disorder research, services, and support activities,” “implement autism spectrum disorder activities,

taking into account the strategic plan developed by the IACC,” and “ensure that autism spectrum disorder activities of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative.”

REPORT TO CONGRESS ON THE HEALTH AND WELL-BEING OF INDIVIDUALS WITH ASD

The following elements of this Report are required by the Autism CARES Act of 2019:

- A** “Demographic factors associated with the health and well-being of individuals with autism spectrum disorder;”
- B** “An overview of policies and programs relevant to the health and well-being of individuals with autism spectrum disorder, including an identification of existing Federal laws, regulations, policies, research, and programs;”
- C** “Recommendations on establishing best practices guidelines to ensure interdisciplinary coordination between all relevant service providers receiving Federal funding;”
- D** “Comprehensive approaches to improving health outcomes and well-being for individuals with autism spectrum disorder, including (i) community-based behavioral supports and interventions; (ii) nutrition, recreational, and social activities; and (iii) personal safety services related to public safety agencies or the criminal justice system for such individuals;” and
- E** “Recommendations that seek to improve health outcomes for such individuals, including across their lifespan, by addressing (i) screening and diagnosis of children and adults; (ii) behavioral and other therapeutic approaches; (iii) primary and preventative care; (iv) communication challenges; (v) aggression, self-injury, elopement, and other behavioral issues; (vi) emergency room visits and acute care hospitalization; (vii) treatment for co-occurring physical and mental health conditions; (viii) premature mortality; (ix) medical practitioner training; and (x) caregiver mental health.”

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

- Physical vitality and fitness;
- Behavioral and mental health;
- Access to ASD-related services and supports (health care, Social Security, etc.); and
- Sense of belonging, inclusion, and participation in meaningful activities, relationships, and community life (appropriate employment, education, housing, transportation, safety, social inclusion, etc.).

This *2021 Report to Congress on the Health and Well-Being of Individuals with Autism Spectrum Disorder (ASD)* describes ASD-related activities and coordination efforts spanning multiple federal agencies and departments that include research on demographic factors associated with ASD, address different social determinants of health and support the health and well-being of autistic individuals, including during the coronavirus disease 2019 (COVID-19) pandemic, and includes recommendations on efforts and activities to improve the health and well-being of individuals on the autism spectrum. This Report includes information submitted by the Departments of Health and Human Services, Defense, Education, Housing and Urban Development, Justice, Labor, Transportation, and Veterans Affairs, as well as the Environmental Protection Agency, National Science Foundation, and Social Security Administration. All departments, agencies, divisions, and offices contributing to this Report conduct activities related to individuals with ASD and/or target intellectual and developmental disabilities (IDD) more broadly while including ASD as a significant focus. The Report covers all elements required in the Autism CARES Act of 2019 for the period of fiscal years (FY) 2018, 2019, 2020, and 2021. Information for FY 2021 may not be complete, as this Report was still in preparation during FY 2021.



REQUIRED ELEMENTS



Required Elements of the Report to Congress on the Health and Well-Being of Individuals with ASD

This Report to Congress provides an overview of federal research, services, and support activities that seek to improve the health and well-being of individuals with ASD and other DD. In addition, demographic information about the health and well-being of these individuals and recommendations for further federal activities are provided.

With data from over 20 federal departments, agencies, divisions, and offices, this Report addresses ASD research and services according to the required elements outlined in the Autism CARES Act of 2019 (see [page 3](#) for a complete list of required elements). Elements (B) and (D) and have been combined into one chapter covering the current federal policies, programs, and comprehensive approaches to understand and improve the health and well-being of autistic individuals. Elements (C) and (E) have been combined into one chapter covering recommendations to ensure interdisciplinary coordination between all relevant service providers receiving federal funding and for further federal activities to continue improving health and well-being for individuals with ASD.

The following federal departments, agencies, divisions, and offices are included in this Report:

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)
- HHS 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)
- HHS Office of Disease Prevention and Health Promotion (ODPHP)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

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)

Interagency Coordination

- Interagency Autism Coordinating Committee (IACC)
- HHS National Autism Coordinator (NAC)

Demographic Factors Associated with the Health and Well-Being of Individuals with ASD

This portion of the Report covers Section 399DD(b) (2)(A) of the Public Health Service Act, as amended by the Autism CARES Act of 2019, which requires: information on (A) “demographic factors associated with the health and well-being of individuals with autism spectrum disorder.” Approximately 1 in 54 children in the U.S. has been identified with ASD according to CDC’s ADDM surveillance data.¹ In addition to the CDC, prevalence and demographics data are also collected by other agencies using a variety of methods in different subpopulations of the autism community, covering different perspectives and giving rise to more nuanced data on the prevalence of ASD in different communities. To present an overview of currently available demographic information, the following section presents information on demographic factors provided by the ACL, CDC, CMS, HRSA, NIH, ED, and EPA.

DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

Administration for Community Living (ACL)

An ACL analysis of existing Medicare administrative claims data for calendar year 2016³³ has yielded the following insights into the health care needs of individuals with ASD, though findings from these data are not generalizable to or representative of all individuals with ASD.

Key Findings

- Medicare fee-for-service (FFS) provided service coverage for 69,844 people with ASD in 2016. This group represented 14.4% of individuals with IDD receiving Medicare FFS and 0.46% of all Medicare FFS beneficiaries.
- In 2016, the large majority of people with ASD (97.4%) who received Medicare FFS qualified for it by disability determination; only 2.3% qualified based on age. In contrast, 7.6% of all individuals with IDD (“Total IDD” as illustrated in **Figure 1**) qualified for Medicare FFS based on age.
- Overall, people with ASD were under 65 years old (92.4%), male (73.7%), White (76.3%), dually eligible or partially dually eligible for Medicare and Medicaid (86.6%), and lived in metropolitan areas (83.8%). Compared to those with ASD, fewer people with IDD overall were under 65 (77.7%), male (56.1%), and lived in a metropolitan area (78.7%). However, the proportion of those with IDD who were White (75.9%) and those who had dual eligibility (85.4%) were similar to those with ASD.

Chronic Health Conditions

People with ASD receiving Medicare FFS had high prevalence of congestive heart failure (CHF) (9.3%), chronic obstructive pulmonary disorder (COPD; 9.4%), diabetes (23.0%), hypertension (38.4%), and obesity (20.7%). However, these rates were substantially lower than prevalence for people with IDD overall receiving Medicare FFS for CHF (20.3%), COPD (20.6%), diabetes (32.4%), and hypertension (55.8%). Gross comparisons of these prevalence rates to the U.S. general population³⁴ shows that they range from 0.5 (obesity) to 2.7 (diabetes) times higher among people with ASD.

PREVALENCE OF CHRONIC HEALTH CONDITIONS

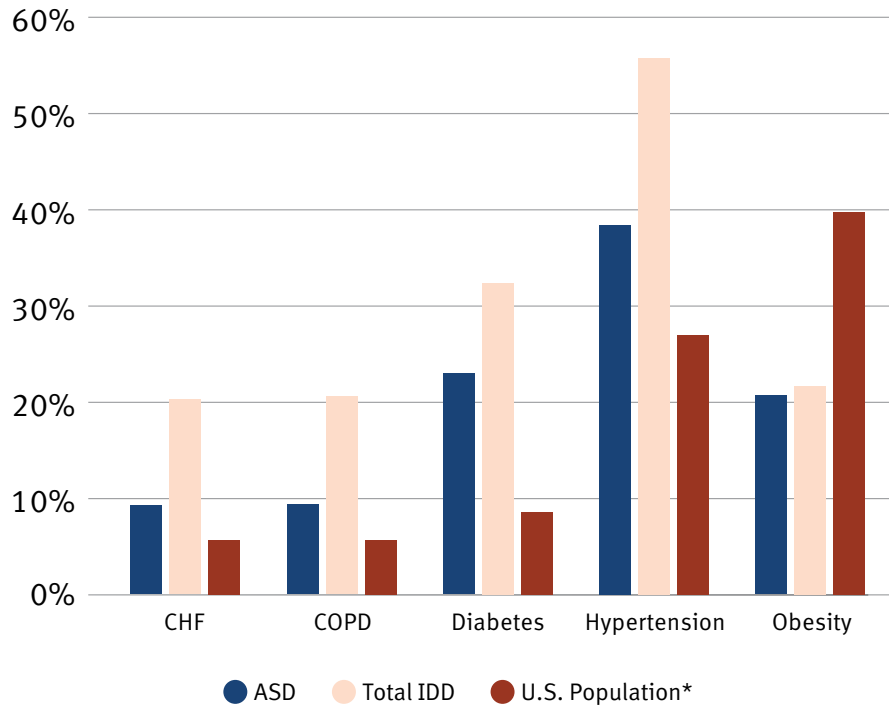


Figure 1

ACL: Prevalence of Chronic Health Conditions Among ASD and Total IDD Medicare FFS Recipients,^v with Gross Comparison to General U.S. Population*

^v = A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, cerebral palsy (CP), intellectual development, learning disability, or other development delay.

* = Gross comparison of current national statistics of the U.S. general population.³⁴

Mental Health

Prevalence of mental health disorders among people with ASD receiving Medicare FFS were high compared to all people with IDD supported by Medicare

FFS (**Figure 2**). Moreover, these prevalence rates were much higher than the prevalence of mental health disorders in the general U.S. population (gross comparison).³⁵

PREVALENCE OF MENTAL HEALTH DISORDERS

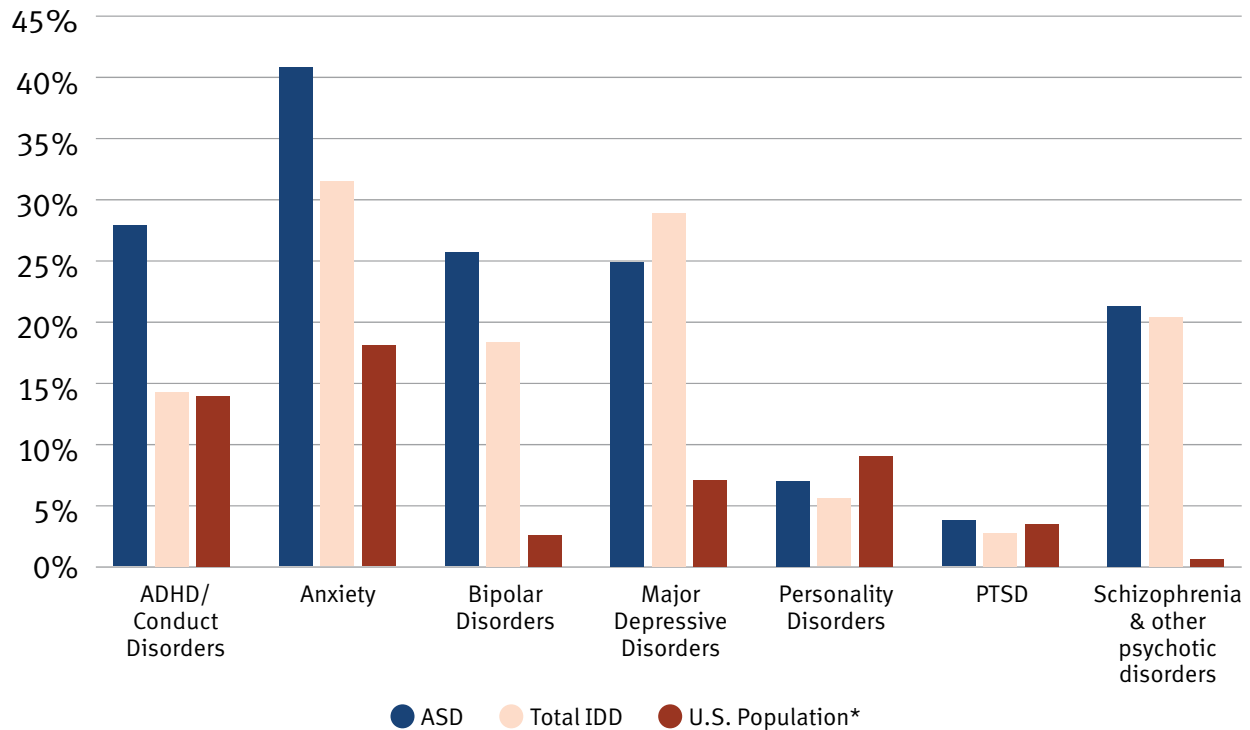


Figure 2

ACL: Prevalence of Mental Health Disorders Among ASD and Total IDD Medicare FFS Recipients,^v with Gross Comparison to General U.S. Population*

^v = A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

* = Gross comparison of current national statistics of the U.S. general population.³⁵

Health Outcomes

- Among people with ASD who had a hospital stay, 1.8% of those under 65 years of age died within 30 days of the hospitalization. This proportion was substantially higher than for people with IDD overall who were under the age of 65 (0.7%) but similar to those with IDD who were 65+ years old (1.7%).
- Almost 43% of people with ASD used the emergency department for outpatient care. Again, this proportion was similar to that for people with IDD overall who were 65+ (43.8%) and higher than that for people with IDD under the age of 65 (38.1%).
- Among those who used emergency departments for outpatient care, 6.7% of people with ASD under the age of 65 and 7.6% of people with IDD overall were considered high utilizers of this type of care.

Centers for Disease Control and Prevention (CDC)

CDC's Child Development and Disability Branch in the Division of Human Development and Disability conducts research to improve the understanding of the factors associated with the development of autism and the health and well-being of children with autism through the Study to Explore Early Development (SEED). SEED is a multi-year, multi-site, case-control study comparing children aged 2 to 5 years with ASD to children with other DD and children from the general population.

The objectives of SEED are to (1) assess the etiologic (causal) risk factors for ASD; (2) describe the phenotypic variability (differences in observable characteristics) of ASD; and (3) assess the health and health care needs of children with ASD. Through this study, CDC has collected detailed data on family sociodemographics, pregnancy and early childhood exposures, child health developmental characteristics, and use of services by families and their children.

Since 2007, more than 6,000 children and their families completed SEED Phase 1-3 data collection, including more than 1,700 children with ASD. While data collection was recently completed for SEED Phase 3, 60 peer-reviewed manuscripts have been published to date using SEED Phase 1 and Phase 2 data. Manuscripts published in the past three years specifically addressing the health and developmental characteristics of children with ASD, use of services among families and children with ASD, and the etiology of ASD are listed in **Appendix II**.

Additionally, in 2020, as part of SEED Phase 3, CDC collected information on the impact of COVID-19 on services, behaviors, and health to help inform public health strategies for children with ASD aged 3 to 9 years and their families, especially during public health emergencies. In-person assessments for ASD were suspended due to COVID-19, but CDC amended the study protocol to collect information to describe the impact of COVID-19 prevention efforts on children with ASD and their families compared to changes among children with other DD and children from the general population. Outcomes of interest among

children included education and use of remote learning; changes in use of services and telemedicine; experiences with testing and mitigation strategies; and changes in routines, health, and well-being. Outcomes of interest among families included changes in household structure; health and well-being; finances, employment, and health insurance; changes in routines and support; and experiences with COVID-19 infection. Additionally, the study measured changes in behavior problems and everyday life skills among children before and after COVID-19.

CDC's Autism and Developmental Disabilities

Monitoring (ADDM) Network is the only collaborative network that tracks the number and characteristics of children with ASD in communities across the U.S. While past reports from the ADDM Network have consistently found that more White children are identified with ASD than Black or Hispanic children, more recent data have shown progress in closing racial and ethnic disparities gaps in the identification of ASD. However, more work is needed to improve identification of ASD within certain communities. Previous studies have shown that stigma, lack of access to health care services, and non-English primary language are potential barriers to identification of children with ASD, especially among Hispanic children. ADDM Network data have also shown racial and ethnic differences in the types of co-occurring conditions documented among children with ASD in particular; the most recent **ADDM Network reports** (March 2020) show that Black children identified with ASD are much more likely to have co-occurring ID than White children with ASD. Black children were also less likely to receive a developmental evaluation by 36 months than White or Hispanic children. Differences in identifying children with ASD means that certain groups of children may not be getting the timely services they need to reach their full potential. ADDM Network data can help inform targeted outreach within these communities and promote efforts to have all children screened for ASD.

In 2020, the ADDM Network initiated a pilot project at a majority of ADDM sites to conduct low-cost statewide ASD surveillance using record linkages. Participating states will link multiple data sources to

generate autism prevalence estimates for the state and each county in the state for children who were between the ages of 3 and 21 years in 2018. This project will explore the feasibility of conducting low-cost statewide ASD surveillance, compare results to areas overlapping with ongoing ADDM surveillance, and provide county-level information to communities with no local data concerning ASD surveillance.

Centers for Medicare & Medicaid Services (CMS)

Children with ASD are a subgroup of children with special health care needs. In 2017, **Medicaid** and the **Children's Health Insurance Program (CHIP)** covered 47% of the 13.3 million children with special health care needs. Thirty-nine percent were covered by Medicaid and CHIP only, and an additional 8% were covered by a mix of both public and private insurance.

Among the 6.1 million children with special health care needs covered by Medicaid and CHIP, 21% are age 5 or younger, 38% are 6 to 11 years old, and 41% are 12 to 17 years of age. Thirty-seven percent are non-Hispanic White, 27% are non-Hispanic Black, 8% are other non-Hispanic, and 28% are Hispanic. The household income of almost half (45%) of the families of children with special health care needs was below the federal poverty level.³⁶

Equivalent data is not available for adults.

Health Resources and Services Administration (HRSA)

Information about health care access among children and youth with ASD/DD is available from the HRSA-funded and directed **National Survey of Children's Health (NSCH)**. The NSCH is an annual, nationally representative survey that provides a unique source of national and state-level data on child health and health care, including health care access for children and youth with ASD/DD. The NSCH collects parent-reported information on whether the child ever received an ASD diagnosis by a care provider, current ASD status, health care use, access and challenges, and methods of treatment. A 2018 paper³² using the NSCH examined the national

prevalence of ASD among children ages 3 to 17, as well as health care access, health care experiences, and factors associated with increased likelihood of receipt of medication and behavioral treatment.

Data from the NSCH indicates that approximately 1 in 40 children in the U.S. are diagnosed with ASD.³⁷ Boys have a 3.46 times higher prevalence of ASD than girls even after adjusting for selected sociodemographic and birth characteristics. ASD prevalence is 47% higher for children with single mothers than children in two-parent, married households, 2.06 times as high for children from households with income at less than 100% of the federal poverty level compared with children from households at more than 400% of the federal poverty level, and 71% higher in children born preterm than term. ASD prevalence is 2.34 times higher for U.S.-born versus foreign-born children. Children with ASD have more needs and difficulties regarding health care access and use compared to children without ASD but who have other emotional behavioral disorders. Further, the study found that 27% of children with ASD were given medication to treat certain symptoms of ASD in the past year, and 64% received behavioral interventions.

National Institutes of Health (NIH)

Some NIH-funded research studies may address demographic, social, and other factors that can affect the risk of ASD. For example, lower income, minority, and rural families receive a diagnosis of ASD up to 1.5 years later than other families and are more likely to miss the window of opportunity for early intervention. Researchers funded by the *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)* are focusing on the development of a telehealth screener and assessment to improve early screening for ASD in toddlers and identify factors that contribute to disparities in screening and surveillance in diverse communities (**R01HD039961**). Despite scientific advances and investments, addressing health disparities in access to evidence-based early intervention for children with ASD remains a major challenge. Using a new interdisciplinary network of eight research institutions, NICHD-funded scientists

are studying individual and combined effects of two evidence-based interventions in real world settings (**R01HD093055**). The first engages families to access resources and support when they first learn their child has signs of ASD, using an evidence-based intervention that integrates motivational interviewing and problem-solving education. The other involves coaching families to embed evidence-based intervention strategies in everyday activities for toddlers with ASD. The National Institute of Mental Health (NIMH) supports research aimed at developing and testing service system interventions that can be broadly implemented and rapidly engage young children with ASD in evidence-based treatment and services early in life. A number of NIMH-funded research projects focused on early intervention for ASD also aim to address health disparities that medically underserved families from diverse racial and ethnic groups face in their efforts to access ASD screening and treatment interventions (e.g., **R01MH104423**, **R01MH104400**, **R01MH104355**, **R21MH118539**, **R21MH120349**).

Department of Education (ED)

In school year (SY) 2019, there were 716,382 children ages 3 through 5 (not in kindergarten) served under Part B, section 619 of the Individuals with Disabilities Education Act (IDEA), which provides IDEA services for preschool-aged children with disabilities. The percentage of preschool children with disabilities identified with autism was approximately 11%. In SY 2019, a total of 6,561,998 students ages 5 (in kindergarten) through 21 were served under IDEA, Part B. The percentage of children ages 5 (in kindergarten) through 21 with disabilities identified with autism was approximately 11%. The number and percentage of school-aged children with ASD served under Part B of the IDEA has steadily increased over the years. During SY 2008-2009, approximately 5% of children with disabilities ages 6 through 21 were served under the category “autism,” and, during SY 2019-2020, it was approximately 11% of children with disabilities ages 5 (in kindergarten) through 21.

In SY 2019-2020, only 40% of students identified with ASD were served inside the regular class 80% or more of the day, compared to 65% of all students with

disabilities, indicating that students with ASD are more likely to be served in more restrictive educational environments, such as separate classrooms or separate schools. In SY 2018-2019, students identified with ASD were less likely to be suspended/expelled than children identified with emotional disturbance or other health impairment and more likely to be suspended/expelled than students who are deaf/blind or with orthopedic impairment. In SY 2018-2019, among students aged 14 to 21 and exiting school, students identified with ASD were less likely to drop out and more likely to receive a certificate than all students with disabilities.

Environmental Protection Agency (EPA)

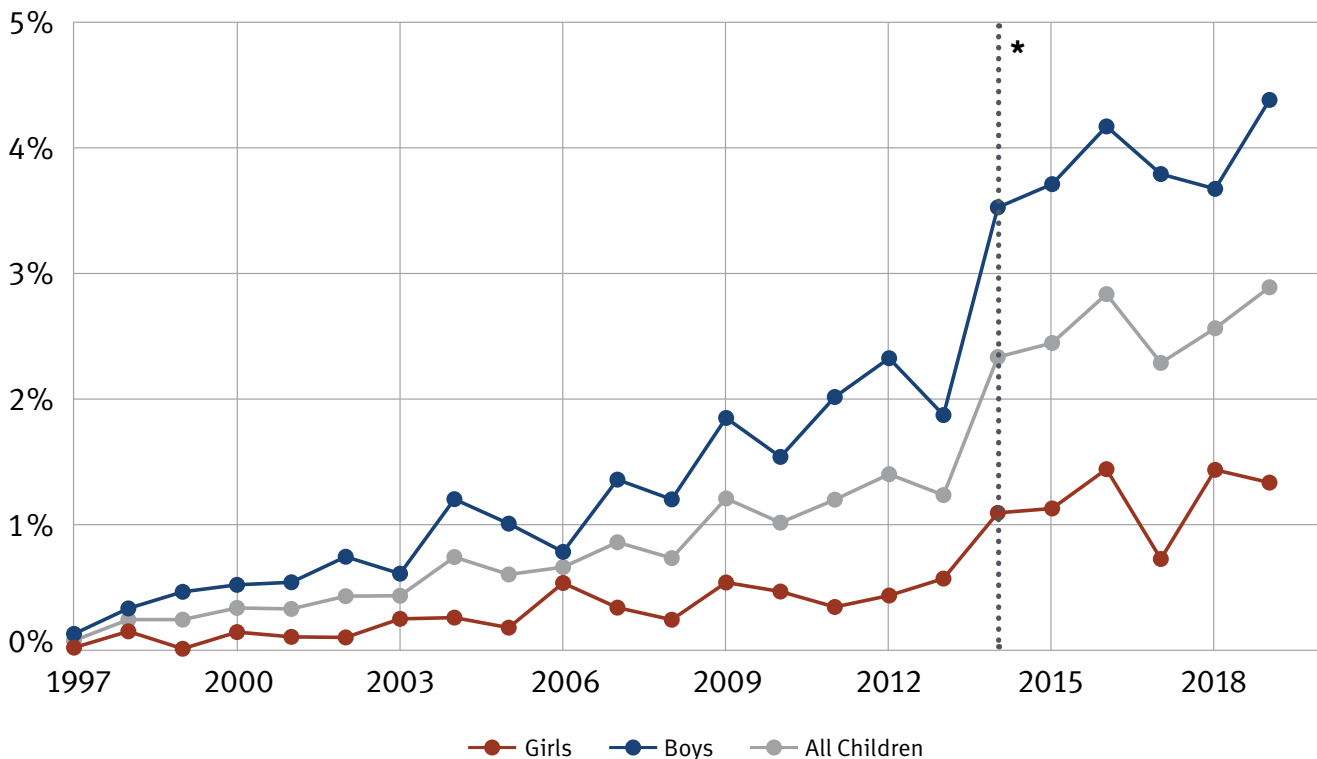
EPA’s **America’s Children and the Environment (ACE) Report** was first initiated by EPA in 2000 and brings together environmental, biomonitoring, and health data from a variety of sources to provide national-level indicator data and related information on the environment and children’s health. The goal of the *ACE Report* indicators is to better understand the impact environmental hazards have on children and educate policy makers, state and local environmental health partners, and the public on trends and areas that need further attention.

For the *ACE Report*, EPA analyzes and summarizes autism prevalence data from children ages 5 to 17, including survey data first collected in 1997 through 2019, the most for which data is available. Data for the autism indicator are obtained from an annual survey conducted by the CDC’s National Center for Health Statistics (NCHS). The survey consists of a parent or other knowledgeable adult in each sampled household being asked questions regarding the child’s health status, including if they have ever been told the child has autism. From 2011 to 2013, the term “autism” in the survey was revised to “autism/autism spectrum disorder.” Beginning in 2014, the term “autism” in the survey was revised to “autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder.” **EPA’s review and summary of the autism indicator**, as part of the *ACE Report*, provides more details.

From 1997 to 2013, the percentage of children ages 5 to 17 years reported to have ever been diagnosed with autism rose from 0.1% to 1.2%. This increasing trend is statistically significant. Between 2014 and 2019, the rates of reported autism ranged from 2.3% to 2.9%. The higher reported percentages in these years might be due in part to the recent broadening of the definition of autism used in the survey question, as discussed on the previous page. **Figure 3** below provides an overview of autism prevalence over time, based on data obtained from NCHS, including 2019 survey data.

Since 1999, the percentage of children reported to have autism in the U.S. has increased by 12-fold. For the year 2019, the rates of autism reported were approximately 3.3 times higher for boys than for girls, at 4.4% and 1.3%, respectively. This difference is statistically significant. Puerto Rican children (4.6%) had the highest rates of autism, followed by American Indian/Alaska Native (AI/AN) children (3.8%), White children (2.9%), Black children (2.7%), Hispanic children (2.3%), Mexican children (2%), and Asian children (1.7%). The prevalence of autism in 2019 was similar for children living below the poverty level (2.8%) and those living at or above the poverty level (2.6%).

AUTISM PREVALENCE BY GENDER (1997 - 2019)



EPA: Prevalence Rates of Autism by Gender from 1997 to 2019

Figure 3

Data for the autism indicator are obtained from an ongoing annual survey conducted by the NCHS. * In 2014, in the survey the term “autism” was revised to “autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder.”

Current Federal Policies, Programs, and Comprehensive Approaches to Improve the Health and Well-Being of Individuals with ASD

This chapter covers Sections 399DD(b)(2)(B) and (D) of the Public Health Service Act, as amended by the Autism CARES Act of 2019, which require: (B) “an overview of policies and programs relevant to the health and well-being of individuals with autism spectrum disorder, including an identification of existing Federal laws, regulations, policies, research, and programs” and (D) “comprehensive approaches to improving health outcomes and well-being for individuals with autism spectrum disorder, including (i) community-based behavioral supports and interventions; (ii) nutrition, recreational, and social activities; and (iii) personal safety services related to public safety agencies or the criminal justice system for such individuals.” Details are provided from the departments, agencies, divisions, and offices that are involved in research and services activities that directly or indirectly involve individuals with ASD, including HHS offices and agencies ACF, ACL, AHRQ, ASPE, CDC, CMS, HRSA, IHS, NIH, ODPHP, and SAMHSA, as well as DoD, ED, EPA, HUD, DOJ, DOL, NSF, SSA, DOT, and VA. The activities described include those undertaken in response to the COVID-19 pandemic to promote the health and well-being of autistic individuals.

DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

The mission of the **Department of Health and Human Services (HHS)** is to enhance and protect the health and well-being of all Americans by providing effective health and human services and fostering advances in medicine, public health, and social services. HHS includes more than 300 programs and 11 operating divisions covering a wide spectrum of activities. The HHS offices and agencies represented in this Report support research and services that address the needs of individuals on the autism spectrum and their families.

Administration for Children and Families (ACF)

The **Administration for Children and Families (ACF)** promotes the economic and social well-being of families, children, individuals, and communities. ACF programs aim to:

- Empower families and individuals to increase their economic independence and productivity;
- Encourage strong, healthy, supportive communities to have a positive impact on quality of life and the development of children;
- Improve access to services through planning, reform, and integration;
- Create partnerships with front-line service providers, states, localities, and tribal communities to identify and implement solutions that transcend traditional program boundaries; and
- Address the needs, strengths, and abilities of vulnerable populations including people with DD, refugees, and migrants.

The ACF does not have any programs or funding specifically focused on provisions of the Autism CARES Act of 2019 or for promoting the health and well-being of individuals on the autism spectrum. However, ACF funds several offices and projects that support inclusion of young children with disabilities, including those with ASD.

The ACF **Office of Head Start (OHS)** promotes the school readiness of children ages birth to 5 from low-income families by enhancing their cognitive, social, and emotional development. According to the 2019 Head Start (HS) **Program Information Report (PIR)**, 0.53% of total HS enrollment were children diagnosed with ASD. These children and their families received HS’s comprehensive services in inclusive settings. The **OHS Training and Technical Assistance**

Centers carry out significant work and activities that promote inclusion of children with disabilities, including those with ASD who are served in Early Head Start (EHS) and HS settings. OHS maintains the **Head Start Center for Inclusion** website, which offers a variety of resources that support early childhood educators to ensure that children with disabilities can participate as full members of their learning communities. OHS also maintains the disabilities services section of the **Early Childhood Learning and Knowledge Center** website which includes evidence-based resources that promote early identification, referrals, family support services, cross-agency collaboration, and resources related to access and full participation of young children with disabilities in inclusive learning environments.

The ACF **Office of Planning, Research, and Evaluation (OPRE)** studies ACF programs and the populations they serve through rigorous research and evaluation projects. These include evaluations of existing programs, evaluations of innovative approaches to helping low-income children and families, research syntheses, and descriptive and exploratory studies. OPRE is currently conducting the **Study of Disability Services Coordinators and Inclusion in Head Start (2019 – 2024)** that will provide a descriptive national picture of the Disability Services Coordinators workforce for EHS and HS, including AI/AN (Region XI) and Migrant and Seasonal Head Start (Region XII) grantees. It will also explore practices and policies for working with staff, families, children, and the community. This effort will explore how EHS/HS serves children with disabilities and their families and will seek to understand how EHS/HS collaborates with services in the community, including health providers, Local Education Agencies, and Part C.

OPRE is also conducting the **Family and Childhood Experiences (FACES; 1997-2022)** study to provide descriptive, nationally representative information on preschool-aged children in HS in Regions I-X, and AI/AN FACES (2015-2022) provides representative information for HS in Region XI, including the characteristics, experiences, and development of children and their families and the characteristics of the HS programs and staff who serve them. This study

collects information on whether children have a disability, what type of disability (autism is grouped into the cognitive disability category), whether the children have multiple disabilities, and how many children with a disability have an Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP). Likewise, the **Early Head Start Family and Child Experiences Survey (Baby FACES; 2009-2023)** reports on the percentage of children in EHS programs in Regions I-X that have any special needs, the type of special needs (e.g., developmental disability or delay), and the percentage of children with an IFSP.

ACF maintains a webpage, “**Autism Awareness and Acceptance in Early Childhood Education**,” which focuses on providing information on ASD to early childhood educators. The webpage includes fact sheets, helpful tips, advice on finding local resources, and links to multiple relevant websites. The tip sheets, compiled by ACF and NICHD at NIH, contain numerous strategies for working with children with ASD suggested by experts from across the country.

In addition to the ASD webpage, ACF has focused its attention on developmental and behavioral screening. While the emphasis of this priority is broad screening, rather than screening for specific disorders, the initiative has helped inform the early childhood field and ultimately helps children with all disabilities, including those with ASD.

The ACF **Office of Refugee Resettlement (ORR)** helps new populations immigrating to the U.S. to maximize their potential, providing people in need with critical resources to assist them in becoming integrated members of American society. Resources disseminated by ORR include ASD-related materials developed by ACF and CDC (i.e., **Learn the Signs. Act Early.**) to assist families with recognizing and addressing autism-related needs.

Administration for Community Living (ACL)

The **Administration for Community Living (ACL)** works to increase access to community support systems for older Americans and for people with disabilities

across the lifespan. Its main activities and statutory authorities include administration of disability programs that support community living from which individuals with ASD may benefit.

The current research and development portfolio of the ACL's **National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR)** focuses on the development of interventions to improve outcomes for individuals with disabilities such as ASD, including (1) community living and participation among children with autism, (2) education (primarily postsecondary education) and employment among transition-aged youth and adults with autism, and (3) community living and participation among transition-aged youth and adults with autism. The following grants either focus exclusively on autism or include people with autism in their populations of interest.

Intervention research to improve community living and participation outcomes for children with autism

- **The Online and Applied System for Intervention Skills (OASIS) - Scaling-up!**
Grant number: 90DPKT0003
Summary: This project follows standard implementation guidelines to scale up OASIS to the broader community. OASIS is a program that uses a Research-to-Practice Outreach Training model to teach parents of children with ASD how to implement empirically based interventions with their children.
- **Increasing Accessibility of Services for Individuals on the Autism Spectrum via Refinement of a Distance-Based Training and Supervision Platform**
Grant number: 90BISA0030; Small Business Innovation Research (SBIR) Phase I – related to **90DPKT0003** above
Summary: While families have increasing access to Applied Behavior Analysis (ABA), an evidence-based treatment for young children with autism, they are often unable to access these services due to a paucity of providers that meet state-mandated certification and licensing requirements. There continues to be a lack of quality, evidence-based distance supervision opportunities for Board

Certified Behavior Analyst (BCBA) supervisees in remote areas. OASIS-S addresses this need.

- **Efficacy of the ASD Screening and Parent Engagement (ASPEN) Intervention Program in Low-Resource Communities**
Grant number: 90IFST0004
Summary: The goal of this project is to examine the efficacy of the ASPEN intervention, a culturally informed parent-mediated intervention program, when delivered to caregivers and children at risk for ASD who reside in low-resource households.
- **Rehabilitation Research and Training Center (RRTC) on Family Support**
Grant number: 90RT5032
Summary: The goal of the RRTC on Family Support is to bridge aging and disability research, practice, and policies to generate new knowledge in family supports which contributes to improvements in community living, participation, health and function, and other outcomes for individuals with disabilities from different racial and ethnic backgrounds who are supported by family members. One project, “Parents Taking Action: A Parent Training Program for Latino Families of Children with Autism Spectrum Disorders (ASD),” tests the efficacy of an intervention that engages parents of children with ASD in providing education and training to other parents.

Intervention research to improve education and employment outcomes for transition-aged youth and adults with autism

- **Rehabilitation Research and Training Center (RRTC) on Employment of People with Intellectual and Developmental Disabilities**
Grant number: 90RTEM0003
Summary: The Virginia Commonwealth University RRTC on Employment of People with IDD provides needed information in employer practices that are associated with better employment outcomes for individuals with IDD. One project investigates how college students with ASD can use cognitive technology to impact their academic and employment outcomes.

- **A Professional Development and Case Management (PDCM) Model for Seamless Transition Planning: Improving Postschool Outcomes**

Grant number: 90DPEM0003

Summary: This project focuses on seamless transition planning for youth with cognitive, intellectual, and developmental disabilities, including youth with traumatic brain injury, autism, and multiple disabilities. Researchers work with 25 vocational rehabilitation special education teams across four regions in Ohio.

- **Efficacy of a Community College Transition Program for Young Adults with Autism Spectrum Disorder**

Grant number: 90IFRE0019

Summary: The goal of this project is to assess the feasibility, social validity, and efficacy of the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) School Transition to Employment and Postsecondary Education (T-STEP) intervention for 17- to 21-year-old community college students with ASD.

- **Effects of Customized Employment on the Employment Outcomes of Transition-Aged Youth with Disabilities: A Randomized Clinical Trial**

Grant number: 90DP0085

Summary: This project researches the use of customized employment as an intervention to assist individuals with ID and/or ASD to achieve integrated employment outcomes.

- **Center on Knowledge Translation for Employment Research**

Grant number: 90DP0077

Summary: The Center on Knowledge Translation for Employment Research has as its purpose: (1) to identify findings related to improving employment outcomes among individuals with disabilities that NIDILRR-funded researchers and other entities have produced, with a focus on the high-needs populations of adults with autism and transition-aged youth and young adults with disabilities; (2) to determine what needs for research-based information are most pressing for stakeholders, such as individuals with

disabilities and their families, vocational rehabilitation practitioners, the business community, and policy makers; and (3) to investigate and test knowledge translation strategies that can increase these stakeholders' appropriate use of identified research findings that meet their reported needs.

- **TRACK (Tools for Reading to Acquire Content Knowledge): An Intelligent Application for Middle and High School Students with Neurodevelopmental Disorders**

Grant number: 90BISA0017; SBIR Phase I

Summary: Using a participatory action research approach, this project develops and evaluates an intelligent web-based application, TRACK for middle and high school students with neuro-cognitive deficits such as individuals with ASD, learning disabilities, attention deficit/hyperactivity disorder (ADHD), or traumatic brain injury.

Intervention research to improve community living and participation for transition-aged youth and adults with autism

- **Using GIS and GPS Techniques to Understand Meaningful Participation for Adults with Autism Spectrum Disorder**

Grant number: 90SFGE0008

Summary: The purpose of this study is to use innovative Global Positioning System (GPS) and Geographic Information System (GIS) measures to systematically assess the community participation of adults with ASD and investigate critical environmental and personal factors associated with participation. The primary goal of this project is to advance the understanding of where and how adults with ASD spend their time, how they interact with their community, and what resources or supports promote community participation.

- **Getting Out: Development of a Web-Based Application to Leverage Social Capital and Enable Self-Directed Community Participation for Individuals with Significant Cognitive Disability**

Grant number: 90IFDV0008

Summary: This project develops an innovative web

application, Getting Out, that provides a cognitively accessible tool for individuals with mild to moderate cognitive disabilities, including autism, to help them effectively maintain social relationships established during high school transition, build new relationships, and turn virtual connections with social network members with and without disabilities into real world relationships around activities of common interest and mutual support.

- **Enhancing Community Participation for Adults with Autism Spectrum Disorders Through Peer-Mediated Transportation Interventions**

Grant number: 90IFRE0013

Summary: Transportation is a major obstacle to accessing essential services and overall community participation for many individuals with ASD. This project develops and tests a peer-mediated intervention to reduce barriers to public transportation for transition-aged youth and adults with ASD.

- **Increasing Community Participation in Young Adults with Autism Living in Rural Communities**

Grant number: 90IFRE0018

Summary: Individuals living in rural communities often experience multiple barriers to community participation. Recent data assessing community participation in young adults with autism demonstrated significantly lower rates and variability of community participation in comparison to same-age peers without autism. This project assesses the impact of PArticipation in Rural Settings to Engage in Communities (PARSEC), an intervention for families of young adults with autism living in rural areas to increase community participation.

- **I-CONNECT PLUS: Enhancing Community Participation for Adolescents and Adults with ASD Using Online Instruction, Coaching, and Accessible Self-Management Technologies**

Grant number: 90DP0058

Summary: This project develops I-CONNECT PLUS, a technology-supported instructional system to teach social competence, problem-solving skills, and organizational/self-monitoring skills for adolescents and young adults with ASD. The project provides remote tele-coaching by

community providers, peers, and family members for promoting generalized use and focuses on the use of self-management and monitoring of outcomes to promote independence and full engagement across settings.

- **SkillTalk: Using Streaming Video for Young Adults with Autism Spectrum Disorder to Build Microskills to Develop and Sustain Relationships for Healthy and Independent Living**

Grant number: 90BISA0037; SBIR Phase I

Summary: This SBIR project develops and tests SkillTalk, a prototype video-delivered microskills training program to improve relationship skills among transition-aged adults between 18 and 28 years with ASD. Microskills such as showing empathy, active listening, and open-ended questioning can help build relationships. During Phase I, this project (1) conducts formative research with transition-aged adults with ASD, (2) develops content for two relationship skillsets and 20 corresponding microskills training, (3) produces training videos approximately 30 to 120 seconds in length, and (4) develops and evaluates a prototype of the SkillTalk platform. Projected outcomes include the successful development of the SkillTalk platform that provides individuals with ASD the skills to increase community involvement, form successful friendships and romantic relationships among their peers, and ultimately improve mental health outcomes and quality of life. This project is conducted in partnership with experts in ASD relationships and sexuality as well as youth with lived experience.

- **Understanding Sexuality and Community Participation in Adults on the Autism Spectrum**

Grant number: 90SFGE0022

Summary: This research aims to describe community participation among LGBTQIA+ autistic adults and develop an approach or support congruent with their perceived needs. Specifically, the project uses an inclusive, qualitative research design to: (a) describe how LGBTQIA+ autistic adults perceive their identity (i.e. autistic and LGBTQIA+) and how these identities influence the nature and extent

of community living and participation, (b) identify the perceived barriers and supports to inclusion for LGBTQIA+ autistic adults, and (c) develop and refine a proposed approach or support that is acceptable to LGBTQIA+ autistic adults to address identified barriers to full inclusion. Project results may inform a research agenda including future directions for feasibility testing of new approaches or supports identified through this study and may inform health policy for LGBTQIA+ autistic adults.

ACL's Administration on Disabilities oversees a number of federal programs that support quality community for individuals with disabilities, including programs funded under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and the Rehabilitation Act. The programs directly or indirectly impact individuals with DD, including those with autism:

- **Centers for Independent Living (CILs)**
CILs are run by and for people with disabilities to support community living and provide independent living services to people with all types of disabilities. These services include:
 1. Information and referral;
 2. Peer counseling;
 3. Individual and systems change advocacy; and
 4. Services that facilitate transition from nursing homes and other institutions to the community, provide assistance to those at risk of entering institutions, and facilitate transition of youth to postsecondary life.
- **State Councils on Developmental Disabilities (Councils)**
Councils pursue systems change that promotes improved outcomes for individuals with DD and their families. Councils pursue capacity building to develop and expand projects that successfully deliver services and supports. Councils also support advocacy activities that promote self-determination and inclusion in the community. Examples of Council activities include demonstration of new approaches, outreach, training, public education, and providing information to policy makers.

- **Protection and Advocacy Systems (P&As)**
P&As protect the legal and human rights of individuals with DD. P&A strategies include legal, administrative, and other remedies (e.g., mediation and alternative dispute resolution); information and referral; investigation of incidents of abuse and neglect; and education of policy makers.
- **University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)**
UCEDDs are either components of a university system or are public or not-for-profit entities associated with a university. UCEDDs are required to carry out four core functions:
 1. Interdisciplinary pre-service preparation and continuing education;
 2. Community services, which includes services, training, and technical assistance;
 3. Research; and
 4. Information dissemination.

COVID-19 Response for Individuals with Disabilities

During the COVID-19 pandemic, ACL has worked in partnership with the **HHS Office for Civil Rights** to ensure that state Crisis Standards of Care do not discriminate on the basis of disability. In addition, ACL has worked to ensure that people with disabilities, including individuals with developmental disabilities and on the autism spectrum, had equitable access to COVID-19 vaccines. ACL issued a **document** in 2021 cataloguing best practices in helping individuals with disabilities and older adults access COVID-19 vaccines.

Furthermore, ACL launched the **Disability Information and Access Line (DIAL)** to provide help with COVID-19 vaccinations for people with disabilities. DIAL is available at **888-677-1199 Monday-Friday from 9 a.m. to 8 p.m. (Eastern) or by email at [DIAL@usaginganddisability.org](mailto:usaginganddisability.org)**.

The DIAL's trained staff is standing by to:

- Help find local vaccination locations;
- Assist with making vaccination appointments; and

- Connect callers to local services, such as accessible transportation, to overcome barriers to vaccination.

The hotline also can provide information and resources to answer questions and address concerns about the vaccines and can connect callers to information and services that promote independent living and address fundamental needs such as food, housing, and transportation.

DIAL is operated as a collaboration between a consortium of organizations serving people with disabilities and the **National Association of Area Agencies on Aging (n4a)**. The consortium includes:

- Association of Programs for Rural Independent Living (APRIL),
- Association of University Centers on Disabilities (AUCD),
- Independent Living Research Utilization (ILRU),
- National Association of Councils on Developmental Disabilities (NACDD),
- National Council on Independent Living (NCIL),
- National Disabilities Rights Network (NDRN), and
- The Partnership for Inclusive Disaster Strategies.

This collaboration benefits from the disability networks' extensive knowledge and expertise in meeting the needs of people with disabilities across the U.S. and n4a's decades of experience operating the **Eldercare Locator**, the only federally funded national information and referral resource that supports consumers across the spectrum of issues affecting older Americans.

Agency for Healthcare Research and Quality (AHRQ)

The mission of the **Agency for Healthcare Research and Quality (AHRQ)** is to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable and to work within HHS and with other partners to make sure that the evidence is understood and used. AHRQ does not receive funds from the Autism CARES Act of 2019 but does support

research to determine the effectiveness and outcomes of interventions for individuals with ASD. Recent research projects that seek to improve the health and well-being of individuals with ASD are described below.

- **Enabling large-scale research on autism spectrum disorders through automated processing of electronic health records (EHR) using natural language understanding**

Grant number: 5R21HS024988-02

Institution: University of Arizona

Summary: With increasing use of electronic medical records for a variety of patients, a large investment is being made in a resource still vastly underused. Especially in mental health, where problems are highly individualized, requiring personalized intervention, and often accompanied by rich data not easily captured in structured templates, the need for extracting information from free text in existing records for use as large-scale stand-alone datasets or in combination with other data is real. Without scalable and effective computational approaches to capture this data, much time, effort, and money is used to create limited-use records that instead could be leveraged into precious data sources to inform existing research and lead to new insights, progress, and treatments. The two specific aims are (1) design and test natural language processing (NLP) algorithms to detect Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria for ASD in free text in EHR and (2) demonstrate feasibility and usefulness of the models for large-scale analysis of ASD cases, which is inconceivable today with current approaches. Through NLP algorithms, this project has the potential to significantly shift away from the current paradigm of attempting to understand ASD by relying on small-scale data from individual interventions and lack of integration between different data sources, to leveraging information from existing large-scale data sources to propose novel analyses and hypotheses.

- **Ambulatory Pediatric Safety Learning Lab**

Grant number: 1R18HS026644-01

Institution: Cincinnati Children's Hospital Medical Center

Summary: After almost two decades of research and quality improvement, hospitalized children in the U.S. are safer from health care-related harm. The vast majority of health care, however, is provided in the clinic and at home, and few studies in this context have demonstrated how to improve safety. Children are especially vulnerable to preventable harm caused by health care for many reasons, including weight-based medication dosing, hand-offs between caregivers, and their limited ability to communicate evolving symptoms. At home, two in five children with chronic disease have a medication error. Of these, 3.6% are injured due to these errors, the same rate as hospitalized children. The Ambulatory Pediatric Patient Safety Learning Lab aims to (1) redesign processes for adjustment of medication dosing based on clinical information gathered by the patient/family to prevent medication errors (this will be studied in type 1 diabetes); (2) create processes for patient/family medication monitoring and communication with clinic to prevent adverse drug events (this will be studied in children with ASD on antipsychotics); and (3) design a workflow to plan for, detect, and prompt management of serious illness among children with chronic conditions at home (this will be studied in both populations). The overarching goal is to redesign systems of care and coordination between the clinic and home to eliminate harm due to health care in these settings.

HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)

The **Assistant Secretary for Planning and Evaluation (ASPE)** is the principal advisor to the HHS Secretary on policy development and is responsible for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis. The **Office of Behavioral Health, Disability, and Aging Policy (BHDAP) within ASPE** focuses on policies and programs that support the independence, productivity, health and well-being, and long-term care needs of people with disabilities, older adults, and people with mental and substance use disorders. The Division of Disability and Aging Policy is responsible for policy and data

development, coordination, research and evaluation of policies and programs focused on the functioning and well-being of persons with disabilities and older adults. The Division is the focal point for crosscutting disability and aging collaboration within HHS and across the federal government. Alzheimer's disease and related dementias and intellectual and developmental disabilities, including ASD, are notable areas of engagement and expertise. Descriptions are provided for some current projects related to autism.

Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person Centered Outcomes Research

ASPE/BHDAP aims to build data capacity for person-centered outcomes research for the population with IDD through the creation of a publicly accessible, de-identified, linked dataset of IDD-relevant state-level data. The \$1.5 million project is funded through the **Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF)**. The period of performance for the project is four years.

This **pilot project** will produce a linked dataset of the following state-level data sources: the National Core Indicators In-Person Survey, Supports Intensity Scale, Medicaid claims, and other relevant state-level data sources. The linked dataset will enable researchers to analyze relationships between various sociodemographic information, need for home and community-based services, service utilization, service expenditures, and person-centered outcomes prior to and during the COVID-19 pandemic for individuals with IDD, including ASD.

The project includes an inter-departmental technical expert panel led by ASPE/BHDAP, with representatives from HHS [ACL/Administration on Disabilities (AoD), ACL/NIDILRR, CDC/National Center on Birth Defects and Developmental Disabilities (NCBDDD), NIH/NICHHD, NIH/NIMH, CMS/Office of Minority Health (OMH), CMS/Center for Medicaid & CHIP Services (CMCS)] and DOL (ODEP).

Response to the Coronavirus Pandemic

In response to the coronavirus pandemic, ASPE published two documents in July 2021: **COVID-19 and People with Intellectual and Developmental Disabilities (Final Report)** and **COVID-19 Data on Individuals with Intellectual and Developmental Disabilities (Issue Brief)**. The purpose of the Final Report and Issue Brief was to examine state collection and reporting of COVID-19 data, COVID-19 infection prevention strategies, and COVID-19 vaccine prioritization for the IDD population at the state level to help inform future policies, programs, and practices that aim to reduce the risk of infection and mitigate adverse effects of COVID-19 and other infectious diseases for the population.

Centers for Disease Control and Prevention (CDC)

The **Centers for Disease Control and Prevention (CDC)** brings a unique public health perspective to the effort to fully understand ASD. This perspective includes reporting data on the occurrence of ASD, contributing to the understanding of risk and protective factors, and working to improve early identification of ASD and other DD. CDC conducts both intramural (internal) and extramural (i.e., grant and contract) activities and partners with grantees, federal and state governments and programs, and other stakeholders in these activities.

Early identification is an important step in promoting the health and well-being of individuals with ASD. CDC's "**Learn the Signs. Act Early.**" program improves early identification through education and tools to identify developmental concerns so that children and their families receive the services and support they need as early as possible. Between January 2014 and August 2021, the "Learn the Signs. Act Early." webpages have received almost 45 million page views and are utilized by health care professionals, parents, early childcare providers, partners, program champions, and other early childhood professionals.

The core activity of "Learn the Signs. Act Early." is providing information to help all families with a child

under the age of 5 years monitor their child's development. This is important because the signs of developmental delays can be subtle; the more parents are aware of and track their child's developmental milestones, the sooner they may be able to recognize a potential concern. The program provides free tools and resources for families and professionals, which have been evaluated through multiple methods. Two new materials include the following:

The Milestone Tracker App makes it easy for parents to track, support, and celebrate their young child's development, as well as take action when there is a developmental concern. This free app is available in both English and Spanish and offers illustrated and interactive milestone checklists, tools to discuss development and concerns with a health care provider, and reminders for appointments and developmental screening. As of August 2021, the app has nearly 900,000 downloads.

Baby's Busy Day: Being One is So Much Fun! is the program's latest children's book meant to help parents learn more about their child's development and encourage them to track developmental milestones. On each page, characters demonstrate developmental milestones and activities that encourage child development. Parents can read this fun story with their child while learning the developmental milestones to look for in their 1-year-old and tips for helping their child's development.

In addition to a range of information resources, "Learn the Signs. Act Early." has worked to establish partnerships to integrate developmental monitoring into programs and systems that serve young children and their families, including public health programs and childcare programs. There continues to be a strong focus on reaching low-resource families through partnerships with the HRSA Maternal, Infant, and Early Childhood Home Visiting and Healthy Start programs, the ACF Child Care Development Fund and Early Head Start/Head Start programs, and, particularly, the U.S. Department of Agriculture Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). The WIC Program aims to safeguard the health of low-income women, infants, and children

up to age 5 who are at nutrition risk by providing nutritious foods to supplement diets, information on healthy eating, and referrals to health care.

In 2019, the program launched the **Developmental Milestone Checklist Program – Online Implementation Guide for WIC Program Staff**. The program itself is simple, with three components: (1) engaging graphics on the walls and floors of the WIC clinic introduce milestone monitoring in a fun and friendly way; (2) staff invite the parent to complete a parent-friendly milestone checklist during certification and mid-certification visits, or whenever there is a question or concern; and (3) staff review the checklist and make a referral if there are any missing milestones or other concerns are noted. Developed by the CDC in collaboration with the University of Missouri and WIC staff in Missouri, and tested in WIC clinics across the nation, the guide provides practical guidance and free access to everything a WIC program would need to implement developmental monitoring and referral, including recruitment and training videos, free customizable materials, access to environmental graphics (wall and floor decals), and practical, WIC-tested tips for implementation.

CDC has also supported six cohorts of **Act Early Ambassadors** since 2011. Ambassadors are state or territorial leaders working to increase collaboration and coordination among early childhood programs and improve early identification. The program currently supports Ambassadors in all 50 states, the District of Columbia, and three territories. This program has proven to be very effective in putting developmental monitoring into practice. Act Early Ambassadors continue to succeed in integrating developmental monitoring resources into state- or territory-wide early childhood systems, including childcare, home visiting, maternal-child health programs, Help Me Grow, early intervention, and care coordination.

In 2020, CDC funded 43 State and Territorial **Act Early COVID-19 Response** Teams to support families and systems affected by COVID-19. Teams were tasked with carrying out a state/territory-wide needs assessment, identifying and addressing barriers to early identification of children with ASD and other DD, and identifying

strategies to improve resiliency among children and families. This initiative is focused on support for early childhood state systems through the network of Act Early Ambassadors to support recovery and strengthen resilience skills, behaviors, and resources of children, families, and communities.

In 2020, CDC also funded and launched a new pilot program, **Children’s Mental Health Champions**, building off and expanding the **Act Early Ambassadors** model for children’s mental health. Four of the twelve Champions, one each in Colorado, Georgia, North Carolina, and New Mexico, work to improve access and coordination of mental health services specifically for children with developmental disabilities and ASD. In addition, these four Champions support workforce development opportunities to increase the capacity and skills of providers to enhance their comfort in serving children with developmental disorders and co-occurring mental disorders.

In 2021, CDC initiated two pilot projects to improve early identification among American Indian/Alaska Native (AI/AN) children with developmental delays and disabilities including autism. The first is a project to fund two federally recognized AI/AN tribal nation or regional AI/AN tribally designated organizations to pilot AI/AN Tribal Act Early Ambassadors and carry out culturally appropriate translation, dissemination, and integration of “Learn the Signs. Act Early.” resources. The second project will support three Public Health Associate Program (PHAP) associates to better understand strategies and opportunities to identify children with developmental delays in tribal communities.

CDC has actively collaborated with other federal agencies and non-federal organizations working to improve early identification and linkage to services for children with ASD and other DD. For example, CDC and HRSA are collaborating on outreach to federally qualified health centers to promote developmental monitoring and make them aware of “Learn the Signs. Act Early.” resources. CDC and HRSA also continue to engage in Autism Coordination meetings and collaborate on Early Childhood Comprehensive Systems projects. CDC also works with ACF and ED to promote

early identification through developmental monitoring and screening resources, including those from **Birth to Five: Watch Me Thrive!**, a coordinated federal effort spanning several HHS agencies (CDC, ACF, ACL, CMS, HRSA, NIH, and SAMHSA) and ED to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them. CDC and the American Academy of Pediatrics are collaborating in several ways to improve early identification in pediatric health care settings, including a messaging campaign and a new training for health care providers, “**Milestones Matter: Don’t Underestimate Developmental Surveillance.**”

CDC’s **ADDM Network** also tracks progress toward early identification of ASD in multiple communities in the U.S. Early detection of ASD is important because an ASD diagnosis is sometimes necessary to begin early intervention services, and early intervention is linked with better outcomes. The ADDM Network has shown that there is considerable variability in the ages at which children with ASD first receive a comprehensive developmental evaluation and are first diagnosed with ASD. Importantly, the **most recent ADDM data** show that children born in 2012 had a higher cumulative incidence of ASD diagnoses by age 48 months compared with children born in 2008, which indicates more early identification of ASD in the younger group. In 2019 and 2020, five sites in the ADDM Network collected follow-up data among 16-year-old children with previous information in ADDM at age 8 years. These data will help inform public health strategies to improve identification of and services for children with ASD. Tracking 16-year-old adolescents with ASD can also provide valuable information on transition planning in special education services and the planned trajectory for post-high school years. Data from the ADDM Network can help inform efforts to ensure that children are evaluated and diagnosed as soon as possible after developmental concerns are identified and promote efforts for early and equitable identification of ASD and timely enrollment in services.

In 2019, CDC launched and updated an interactive **autism data visualization website** which presents the most up-to-date state-based autism prevalence

information from four major data sources (ADDM Network, Special Education, Medicaid, and National Survey of Children’s Health).

CDC’s Child Development and Disability Branch in the Division of Human Development and Disability also conducts the **Study to Explore Early Development (SEED) Teen**, a follow-up study of SEED Phase 1 participants as they reach adolescence. The objectives of SEED Teen are to (1) describe the developmental trajectory of children identified at young ages as having ASD; (2) assess the health and functioning of adolescents with ASD and other DD; (3) characterize the health care utilization and needs of adolescents with ASD and other DD; (4) characterize the educational attainment and needs of adolescents with ASD and other DD; and (5) assess family impacts associated with having a child with ASD or other DD, with the goal of identifying strategies to help meet the unique needs of these families.

Through SEED Teen, CDC is collecting detailed data on the following topics: adolescent health, including overall health and co-occurring medical, mental health, and developmental conditions; use of health care services, medications, experiences with health care providers, and transition services; education, including use of school and other developmental services; current level of functioning and strengths and difficulties; child safety and stressful life events; and parental expectations and family impacts.

Data collection for SEED Teen began in July 2018 and was completed in March 2021. The final sample included over 850 participants, aged 12 to 16 years. A **report** using interim data was recently published in CDC’s Morbidity and Mortality Weekly Report. This report found physical difficulties and co-occurring conditions, such as ADHD or anxiety, were more common among adolescents in the autism group, yet they were three times more likely than adolescents in the control group to have an unmet health care service need.

In 2020, as part of SEED Phase 3, CDC also collected information on the impact of COVID-19 on services, behaviors, and health to help inform public health

strategies for children with ASD aged 3 to 9 years and their families, especially during public health emergencies. In-person assessments for ASD were suspended due to COVID-19, but CDC amended the study protocol to collect information to describe the impact of COVID-19 prevention efforts on children with ASD and their families compared to changes among children with other DD and children from the general population. Outcomes of interest among children included education and use of remote learning; changes in use of services and telemedicine; experiences with testing and mitigation strategies; and changes in routines, health, and well-being. Outcomes of interest among families included changes in household structure; health and well-being; finances, employment, and health insurance; changes in routines and support; and experiences with COVID-19 infection. Additionally, the study measured changes in behavior problems and everyday life skills among children before and after COVID-19. The study was completed in July 2021 with over 1,000 participants.

Over the next five years (2021-2026), CDC will invest more than \$16 million to carry out follow-up studies on children and their families from all three phases of SEED (SEED 1-3) through a recent funding opportunity, **CDC-RFA-DD-21-001**. This study will include over 6,000 children and their families who completed the study, including approximately 1,700 children with ASD. Understanding the risk factors and expression of ASD from childhood through early adulthood will help us gain knowledge to improve the health and functioning of individuals with ASD as they mature, as well as service use and needs, and impact of ASD on their families.

Centers for Medicare & Medicaid Services (CMS)

The **Centers for Medicare & Medicaid Services (CMS)** is committed to strengthening and modernizing the nation's health care system to enhance quality, accessibility, and improved outcomes in the most cost-effective manner possible. CMS administers several programs that are available to individuals with disabilities, including those with ASD. These programs do not receive appropriations from the Autism CARES Act of 2019.

Medicaid is a federal-state partnership, in which states administer their Medicaid programs according to federal requirements. There are several eligibility pathways to Medicaid coverage, and individuals with ASD could be eligible through many of them, including the adult expansion group authorized by the Patient Protection and Affordable Care Act (PPACA; **Public Law 111-148**).

CMS has provided a series of guidance documents intended to increase awareness and understanding of ASD and the role that Medicaid can play in supporting beneficiaries diagnosed with ASD. This includes an **Informational Bulletin** and a set of **Frequently Asked Questions** regarding options available under Medicaid for furnishing services to eligible beneficiaries with ASD. The Informational Bulletin outlines services to address ASD that may be covered under different section 1905(a) benefit categories, which includes: section 1905(a)(6) – services of other licensed practitioners; section 1905(a)(13)(c) – preventive services; and section 1905(a)(10) – therapy services. The Informational Bulletin also discusses requirements related to services for children beneficiaries under the age of 21 specified by section 1905(r) of the Social Security Act (the Act), known as **Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)** benefit. Further, it discusses how states furnishing services to treat ASD under a section 1915(c) home and community-based services (HCBS) waiver or section 1915(i) Medicaid state plan HCBS benefit of the Act to children under 21 may have to transition those individuals to EPSDT coverage.

Medicaid's EPSDT benefit includes a comprehensive array of preventive, diagnostic, and treatment services for low-income infants, children, and adolescents under age 21. The EPSDT benefit requires screening services as well as physical, mental, vision, hearing, and dental services for children beneficiaries under age 21 that are appropriate and medically necessary services needed to correct and ameliorate health conditions, based on certain federal guidelines.

CHIP provides health coverage to eligible children, through Title XXI-funded Medicaid expansion programs and/or separate CHIPs. CHIP is administered by

states, pursuant to federal requirements. Children beneficiaries in states providing a Title XXI-funded Medicaid-expansion receive the EPSDT benefits described above. Children beneficiaries in states providing a separate CHIP receive a set of benefits that may (but are not required to) include the EPSDT benefit. Approximately 15 states have elected to cover the EPSDT benefit in their separate CHIPs.

Since 2014, CMS has been providing technical assistance to state Medicaid agencies on coverage of services to children with autism under the state plan and adjudicating state plan amendments (SPAs) to add coverage of medically necessary section 1905(a) state plan services to children with ASD.

Home and Community-Based Services (HCBS)

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutional or other isolated settings. States can utilize a variety of federal authorities to design their HCBS programs, such as: section 1915(c) HCBS waivers, section 1915(i) state plan HCBS benefit, section 1915(j) self-directed personal assistance services state plan benefit, section 1915(k) “Community First Choice” option, and section 1115(a) demonstrations. HCBS programs afford states a way to provide services to various targeted populations which include those with IDD (including persons diagnosed with ASD), physical disabilities, and/or mental illness. States may propose to provide defined populations services such as behavioral therapies, respite care, personal care, and expressive therapies. These services must be coordinated with state plan services required under the EPSDT provisions discussed above, to ensure children beneficiaries under the age of 21 are receiving appropriate services.

The Medicaid HCBS authorities discussed above may authorize Medicaid payment of nutritional and social activities, when linked to an assessed need of a Medicaid-eligible individual and reflected in his/her person-centered service plan. States determine which HCBS service array to provide to targeted populations, which can include individuals diagnosed with ASD.

In September 2019, CMS initiated the HCBS Special Projects contract to advance the delivery of HCBS for specific Medicaid-eligible populations, including youth with disabilities who are transitioning out of the foster care system and adults with IDD living with and cared for by aging parents and guardians. In addition, the contract focused on strategies to address the direct service workforce furnishing home and community-based services under the Medicaid program.

Specific activities under this contract include:

- Identifying and disseminating promising practices to improve quality of care and services and/or promote positive outcomes for youth with disabilities as they transition out of foster care and adults with IDD who are living with and cared for by aging parents and guardians, particularly as aging parents and guardians are unable to care for their adult children with IDD because of functional limitations, acute or chronic illness, or death;
- Convening a summit for each of these population groups, as well as on direct service workforce strategies, focused on identifying specific policy or programmatic recommendations for improving the system of care; and
- Producing and disseminating training and technical assistance products focused on these populations and the workforce serving individuals receiving home and community-based services.

CMS has also incorporated a technical expert workgroup for each project. This contract continues through September 29, 2022.

Health Homes

Health Homes is a Medicaid State Plan optional benefit authorized under section 1945 of the Act. In addition, beginning October 1, 2022, as authorized under section 1945A of the Act, a new Medicaid state plan optional benefit will be available to states who elect to provide coordinated care through a Health Home for children with medically complex conditions. Health Homes provide a comprehensive system of care coordination for qualified Medicaid beneficiaries with

chronic conditions, such as mental health conditions, substance use disorder, asthma, diabetes, heart disease, and overweight (body mass index [BMI] over 25). States may target other conditions like IDD, including autism. For example, Delaware elected to add the Health Home benefit to target individuals with IDD, including autism, along with other conditions. States also have the option to provide Health Homes in CHIP.

Health Home providers integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the “whole-person.” Health Homes are responsible for both clinical and non-clinical needs of the individual and work with all the individual’s care providers to establish prevention strategies and ways to educate the individual about their condition and to support the individual in maintaining wellness and improving overall health quality. States receive a 90% enhanced match for the first eight quarters from the effective date of their state plan amendment and their regular service match rate thereafter. More information about this program is available [online](#).

Listed below are the six Health Home services provided under the Health Home state plan benefit:

- *Comprehensive Care Management* refers to the initial and ongoing assessment of an enrollee’s needs and management of services aimed at the integration of primary, acute, behavioral and specialty health care, long term services and supports, and community support services, using a comprehensive person-centered care plan, which addresses all clinical and non-clinical needs and promotes wellness and management of chronic conditions in pursuit of optimal health outcomes.
- *Care Coordination* refers to facilitating access to, and the monitoring of, services identified in a person-centered care plan to manage chronic conditions for optimal health outcomes and to promote wellness.
- *Health Promotion* refers to the education and engagement of an individual in making decisions that promote his or her maximum independent

living skills and lifestyle choices that achieve goals including good health, proactive management of chronic conditions, early identification of risk factors, and appropriate screening for emerging health problems.

- *Comprehensive Transitional Care* refers to the facilitation of services for the individual and family/ caregiver when the individual is transitioning between levels of care (including, but not limited to, hospital, nursing facility, intermediate care facility, rehabilitation facility, community-based residential setting, family, or self-care) or when an individual is electing to transition to a new Health Home provider.
- *Individual and Family Supports* refers to the provision of information and activities that support enrollees and the enrollee’s support members to maintain and promote quality of life, with particular focus on community living options.
- *Referral to Community/Social Supports* refers to the provision of information and assistance for the purpose of referring enrollees and enrollee support members to community-based resources that can meet the needs identified on the enrollee’s person-centered care plan.

Money Follows the Person (MFP)

The **Money Follows the Person (MFP) Demonstration** supports state efforts to rebalance their long-term support systems so that individuals have a choice of where they live and receive services. Individuals with IDD, including autism, represent approximately 14% of MFP program participants. States have used the flexibility made available through MFP to provide HCBS to support individuals with IDD who may have more complex and behavioral needs, including individuals with autism, so they can transition from medical institutions to community-based settings without losing access to appropriate and necessary long-term services and supports.

Under the Consolidated Appropriations Act, 2021, (CAA; **Public Law 116-260**) the MFP demonstration received additional funding through federal FY 2023. In addition, the CAA made the following changes to

MFP participant eligibility criteria: (1) the minimum length of time required in an inpatient facility changed from 90 days to 60 days and (2) struck the text related to “short-term rehabilitative services” after section 6071(b)(2) of the Deficit Reduction Act, as amended by section 2403 of the PPACA. These statutory changes to the length of time required in an inpatient facility to determine MFP eligibility allow state recipients to provide community transition services under MFP earlier in an eligible individual’s inpatient stay. These changes were effective 30 days after enactment of the CAA on December 27, 2020.

Health Resources and Services Administration (HRSA)

The **Health Resources and Services Administration (HRSA)** is the primary federal agency for improving health care for people who are geographically isolated, economically or medically vulnerable. Under the Autism CARES Act of 2019, HRSA received funding to increase awareness of ASD and other DD; reduce barriers to screening and diagnosis; support research on evidence-based interventions; promote the development of guidelines for evidence-based practices; and train health care professionals to provide screening, diagnostic, and early, evidence-based intervention services for children with a confirmed diagnosis. To meet these objectives, HRSA funded grant programs in three areas: Training, Research, and State Systems Development. HRSA also funded two national resource centers to provide technical assistance to and promote collaboration among grantees.

Through their collective efforts, HRSA’s programs are increasing access to early and appropriate developmental screening, diagnostic, and intervention services, and improving effectiveness of support services available to youth making the transition to adulthood. A description of significant progress follows.

Training Programs

HRSA supports 52 **Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs** and 12 **Developmental-Behavioral**

Pediatric (DBP) training programs to address the shortage of trained professionals who can provide screening, diagnostic services, and treatment for children and youth with ASD/DD. Programs are located in 44 states, with partnerships that extend to several U.S. territories. The current cohort of LEND grantees was awarded funding in 2016 for a five-year project period. In 2018, HRSA expanded the DBP program from 10 to 12 grants for a five-year project period.

The LEND training program provides interdisciplinary training to enhance the clinical expertise and leadership skills of professionals dedicated to caring for children with neurodevelopmental and other related disabilities, including ASD. The LEND program promotes education, early detection, and intervention in ASD. LEND program trainees participate in academic, clinical, leadership, and community learning opportunities and receive training in cultural and linguistic competence using a family-centered approach.

The DBP training program trains the next generation of leaders in developmental-behavioral pediatrics to build capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions to individuals with ASD/DD. The DBP training program promotes the health and well-being of individuals with ASD/DD with specific attention to the broad range of behavioral, psychosocial, and developmental issues that present in primary care pediatric practice. The primary focus of the program is to train subspecialists in DBP to expand the workforce able to diagnose ASD/DD; provide effective treatment and interventions; support systems of care, such as state Title V and other maternal and child health (MCH) agencies; and conduct research.

Interdisciplinary clinics associated with the LEND and DBP training grants are making evidence-based interdisciplinary services available across the nation, particularly in underserved communities. Each year, the LEND and DBP programs enroll long-term trainees to receive at least 300 hours of intensive didactic training and clinical experience working in hospitals, clinics, and community-based settings that provide diagnostic or intervention services for children and youth with ASD/DD. Collectively, the programs also

provide training to other health professionals, including medical residents, to increase their understanding of ASD/DD and make them aware of emerging evidence regarding ASD evaluation and interventions.

The most recent publicly available data for LEND and DBP programs is from FY 2019. In FY 2019, the LEND and DBP programs reached 1,596 long-term trainees, 4,786 medium-term trainees, and 18,871 short-term trainees. By preparing these professionals to implement recommended screening practices and use evidence-based tools, the training programs are improving early identification of ASD/DD. The training programs also reach an extensive network of providers with continuing education, reaching 152,021 participants in FY 2019.

Data collected from the LEND and DBP programs show the direct impact of these investments on families affected by ASD/DD. The programs provided interdisciplinary diagnostic services for 121,610 infants and children in FY 2019. By training providers to gain additional skills in these areas, the programs contribute to the pool of providers able to provide diagnostic evaluations and entry into intervention services. The training programs are helping to address disparities in early identification of ASD by expanding their reach to underserved populations through innovative mechanisms including telehealth and teleconsultation. During the COVID-19 pandemic, most LEND activities were delivered virtually, including didactic training for trainees and fellows. Some sites were able to conduct virtual interdisciplinary clinical activities that involved trainees. For example, telehealth and teleconsultation increased during the pandemic in order to meet the needs of individuals and families with ASD/DD.

As part of the training grants, LEND and DBP programs provide technical assistance to and collaborate with other entities to enhance systems of care for children and youth with ASD and their families. Some LEND grantees have implemented innovative programming activities to address improved health outcomes and well-being for individuals with ASD. A few examples that highlight the ways in which LEND and DBP programs address comprehensive approaches to

improving health and well-being for individuals with ASD/DD through community-based supports, nutritional, recreational and social activities, and personal and public safety services are included below.

- **Nutrition:** The LEND clinic at the University of Massachusetts Center for Autism and Neurodevelopmental Disorders (CANDO) supports nutrition trainees to work with children and families around weight management and nutrition.
- **Public Safety:** The University of Alabama at Birmingham LEND faculty and trainees have provided technical assistance in two separate initiatives to train law enforcement and related personnel on improved identification, understanding, and management of individuals with neurodevelopmental differences in emergency and other contexts.
- **Social Skills:** The Kansas LEND continues to expand the Girls Night Out (GNO) program, which provides evidence-based social skills supports to girls with ASD, many of whom have co-occurring mental health diagnoses.
- **Transition:** The Iowa LEND's Transition Clinic is a service for youth with special health care needs, helping adolescents and their families move from pediatric health care to the adult service system by providing tools to teach self-advocacy and independence. Primary team members include a social worker, nurse practitioner, employment specialist, and other disciplines as needed. Areas of discussion include guardianship and living arrangements, health insurance, mental health, relationships and sexuality, nutrition and healthy lifestyle, activities of daily living, physical activity, education, and employment.
- **Community-Based Support:** Several DBP training programs are engaging in autism-friendly initiatives at their hospitals to address the challenges patients with autism may face in hospital settings, including sensory and communication barriers.
- **Community-Based Support:** The Stanford DBP program is introducing the construct of "**Growth Mindset**" to improve the outcomes of a diverse population of students in San Francisco. This community-participatory research project is engaging

families from five language groups, all of whom live in poverty, in the development and delivery of curricula about Growth Mindset, the notion that abilities of all kinds, including learning, behavior, and health, are to a large extent modifiable through environmental experiences and practice. The goal is to improve the developmental standing, academic achievement, and mental health of children and their families.

Research Programs

HRSA's **autism research programs** currently support four national Autism Intervention Research Networks (five-year project period), two Autism Single Investigator Innovation Programs (Autism SIIP) (five-year project period), the Autism Field-Initiated Research Studies (Autism FIRST) Program (three-year project period), and the Autism Secondary Data Analysis Research (Autism SDAR) Program (one-year project period) to advance the evidence base on effective interventions to improve the health and well-being of children and adolescents with ASD/DD. These programs address the needs of underserved populations, such as low-income, racial/ethnic minorities, individuals who have limited access to services, and other underserved populations. The research programs promote the development of evidence-based guidelines for interventions, validate tools for screening and interventions, and disseminate information to health professionals and the public. In FY 2019, the Autism Research Networks and Autism Single Investigator Innovation Programs collectively enrolled over 7,831 participants in primary studies through 44 sites and 228,770 participants in secondary studies. Over 250 researchers were engaged in autism research and developed 46 peer-reviewed publications in leading scholarly journals.

HRSA's autism research programs support interdisciplinary, applied, and translational research that advances the evidence base on effective interventions to improve the health and well-being of children and adolescents with ASD/DD. The programs implement comprehensive approaches to improving health outcomes and well-being for individuals with ASD/DD, including community-based behavioral supports

and interventions; nutrition, recreational, and social activities; and transition to adulthood as it relates to employment and social skills development. **Tables 1-14 in Appendix III** provide a detailed description of these projects/studies and the tools/guidelines developed under each autism research program.

Autism Intervention Research Networks

The Autism Intervention Research Networks establish and maintain an interdisciplinary, multicenter research forum for scientific collaboration and infrastructure building. They provide national leadership in research to advance the evidence base on effective interventions for children and adolescents with ASD/DD as they transition to adulthood across the lifespan. The Research Networks develop guidelines for those interventions and disseminate information related to such research and guidelines as authorized by the Autism CARES Act of 2019.

- The Autism Intervention Research Network on Physical Health (AIR-P) provides national leadership in research to advance the evidence base on effective interventions for children and adolescents with ASD/DD, with a focus on addressing physical health and well-being across the lifespan. Physical health may include, but is not limited to, medical, dental, visual, nutrition, and speech/hearing components. A **new grantee** was awarded for the most recent funding cycle starting in FY 2020 for a five-year project period.
- The **Autism Intervention Research Network on Behavioral Health (AIR-B)** provides national leadership in research to advance the evidence base on effective interventions for children and adolescents with ASD/DD, with a focus on addressing behavioral health and well-being across the lifespan.
- The **Developmental Behavioral Pediatrics Research Network (DBPNet)** provides national leadership in research to advance the evidence base in the developmental, behavioral, and psychosocial aspects of pediatric care. DBPNet works to develop effective interventions in clinical services and health and related outcomes for children and adolescents with ASD/DD across the lifespan.

- The **Healthy Weight Research Network (HWRN) for Children with ASD/DD** provides national leadership in research designed to improve the promotion of healthy weight through the prevention and treatment of overweight, obesity, and underweight among children and adolescents with ASD/DD.

Autism Single Investigator Innovation Program (Autism SIIP)

The Autism SIIP supports two projects focused on priority or emerging ASD/DD research areas and research topics with limited research.

- The **Autism Longitudinal Data Project (ALDP)** supports the implementation and completion of research studies that examine longitudinal data on ASD/DD to study risk factors for these conditions, the effects of various interventions, and trajectories of child development over the life course. ALDP addresses the following:
 - Physical and behavioral aspects of development and assessment at different stages of life course development;
 - Underserved populations, including minority, urban, or rural populations;
 - Early life origins and onset;
 - Maternal and perinatal origins;
 - High-risk populations;
 - Development and course of condition;
 - Primary prevention; and
 - Development of potential intervention studies.
- The **Autism Transitions Research Project (ATRP)** supports the implementation and completion of research studies that examine factors associated with healthy life transitions among adolescents and young adults with ASD who are transitioning to adulthood in order to:
 - Advance the evidence base available to researchers, providers, policy makers, educators, adolescents and young adults with ASD and their families, and the public regarding factors associated with healthy life (physical, social,

mental health, and educational/occupational) outcomes among this population;

- Address the critical need that exists for ASD transitions research that targets the social environment and not just the individual; and
- Provide national leadership and education in research on healthy transitions to adulthood for this population.

Autism Field-Initiated Innovative Research Studies (Autism FIRST) Program

The **Autism FIRST** program supports research studies testing the implementation of new/innovative strategies that address critical issues surrounding the health of children and adolescents with ASD. There is a special focus on addressing the needs of underserved populations and promoting health and well-being through supports and services offered to children and youth with ASD/DD (and their families) up to the age of 21, recognizing that these years lay the foundation for health and well-being across the lifespan.

Autism Secondary Data Analysis Research (Autism SDAR) Program

The **Autism SDAR** program supports secondary data analyses of national datasets and/or administrative records to advance the evidence base on interventions designed to improve the health and well-being of children and adolescents with ASD/DD, with a particular focus on addressing barriers to identification, diagnosis, interventions, and services among underserved populations.

State Programs

In FY 2019, HRSA funded five grants through the Innovations in Care Coordination for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities Program. The purpose of the program is to improve access to coordinated and integrated care for children with, or at risk for, ASD/DD and their families in medically underserved areas and populations. The grantees are implementing two strategies to achieve their goal: (1) increasing

family navigation services to improve communication between families and primary and specialty providers and (2) providing education, training, and technical assistance through a learning community to providers and community-based organizations on improving care for children with/at risk for ASD/DD.

The state system grantees improved quality of care among children and youth with ASD/DD by promoting family engagement through training, outreach, resource development, and quality improvement activities, which included children and youth with ASD/DD and their family members. During FY 2018, nearly 80,000 individuals received services to facilitate family engagement including through family navigation and other strategies. More than 37,000 individuals were reached by services to promote and facilitate screening and follow up care, and the grants helped more than 200 individuals access and use services through medical homes.

Indian Health Service (IHS)

The **Indian Health Service (IHS)** is responsible for providing federal health services to American Indians and Alaska Natives (AI/AN). The provision of health services to members of federally recognized Tribes grew out of the special government-to-government relationship between the federal government and Indian Tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. The IHS is the principal federal health care provider and health advocate for American Indian people, and its goal is to raise their health status to the highest possible level. The IHS provides a comprehensive health service delivery system for approximately 2.6 million American Indians and Alaska Natives who belong to 574 federally recognized tribes in 37 states.

The IHS mission is to *raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level*. The IHS vision is to promote healthy communities and quality health care systems through strong partnerships and culturally responsive practices.

The strategic goals of IHS are to:

- Ensure that comprehensive, culturally appropriate personal and public health services are available and accessible to American Indian and Alaska Native people;
- Promote excellence and quality through innovation of the Indian health system into an optimally performing organization; and
- Strengthen IHS program management and operations.

The IHS does not have any programs or funding specifically focused on provisions of the Autism CARES Act of 2019 or for individuals on the autism spectrum. However, as a federal health care organization, IHS does provide services to AI/AN patients with ASD.

Indian Children's Program (ICP)

As part of the IHS mission to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level, IHS is committed to providing education, training, consultation, and resources to clinicians treating patients with neurodevelopmental disorders, including ASD, through the IHS **Indian Children's Program (ICP)**. In 2016, the ICP transitioned under the IHS **Telebehavioral Health Center of Excellence (TBHCE)** to become a national program. The TBHCE currently provides training and support to health care providers regarding behavioral health, family, and social issues facing AI/AN youth diagnosed with neurodevelopmental disorders, including ASD. These services are available to all IHS, Tribal, and urban Indian organization providers and include no-cost continuing education credits. Currently, IHS has 28 webinars on ASD and autism-related topics available any time to any health care provider providing care to American Indian and Alaska Native patients.

In response to COVID-19, IHS provided three webinars to assist health care providers in supporting families of children with ASD and other neurodevelopmental disorders during the COVID-19 pandemic. Topics in the IHS COVID-19 Response Webinar Series included:

- **Supporting Safety for Families of Children with Neurodevelopmental Disorders during COVID-19;**
- **Emotion and Behavior Regulation Support for Families of Children with Neurodevelopmental Disorders during COVID-19;** and
- **Learning Support for Families of Children with Neurodevelopmental Disorders during COVID-19.**

In 2021, IHS hosted a webinar training series on ASD to develop health care providers' skills to treat individuals with ASD. Topics included:

- **Introduction to Autism Spectrum Disorder;**
- **Screening and Diagnosis of Autism Spectrum Disorder;**
- **After an Autism Spectrum Diagnosis: Next Steps;**
- **Applied Behavior Analysis for Autism Spectrum Disorder;** and
- **Supports for Transition-Aged Individuals with Autism Spectrum Disorder.**

In observance of World Autism Day on April 2, 2021, IHS hosted the third annual **Autism Awareness Interagency Roundtable**. Various agencies shared their ASD policies and how each aims to maximize the quality of life of those with ASD. Federal officials and Autism Speaks also discussed recent collaborations, important resources for those with ASD, the impact of COVID-19 on services, and held a Q&A session.

Behavioral Health Integration Initiative (BH2I)

The IHS established the **Behavioral Health Integration Initiative (BH2I)** in 2017, awarding \$6 million to 12 projects for a three-year funding cycle. BH2I projects plan, develop, implement, and evaluate behavioral health integration with primary care, community-based settings, and/or integrating primary care, nutrition, diabetes care, and chronic disease management. The purpose of BH2I is to improve the physical and mental health status of people with behavioral health issues by developing an integrative, coordinated system of care between behavioral health and primary care providers.

One example of how IHS and other federal agency programs can work together to benefit AI/AN children is shown in funding to the Muscogee (Creek) Nation (MCN). In 2012, the MCN received funding as a part of SAMHSA's Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) grant allowing them to identify the needs, barriers of services, gaps in the current provision of services, and other problems related to the needs and implementation of wellness activities and services for Native American children from birth to 8 years of age. The Survey of Well-Being of Young Children (SWYC) developmental screening was used to help in the assessment process. Through this assessment, they identified their best course of action was early intervention with the Tribal Head Start population. Though the Head Start programs were a good start in the identification and intervention of services to children, they soon realized they needed to add services within the tribal pediatric primary care clinics. The request for the BH2I grant was written to help fill that need. In 2017, MCN Behavioral Health Services was awarded a BH2I grant to address the unmet needs for children and youth.

MCN continued infrastructure development while providing early identification, intervention, and treatment services. BH2I continues to provide some services in Head Starts, but its primary role is integration of behavioral health services in the pediatric primary care clinics. Services are provided to all patients, ages 0 to 18, as well as parental screening and supports. Behavioral Health Clinicians (BHCs) are housed in the primary care clinic alongside the pediatrician and nursing staff. The BHCs have specialized training in Integrated Medicine and are able to offer patients a range of services from basic mental health to full wellness services.

Upon entry to the pediatrician's office, universal screening instruments are administered to each patient whose guardian consents to participate. The age of the child determines which standardized screening is offered. In addition, the SWYC is completed, for ages 0 to 5, by the parent every three months or at well-child exams to screen for development, additional symptoms, parental, and environmental concerns. Other screening instruments that are administered are listed below:

- Multiple versions of the Pediatric Symptom Checklist (PSC) have been developed for babies as well as preschool-aged children and are built into the SWYC. The PSC screens for symptoms of distress and mood, interpersonal relations and behavior, and attention. The standard PSC is given to all children 6 to 10 years old. The Youth Pediatric Symptom Checklist (YPSC) is a youth self-report that screens for emotional, behavioral, and physical symptoms for ages 11 or older. The Patient Health Questionnaire (PHQ-9) modified for Adolescents (PHQ-A) and General Anxiety Disorder-7 (GAD7) are completed together, and the YPSC is optional for children between the ages of 11 and 16. The PHQ screens for depression, and the GAD-7 screens for anxiety.
- The Car, Relax, Alone, Forget, Friends, Trouble (CRAFT) screening test is completed for ages 12 to 17. It screens for substance use, substance-related riding/driving risk, substance use disorder, and associated risky behaviors. Additional screeners include the Center for Youth Wellness (CYW) Adverse Childhood Experiences Questionnaire for all children over 6 years old, which screens for trauma and adverse events.
- The Columbia Suicide Severity Rating Scale (C-SSRS) screener is given to all children over 11 years old if there is concern for suicidality.
- The Edinburg Depression Scale is given to new mothers. If a young child ages 16 to 30 months shows signs of developmental delays, even after parent coaching, patient coaching, and behavioral health intervention, a Modified Checklist for Autism in Toddlers (M-CHAT) is provided. Many pediatricians prefer to monitor the child over the course of months before further screening and testing is administered. All screening instruments are also used as measurement tools to gauge progress or decline in the patient.

If any concerns are identified from the screening instruments or from the pediatrician's exam, the BHC is asked to meet with the patient and offer brief services. The BHCs attend the behavioral health staff meetings to consult on the most concerning patients. If a patient has received all services available within

the pediatric clinic with no progress, then a referral is made to a partnering internal tribal provider or an outside partnering provider such as outpatient mental health treatment, psychiatry or psychology, occupational or speech, nutrition or dietician, or other specialty treatment providers.

National Institutes of Health (NIH)

The **National Institutes of Health (NIH)** is the nation's medical research agency. NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. As part of this mission, NIH supports scientific research to better understand the causes and mechanisms underlying ASD, improve methods of early identification and diagnosis, and develop interventions to improve overall health among children, adolescents, and adults with ASD (e.g., **PA-21-199/-200/-201**). NIH makes coordinated efforts to invest in a wide range of ASD research. Information on aggregate NIH funding for autism can be found on NIH's **Research Portfolio Online Reporting Tools (RePORT)** under **Research, Condition, and Disease Categories (RCDC)**.

NIH Autism Centers of Excellence (ACE)

NIH created the **ACE Program** in 2007 with a series of five-year awards to launch an intense and coordinated research program into the causes of ASD and to find new treatments. Now in its 14th year, the ACE Program continues to make substantial progress in addressing a wide array of important issues facing the health and well-being of individuals with ASD and their families. Current **ACE grantees** are examining issues that include the genetic etiology of autism, the neurodevelopmental underpinnings of ASD, improving cognitive and developmental outcomes, how boys and girls with ASD differ in their brain circuitry, improving screening and diagnosis of ASD, improving access to services for minority children with ASD, and developing novel interventions and services through new delivery methods. Furthermore, the five ACE Centers (**P50HD093079, P50HD055784, P50MH115716, P50HD093074, P50MH100029**)

and five ACE Networks, which involved multiple institutions (**R01MH100027**, **R01MH100028**, **R01HD055741**, **R01MH115715**, **R01HD093055**), have been critical training venues for developing and mentoring the next generation of leading investigators and clinicians in the field of autism research and treatment. The ACE Program is supported by the NICHD, the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institute of Environmental Health Sciences (NIEHS), NIMH, and the National Institute of Neurological Disorders and Stroke (NINDS). These Institutes plan to renew the ACE Program in 2022 (**NOT-HD-21-006/-007**).

NIH Early Autism Screening Initiative

In October 2019, the NIH awarded research grants to seven separate teams of investigators to support projects focused on developing and validating screening tools to detect signs of ASD in the first year of life. Efforts to improve our ability to screen and identify autism at earlier ages will allow families and care providers to enroll children in early interventions, services, and treatments that have been shown to improve developmental outcomes, overall well-being, and readiness for school (**R01MH121363**, **R01MH121364**, **R01MH121329**, **R01MH121345**, **R01MH121344**, **R21HD102078**, **R21HD100372**). NICHD, NIDCD, NIMH, and NINDS support these projects.

Autism Biomarker Development

An NIH-funded multi-site study, the Autism Biomarkers Consortium for Clinical Trials (**U19MH108206**) has made substantial progress in developing electroencephalogram (EEG) and eye tracking measures that show promise as potential biomarkers that can reduce heterogeneity within research samples via stratification and/or serve as sensitive and reliable objective measures of social impairment in ASD clinical trials. The EEG and eye-tracking measures were accepted by the U.S. Food and Drug Administration (FDA) in its **Center for Drug Evaluation and Research (CDER) Biomarker Qualification Program** as potential stratification markers in ASD clinical trials. In 2020, the same investigative team received NIH funding to

conduct the **second stage** of this study. In this second stage, researchers aim to follow-up with the original study cohort to examine the longer-term stability of these measures, with re-administration of the biomarkers and clinical tests; sample a new cohort of children to see if the original findings can be replicated and confirmed; perform a feasibility study to examine how the same EEG and eye tracking measures operate in children ages 3 to 5, both with and without ASD; and continue collecting blood samples and data sharing. This research is supported by NICHD, NIDCD, NIMH, and NINDS.

Autism Genomics Research

In the area of genomics research, NIH initiatives and programs continue to make significant strides to better understand and identify the biological cause(s) of autism and its genetic architecture. Through large-scale efforts that involve multi-site research collaborations and extensive data sharing, the NIH has significantly broadened the repository of genetic data on individuals and families affected by ASD. This has enabled researchers to interrogate the vast array of potential genetic mechanisms that increase risk for ASD and to increase the ancestral diversity of ASD participants in genomics research. Examples include the renewal of an NIMH-funded Autism Center for Excellence focused on recruitment in the African American community (**R01MH100027**), as well as an effort to explore the genetic relationship between ASD, ADHD, and IDD in South Africa (**U01MH119689**). The South Africa project came in response to the rare disorder initiative (**RFA-MH-19-200/-201**).

NIMH-supported genomics consortiums are continuing to increase the size of their ASD cohorts to increase power. As the size of cohorts increase and enable higher powered studies, researchers are now seeking to disentangle the relationship between genetic architecture and the heterogeneity of observed traits (e.g., **R01MH111813**), as well as the relationship to IDD and the role of mutations on the X chromosome. There is ongoing work following up on possible genetic risk mechanisms. For example, a recent large-scale sequencing study identified specific genes differentially related to two distinct types of ASD:

ASD characterized by extensive co-occurring neurodevelopmental or cognitive deficits and ASD without co-occurring neurodevelopmental or cognitive disorders.³⁸ Furthermore, the **Report of the National Advisory Mental Health Council Workgroup on Genomics** specifically encouraged follow-up of high-confidence genes with strong genome-wide significance.³⁹

Deeper understanding of rare genetic disorders thought to be associated with autism and co-occurring conditions may advance understanding of ASD due to other causes and pave the way for broadly applicable treatments. NINDS, NIMH, NICHD, and the National Center for Advancing Translational Sciences (NCATS) support the Developmental Synaptopathies Consortium (**U54NS092090**), which conducts studies of genetic conditions (e.g., associated with TSC1/2, PTEN, and SHANK3 mutations) that affect the synapses between neurons in the brain and are associated with a high risk for ASD and ID, to uncover shared molecular pathways and new therapeutic targets. This consortium led to an additional project that aims to establish electrophysiological biomarkers of Phelan-McDermid syndrome (resulting from SHANK3 mutations), use these biomarkers to identify an overlapping subset of children with ASD, and evaluate whether the biomarkers are predictive of treatment response in a clinical trial (**R01NS105845**). Another project will use neuroimaging to investigate brain mechanisms underlying autism in children with neurofibromatosis type 1 (**R21NS106135**).

Autism Gene-Environment Interaction Research

NIEHS supports research on the interplay of genetic predisposition in the presence of certain environmental factors (e.g., infection, air pollution, nutrition) in an effort to provide a more complete picture of how ASD and relevant comorbidities may arise. Gene-environment interaction research may help identify/characterize high-risk groups or subgroups of individuals with ASD, identify potentially modifiable risk factors, and inform novel treatments, as well as the development of targeted interventions that may reduce disability and comorbidity (e.g., ADHD). For example, one NIEHS-funded study is building on

18 years of research, having identified numerous chemicals (e.g., air pollutants), nutritional factors (e.g., folic acid), and maternal health conditions (e.g., infection) associated with altered risk for ASD and secondary disabilities (**R01ES031701**). NIEHS-funded researchers are also examining how traffic-related pollution, in the context of many genes that include those involved in detoxifying chemical and nervous system development, may increase risk for ASD or ADHD in children (**R01ES026993**). Given the shared biologic pathways between some genes and certain environmental exposures, these projects may help advance etiologic research toward targeted interventions that reduce risk for ASD-associated disabilities and co-occurring conditions.

Additionally, understanding the role that maternal exposures have on brain development and other birth outcomes may lead to new strategies to prevent or ameliorate ASD-associated disabilities. For example, NIEHS-funded researchers aim to determine associations between ASD risk and prenatal serum concentrations of endocrine disruptors (chemicals that interfere with the hormonal system; **R01ES026904**). They are also assessing whether gender modifies sensitivity to prenatal endocrine disruptor exposure and whether concentrations of endocrine disruptors, singly and in combination, contribute to individual differences in ASD phenotype and severity. Other NIEHS-supported researchers are examining common, early-life metals exposure (via shed deciduous teeth as biomarkers) on the development of ASD and dimensional ASD phenotypes, as well as cognitive development and adaptive function (**R01ES029511**). NIEHS-funded researchers are also examining the relationship between prenatal exposure to environmental contaminants and vitamin supplements as risk factors for ASD, schizophrenia, and ADHD (**R01ES028125**).

Eunice Kennedy Shriver Intellectual & Developmental Disabilities Research Centers

NICHD's **Eunice Kennedy Shriver Intellectual & Developmental Disabilities Research Centers** support research at 14 universities and children's hospitals across the U.S. to provide support for research in people who have IDD, including some individuals on

the autism spectrum, and advance the development of therapeutics and interventions for these conditions. Research projects include comprehensive “-omics” (i.e., genes, proteins, and metabolites that may underlie fundamental mechanisms) approaches to increase our understanding of risk and resilience, development of innovative technologies to improve assessment and intervention, characterization of auditory brain processing in those with ASD who are minimally verbal or nonverbal, and testing interventions and management of co-occurring health conditions. A group of scientists at one of these centers discovered that identical twins with ASD often experience large differences in severity of disability, even though they share the same DNA. Scientists are working on identifying the causes of this variability to inform the treatment of disabling aspects of ASD (**U54HD087011**).

Interventions Research

NIH Institutes and Centers are funding projects that are developing and evaluating a range of interventions. For example, an NINDS clinical trial is testing whether presymptomatic treatment with anti-seizure medication prevents epilepsy in infants with Tuberous Sclerosis Complex (TSC, a genetic condition with high risk for ASD and IDD) and whether treatment improves cognitive and behavioral outcomes or reduces the likelihood of developing ASD (**NCT02849457**, **U01NS092595**). NINDS, NICHD, and NIDCD are supporting a second trial (**NCT02920892**, **U01NS096767**) testing whether an mGluR5 inhibitor, in combination with an intensive language intervention, can boost language learning in children with Fragile X Syndrome (FXS). Negative modulators of mGluR5 have been reported to correct a broad range of phenotypes related to FXS, many of which are similar to ASD. Another NINDS-funded research study aims to develop quantitative brain imaging biomarkers that could be used to identify ASD and to evaluate and predict responses to therapeutic interventions (**R01NS035193**).

NIDCD is supporting intervention development targeting the language and communication challenges associated with ASD. Examples include studies to improve language outcomes in minimally

verbal children with ASD (**P50DC018006**, **K99DC017490**), a web-based program to enhance social communication skills for employment success in autistic youth (**R43DC016769**), a visual communication aid for improved comprehension of classroom instruction for students with ASD (**R43DC017633**), and an intervention to improve reading in children with ASD (**R01DC016303**).

NICHD-funded researchers are also developing a variety of therapeutic and intervention approaches, including a community-based adaptive intervention for toddlers with ASD (**R01HD098248**) and an evaluation of augmentation strategies for use when children with ASD are slow to respond to initial interventions. A small controlled clinical trial of a drug, arginine vasopressin (AVP), showed that intranasal AVP may improve social behaviors in children with ASD. The AVP medication was well-tolerated and produced minimal adverse effects.⁴⁰

NICHD also supported the development of a virtual reality “smart glasses” application to encourage facial engagement and provide feedback to a child with ASD during social interactions. Children using the application to augment ABA showed significantly improved emotion recognition and facial engagement.⁴¹

Research on Long-term Outcomes

Children who have ASD often receive services through school systems. A longitudinal analysis of services, ranging from physical or speech therapy to personal care or respite services over 14 years, found that people with ASD received significantly fewer services after high school. The decrease in services was greater for those who had ASD and ID than it was for those who only had ASD.⁴² NICHD-funded scientists are working to address long-term outcomes of children with ASD. For example, one group of researchers is assessing the long-term outcomes of children with ASD at ages 14 to 15 who received early intensive behavioral intervention in the preschool years (**R01HD087302**). Another group of researchers is working to identify the behavioral and social factors in early childhood that contribute to positive and negative outcomes in adults with ASD (**R01HD081199**).

ASD Pediatric Early Detection, Engagement, and Services (PEDS) Network

Beginning in 2014, NIMH supported five research grants that composed the ASD PEDS Network (R01MH104302, R01MH104355, R01MH104400, R01MH104423, R01MH104446). ASD PEDS researchers tested strategies for universal screening coupled with referral to and engagement in services when indicated for children with ASD from 12 to 36 months of age. The researchers also examined the issues surrounding coordination among different settings including primary care and community service agencies. The ASD PEDS investigators compiled information across their individual studies and identified common implementation strategies (e.g., developing stakeholder relationships and provider trainings) and barriers (e.g., inefficient systems of care, difficulty engaging families in the interventions, provider attitudes, and organizational culture). They found that despite diverse settings and a variety of innovation content, common facilitators and challenges exist in implementing innovations to enhance access to early ASD screening, diagnosis, and treatment.⁴³ Findings from one of the ASD PEDS projects suggest that an ASD diagnosis becomes stable starting at age 14 months and overall is more stable than any other diagnostic category including language or developmental delay.⁴⁴ Furthermore, once a child is identified as having ASD, there is an extremely low chance that he or she will test within typical levels at age 3. This finding opens the opportunity to test the impact of very early age treatment of ASD. Main findings from a second ASD PEDS project suggest that utilizing “family navigators” to engage caregivers in recommended services improved the likelihood of diagnostic ascertainment among children from racial/ethnic minority, low-income families who were detected in primary care as at-risk for ASD.⁴⁵

Early Screening Recommendation

In February 2016, the **U.S. Preventive Services Task Force (USPSTF)** issued a **recommendation** on early screening for ASD. The USPSTF found that the evidence at the time of their review was insufficient to assess the balance of benefits and harms of screening for

ASD in children aged 18 to 30 months for whom no concerns of ASD have been raised by their parents or a clinician. In 2017, NIMH issued a Notice (**NOT-MH-18-001**) to encourage administrative supplement requests to collect data from active NIMH-funded studies that were relevant to the 2016 USPSTF recommendation. In April 2018, NIMH supported five supplement requests focused on the measurement of short-term and intermediate risks and benefits of early ASD screening and preliminary validation of broadband screening instruments testing young children at age 12 months. In addition, NIMH-funded research is identifying and addressing disparities in access to screening, diagnosis, and treatment services among ethnic and racial minority children at risk for ASD. In March 2021, NIH Institutes and Centers provided feedback to the USPSTF request for public comment on its draft research plan on screening for ASD in young children. In June 2021, USPSTF posted the **final research plan**.

Identifying and Addressing the Needs of Transition-Aged Youth and Adults with ASD

NIMH supports services research projects on transition-aged youth and adults with ASD. “Transition-aged youth with ASD” refers to individuals with ASD who, in the coming months or years, will age out of the services and supports delivered via K-12 education and other child/adolescent service systems. NIMH’s portfolio includes development and preliminary testing of interventions to improve a range of skills and functional outcomes. Additionally, researchers aim to refine strategies to measure functional outcomes in these age groups. Research projects also include a focus on improving competitive employment outcomes, strategies for achieving self-management of co-occurring health conditions, improving understanding of social relations, and engaging siblings of adults with ASD in future planning to achieve optimal long-term outcomes (R34MH111556, R34MH111536, R34MH111531, R34MH111491, R34MH111489). NIMH is also addressing the need for more research aimed at fostering effective and developmentally appropriate services for adults and transition-aged youth by enriching the pool of autism researchers focused on this specific population, through

career development and enhancement awards (RFA-MH-20-420/-421). One NIMH-funded career enhancement award recipient is examining a strength-based intervention to improve job interview skills in transition-aged youth with ASD (K18MH122847). In addition to NIMH's efforts, NINDS is supporting research to address complex, real-world activities that may present challenges for transition-aged youth and adults with ASD. For example, NINDS-funded researchers are using brain imaging to evaluate motor and cognitive control impairments associated with driving performance in adolescents with ASD (R21NS118410).

NIH Rapid Acceleration of Diagnostics-Underserved Populations (RADx-UP) Initiative

NIH created the **RADx-UP initiative** to reduce COVID-19-associated morbidity and mortality disparities for those vulnerable and underserved populations that are disproportionately affected by, have the highest infection rates of, and/or are most at risk for adverse outcomes from contracting the virus. This initiative encourages researchers to leverage partnerships with key stakeholders to conduct community-engaged research to understand COVID-19 disparities and to increase the effectiveness of and access to COVID-19 diagnostic testing interventions among medically underserved and/or socially vulnerable populations. Through the RADx-UP initiative, NIH-funded researchers aim to address the urgent needs of vulnerable populations, such as individuals with IDD, including individuals on the autism spectrum. For example, NICHD-funded researchers are examining an FDA-approved saliva-based SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2, the virus that causes COVID-19) tests for students, teachers, and staff in special education schools (P50HD103525). Other NICHD-funded researchers are evaluating surveillance testing approaches and mitigation strategies to guide the safe return to school for vulnerable children with IDD and staff (OT2HD107556) and assessing national perspective among parents of children with IDD and school staff regarding the impact of COVID-19 and the importance of SARS-CoV-2 testing (OT2HD107553).

HHS Office of Disease Prevention and Health Promotion (ODPHP)

The HHS **Office of Disease Prevention and Health Promotion (ODPHP)** establishes and promotes national public health priorities to improve the health and well-being of all people, including those with ASD or other developmental disabilities. ODPHP manages the **HHS Healthy People** initiative, which helps individuals, organizations, and communities committed to improving health and well-being address public health priorities through evidence-based, 10-year national objectives. Objectives for **Healthy People 2030**, the fifth and current iteration of the initiative, include increasing the proportion of children with ASD who receive special services by age 4 years and increasing the proportion of children who receive a developmental screening.

Substance Abuse and Mental Health Services Administration (SAMHSA)

The **Substance Abuse and Mental Health Services Administration (SAMHSA)** leads public health efforts to advance the behavioral health of the nation. SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities. SAMHSA-funded activities broadly impact the health and well-being of individuals with mental health conditions, including those with ASD, and their families.

Since 1993, SAMHSA has implemented the Congressionally mandated Comprehensive Community Mental Health Services for Children with Serious Emotional Disturbances Program, also known as the Children's Mental Health Initiative (CMHI). CMHI serves children and young adults (birth through 21) who are at risk or meet criteria for serious emotional disturbance. Approximately 3.7% of this population also has a comorbid pervasive developmental disorder, which may include ASD. This initiative provides funds to public entities to create "systems of care," which are defined as a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth,

and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.

SAMHSA currently funds 95 CMHI grants to support expansion of systems of care. Additionally, SAMHSA also funds 28 Circles of Care grants, which are planning grants specifically to tribal communities to assist in building the infrastructure to implement systems of care approach. These grants promote the expansion of system of care services and supports, including infrastructure development and collaboration and partnership between child-serving systems (e.g., child welfare, education, juvenile justice, primary care and substance abuse services and systems, and strategic financial planning), so that the system of care framework can be brought to scale and sustained after grant funding has ended. The most recent **Report to Congress** on this program details outcomes from a national evaluation of nine demonstration grants and presents information on Expansion and Sustainability grants.

DEPARTMENT OF DEFENSE (DOD)

The **U.S. Department of Defense (DoD)** is charged with coordinating and supervising all agencies and functions of the government concerned directly with national security and the U.S. Armed Forces. This Report provides details on research and service and support activities in the Army and the Military Health System (MHS)/TRICARE.

Army

The DoD **Autism Research Program (ARP)** was first established through language in the 109th United States Congress, House of Representatives Conference Report (H.R. 5631) in FY 2007 with an appropriation of \$7.5 million for research on ASD in the military. Following in FY 2008 through FY 2020, the DoD ARP has continued through the Defense Health Program with additional appropriations. From FY 2007 to 2020, a total of \$104.4 million has been designated for research into ASD through an addition to the DoD appropriation bill. This program is not authorized or funded through the Autism CARES Act of 2019.

The ARP is a partnership between the DoD, researchers, and consumers. The vision and mission of the ARP has been to improve the lives of individuals with ASD now by promoting innovative research that advances the understanding of ASD and leads to improved outcomes for Service Members, their families, and the American public. This sense of urgency has resulted in funding research aimed at having an immediate impact on the health and well-being of those with ASD. These projects include those focused on investigating and improving health outcomes and promoting community inclusion for those living with ASD.

Physical and Mental Health

- Dr. Nancy Cheak-Zamora (University of Missouri) examined how often youth with ASD are taught to manage their health and self-care needs and thereby achieve health-related independence (HRI). The HRI measures developed were the first to specifically measure independence in youth with ASD as well as identify specific areas in which clinicians, ASD specialists, and caregivers should focus to improve independence.
- Dr. David Beversdorf (University of Missouri) is investigating the use of propranolol on social interaction and secondarily on language tasks, anxiety, adaptive behaviors, and global function in high-functioning autistic youth. Findings from this randomized clinical trial could result in a new evidence-based treatment option for core features of ASD.
- Dr. Nathan Call (Emory University) is investigating the combination of therapeutic treatment and behavioral approaches to treat encopresis (fecal incontinence) in children with ASD. By examining potential treatment methods for encopresis through this clinical trial, ASD children and their families will benefit through decreased parental stress and increased inclusion in the community.
- Dr. Cynthia Johnson (Cleveland Clinic Foundation) is developing a parent training program targeting sleep disturbances in young children with ASD. Sleep issues in children with ASD can amplify already

delayed social interactions, repetitive behaviors, affective problems, inattention/hyperactivity, and irritability. Treating these sleep disturbances in ASD children may promote overall improvement in daily life.

- Dr. Carla Mazefsky (University of Pittsburgh) is evaluating the efficacy of an intervention termed Emotion Awareness and Skills Enhancement (EASE) in improving functional impairment and psychiatric symptoms in young adults with ASD.

Employment, Education, and Social Inclusion

- Dr. Paul Wehman (Virginia Commonwealth University) is looking at the impact of Project Search on employment outcomes of military dependents with ASD. Preliminary data show that the Project Search is highly successful in enhancing employment outcomes in the study population.
- Dr. Connie Sung (Michigan State University) is evaluating the effectiveness of a manualized work-related social skill training intervention to improve social skills and self-efficacy in youth with ASD. Individuals who participate in this study are expected to show gains in social skills, social self-efficacy, adaptive functioning, anxiety, and work readiness.
- Dr. Amie Duncan (Cincinnati Children's Hospital) is testing an intervention that aims to improve daily living skills in adolescents with ASD. Outcome measures of this study include college placement, employment, independent living, social participation, and quality of life.
- Drs. Klinger and Tomaszewski (University of North Carolina) are assessing the efficacy of the manualized intervention T-STEP on school transition and employment in young adults with ASD. This intervention includes a combination of a job internship, academic counseling, and career counseling.

Military Health System (MHS)/TRICARE

TRICARE offers comprehensive medical care to over 9.4 million beneficiaries (active duty service members, military retirees, and their eligible family members), including approximately 2 million children. This also includes over 35,000 MHS beneficiaries (in FY 2020) diagnosed with ASD.

The **Military Health System (MHS)** includes physician and other licensed independent provider services, pharmacy coverage, psychosocial treatment, psychological testing, occupational therapy, physical therapy, and speech and language pathology for the treatment of ASD to all eligible TRICARE beneficiaries under the TRICARE Basic Program, which is the medical benefit plan of the MHS. A separate but related TRICARE program, the **Extended Care Health Option (ECHO)**, offers supplemental services to Active Duty Family Members (ADFMs) with a qualifying physical or psychologically disabling condition, including ASD. The Department has provided coverage for ABA services to family members of active duty service members since 2001 under various coverage authorities. Coverage for retiree family members was added on July 26, 2012.

On July 25, 2014, all existing ABA service programs were consolidated into one demonstration, the Comprehensive Autism Care Demonstration (ACD), which provides a consistent ABA benefit program to all TRICARE eligible beneficiaries diagnosed with ASD. Approximately 16,000 TRICARE eligible beneficiaries are currently enrolled in the ACD (for FY 2020), with over 53,000 ABA providers rendering ABA services. Participation in ABA service programs has significantly increased since FY 2009. For FY 2019, the ACD costs totaled \$376.9 million dollars. The ACD was originally scheduled to end December 31, 2018; however, the ACD has been extended until December 31, 2023, to obtain more information on how to classify ABA services under the TRICARE benefit and best serve military beneficiaries with ASD. The ACD removed all quantitative and non-quantitative limits on ABA services, including dollar caps, hour caps, and age

caps. Over the course of the demonstration, the Defense Health Agency (DHA) has hosted various round table and information sessions for interested stakeholders including, but not limited to, ABA providers, Active Duty military providers, advocates, families, and congressional staff. Additionally, current ACD initiatives include TRICARE quality management audits, outcome measures, parent surveys, and DoD Office of the Inspector General audits. Most recently, the Department published a policy change that included a number of improvements to the ACD, including enhanced support to parents and caregivers, improved care coordination, and ensuring that services are directed to those beneficiaries who will benefit the most, with the focus always being on helping military beneficiaries diagnosed with ASD, and their families, to reach their maximum potential.

Most services for military beneficiaries are provided through a contracted network of civilian providers; however, several military medical treatment facilities have recently developed programs to support beneficiaries diagnosed with ASD and their families. These initiatives include:

- The Fort Belvoir Community Hospital (FBCH) Autism Resource Center, which is designed to provide resources for beneficiaries newly diagnosed with ASD and their families;
- The Joint Base Lewis McChord Center for Autism Resources, Education and Services (JBLM CARES) program, which provides patient-centered care services for beneficiaries diagnosed with ASD and their families during the transition period of locating purchased care services; and
- Deployment of the Play & Language for Autistic Youngsters (PLAY) Project, first launched within the MHS at Wright Patterson Air Force Base (WPAFB), which provides training of a portable parent-focused early childhood intervention to beneficiaries diagnosed with ASD.

To acquire additional information on ABA services under TRICARE, the DHA has been working with the Congressionally Directed Medical Research Program (CDMRP), which awarded a \$7 million **contract** to a

research group from the University of Rochester. The results of the CDMRP study will further DHA's understanding of the impact of ABA services delivered to ACD participants and aims to provide important data regarding the most beneficial amount of ABA services. Additionally, findings from this study may benefit the larger community of individuals diagnosed with ASD and their families in several ways, including, but not limited to, offering more choices to families, potentially identifying response to treatment through predictive factors, and lowering cost while increasing access. The CDMRP study was awarded September 2018. This study will provide annual reports to CDMRP starting in 2020 and has a duration of five years. Participant recruitment is ongoing at three sites: Vanderbilt University, Nationwide Children's Hospital, and the May Institute.

DEPARTMENT OF EDUCATION (ED)

The mission of the **U.S. Department of Education (ED)** is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. ED supports programs to develop and implement evidence-based practices for services to youths and postsecondary students, as well as programs for individuals with disabilities who have graduated from high school or a postsecondary institution and are seeking vocational rehabilitation services. ED supports ASD-related services, supports, and research through programs administered by ED's Institute of Education Sciences (IES), the Office of Special Education and Rehabilitative Services (OSERS), and the Office of Postsecondary Education (OPE). An overview of these programs is provided below.

Institute of Education Sciences (IES)

The **Institute of Education Sciences (IES)** is the independent research, evaluation, and data collection arm of ED whose mission is to provide scientific evidence on which to ground education practice and policy and to share this information in formats that are useful and accessible to educators, parents, policy makers, researchers, and the public. Each of the four IES

Centers supports work related to ASD. The programs and projects administered by the four IES Centers, which do not use Autism CARES Act of 2019 funds, are described below.

National Center for Special Education Research (NCSER)

The **National Center for Special Education Research (NCSER)** funds research on ASD primarily under the **Special Education Research Grants Program (84.324A)**. This program supports research on comprehensive interventions that target multiple, coordinated outcomes, as well as targeted interventions focused on a single outcome (such as social communication). Studies funded under this program examine children with or at risk for ASD from infancy through the transition of secondary students to post-secondary outcomes. Additional research projects on ASD have been funded through **Research Training Programs in Special Education; Special Education Research and Development (R&D) Centers; Low-Cost, Short-Duration Evaluation of Special Education Interventions;** and **unsolicited grant opportunities**. In 2012, as part of the R&D Centers competition, NCSER funded the **Center on Secondary Education for Students with Autism Spectrum Disorders (CSESA)** to develop and test a comprehensive, school-based intervention to improve the cognitive, communicative, academic, social, behavioral, functional, and transition outcomes of secondary students with ASD. CSESA also disseminated information regarding evidence-based practices and reviews of research. Between FY 2012 and 2020, NCSER has funded 56 research projects related to improving outcomes for students with ASD for a total of approximately \$96 million in funding.

In June 2021, NCSER announced two new **Research to Accelerate Pandemic Recovery in Special Education** competitions to consider applications that directly address a problem, issue, program, policy, or practice that is related to the COVID-19 pandemic, important to a state or local education agency, has the potential to improve outcomes significantly and rapidly for students with or at risk for disabilities, and will provide actionable and timely results to districts and schools. While

not specifically focused on students with ASD, research funded would benefit all students with disabilities, including students on the autism spectrum.

National Center for Education Evaluation and Regional Assistance (NCEE)

Through the Special Education Studies and Evaluation program, the **National Center for Education Evaluation and Regional Assistance (NCEE)** supports large-scale studies focused on children or youth with disabilities, including those with ASD. The **National Longitudinal Transition Study 2012 (NLTS 2012)** supports the collection of data on characteristics, school experiences, and outcomes after high school for a nationally representative sample of over 10,000 transition-aged youth with disabilities (ages 13 to 21), including approximately 1,000 youth with ASD. In 2017, NCEE released reports using NLTS 2012 data that included comparisons of youth with IEPs to youth without IEPs and outcomes for youth by disability category. A subsequent report released in 2018 compared survey data in 1987, 2003, and 2012 from the three NLTS, focusing on 15- to 18-year-olds with an IEP, including youth with ASD.

National Center for Education Statistics (NCES)

The **National Center for Education Statistics (NCES)** conducts longitudinal surveys as part of its mission to collect and analyze data related to education in the U.S. The **Early Childhood Longitudinal Study, Kindergarten Class of 2010-11 (ECLS-K:2011)**, is a part of a series of longitudinal studies supported by NCES that provide information about children's cognitive, social, emotional, and physical development, as well as their home environment, educational activities, school and classroom environment, classroom curriculum, and before- and after-school care. This study included a nationally representative sample of kindergartners selected from public and private schools in 2010-11 who were followed through fifth grade. Approximately 4,920 students had been diagnosed with a disability by the end of the study, with approximately 240 of these students reported by their parents as having an ASD diagnosis. The **Middle Grades Longitudinal Study (MGLS:2017)** collected

information on a cohort of sixth-graders in 2018 and then again in 2020. The study provides information on students' developmental and learning trajectories, as well as experiences in education, including those specific to students with disabilities, such as special education services and transition supports.

National Center for Education Research (NCER)

The **National Center for Education Research (NCER)** supports ED's **SBIR** program, which funds the development and testing of education technology products to improve education outcomes. One priority area within the SBIR program focuses on improving outcomes for children with or at risk for disability. As part of this priority area, NCER has supported the development of products aimed at improving outcomes for students with ASD. NCER may also support projects focused on students with disabilities under their **Postsecondary and Adult Education** research topic, though no studies focused on ASD have been funded to date under this program.

Office of Special Education and Rehabilitative Services (OSERS)

The mission of the **Office of Special Education and Rehabilitative Services (OSERS)** is to improve early childhood, educational, and employment outcomes and raise expectations for all people with disabilities, their families, their communities, and the nation.

Office of Special Education Programs (OSEP)

The **Office of Special Education Programs (OSEP)** within OSERS is responsible for overseeing the administration of the IDEA. OSEP provides formula grants to states to make available early intervention services to infants and toddlers with disabilities and their families under IDEA Part C. OSEP also provides formula grants to states to assist them in providing a free appropriate public education in the least restrictive environment to children with disabilities, ages 3 through 21, under IDEA Part B. Through these formula grants, children with ASD are served as part of all infants, toddlers, and children with disabilities. Autism is one of the thirteen disabilities that is included

in IDEA's definition of "child with a disability" in 20 U.S.C. 1401(3). OSEP also provides discretionary grants through IDEA's Part D national activities to improve education of children with disabilities, including some grants that have a focus on improving services for children with ASD. These grants are not specifically in place to implement the Autism CARES Act of 2019.

Under Part D of the IDEA, OSEP funds discretionary grants to improve outcomes for children with disabilities and their families. These include grants in personnel development, technical assistance and dissemination, and parent training and information. OSEP funds some projects that are specific to children with ASD and some projects that develop products and provide services that are relevant to children with ASD, even though they do not focus specifically on ASD. Some examples are listed below.

- During FY 2018 and 2019, OSEP funded 15 new personnel development grants that prepare master's level personnel (e.g., early interventionists, special educators, and related services providers) to serve children with disabilities, including children with ASD.
- The **Early Childhood Technical Assistance Center** supports states in implementing Part C and Part B, Section 619 of the IDEA. The Center has a number of **resources for state staff** on ASD.
- The **Center on Positive Behavioral Interventions and Supports** provides schools with capacity-building information and technical assistance for identifying, adapting, and sustaining effective school-wide disciplinary practices and provides resources on how to prevent and address challenging behavior, including behavior related to ASD.
- The **National Center for Pyramid Model Innovations** promotes the positive social, emotional, and behavioral outcomes of young children. The center focuses on reducing the use of inappropriate discipline practices and increasing the inclusion and ongoing participation of young children with disabilities, including those with ASD.

- The **IRIS Center** develops evidence-based professional development and college coursework instructional modules that have addressed aspects of ASD.
- The **Autism Focused Intervention Resources and Modules (AFIRM)** are 27 professional development learning modules that address instructional and behavioral interventions for young children with ASD. The AFIRM modules are designed to help practitioners learn the step-by-step process of planning for, using, and monitoring evidence-based practices of children with ASD from birth to 22 years of age.
- The **National Technical Assistance Center on Transition** assists state educational agencies and vocational rehabilitation agencies to implement evidence-based and promising practices ensuring students with disabilities, including those with ASD, graduate prepared for success in postsecondary education and employment. The center has specific resources on secondary transition for **students with ASD**.
- The **State Personnel Development Grants** program provides grants to state educational agencies to provide in-service professional development to personnel serving children with disabilities, including children with ASD.
- **Parent Training and Information Centers (PTIs) and Community Parent Resources Centers (CPRCs)** provide families with information about a range of topics to better understand the nature of their children's disabilities and their educational, developmental, and transitional needs; help families obtain appropriate information about the range, type, and quality of options, programs, services, technologies, practices, and interventions; and understand their rights and responsibilities under the IDEA. PTIs report that over one in five requests for assistance involve families of children with autism. Additionally, PTIs and CPRCs support youth, including youth with ASD, in building their self-advocacy skills.
- The **Center for Parent Information and Resources (CPIR)** houses materials for PTIs and CPRCs to use with families. One of CPIR's resources is the **Autism**

Navigator, which provides information on autism screening, diagnosis, and interventions for young children. CPIR also has an **inter-related series of parent guides on youth transition to adult life**. While not specific to youth with autism, the series tackles how to develop independent decision-making in youth with disabilities as they and their parents navigate the age of majority and legal adulthood.

In mid-March of 2020, within one week of the vast majority of America's schools shifting to distance and hybrid education, ED marshalled its technical assistance resources to support children and families as they struggled with the new reality of distance education. OSEP led the effort to support the families of the nation's nearly seven million children with disabilities to address their unique needs. OSEP's strategy focused on the curation and dissemination of resources that addressed the provision of evidence-based instruction and creating/maintaining an environment conducive to learning. OSEP did not develop or disseminate resources specifically to support children with autism, with the exception of disseminating the AFIRM autism training modules that were accessed by over 200,000 new users during the pandemic.

Given that 80% of children with disabilities spend at least 40% of their time in the general education classroom, OSEP collaborated with the **Office of Elementary and Secondary Education (OESE)** and the IES to curate, develop, and disseminate resources to support all children and families. Examples of activities undertaken by ED that supported families and addressed the needs of children with disabilities include:

- Activities to collect and disseminate resources, including:
 - Collecting Continuity of Learning Resources,
 - Creating COVID-19 resource pages,
 - Cross-posting and sharing resources, and
 - Hosting webinars with grantees;
- Coordinating with disability focused partner/stakeholder organizations to establish the needs of the disability community;

- Creating early childhood and school-aged technical assistance hubs to house the curated information from over 30 OSEP-funded technical assistance centers to enhance the continuity of learning during the pandemic for teachers and parents;
- Coordinating the OSEP, OESE, and IES technical assistance and dissemination of resources to ensure nonduplication, including linking and cross-referencing websites;
- Disseminating resources to highlight strategies and practices for providing remote provision of related services (e.g., speech, physical therapy, occupational therapy) to children with disabilities;
- Creating and disseminating topical briefs on practices and resources to support parents and families, teachers, and related services providers;
- Creating and disseminating resources to support the provision of early childhood special education and early intervention such as methods to support mask wearing for young children;
- Creating guides for supporting children and staff as they return to school after a crisis such as the pandemic;
- Conducting a series of webinars focused on supporting children (including those with social and emotional needs) with disabilities and their families during the pandemic that were attended by thousands of parents and professionals;
- Disseminating resources that targeted children with the most significant needs, including those with autism and deaf blindness, that focused on supporting communication while at home;
- Developing 16 disability-related documents addressing high interest/high impact topics such as service delivery, evaluation and assessment, dispute resolution, procedural safeguards, and use of IDEA funds;
- Articulating from the beginning of the pandemic that school districts must provide a free and appropriate public education (FAPE) to children with disabilities consistent with the need to protect their health and safety as well as the health and safety of those individuals providing education, specialized instruction, and related services;
- Including the development of the skills to deliver remote and distance instruction as a requirement in new funding priorities for training and personnel-related grants;
- Significantly increasing the provision of accessible books, textbooks, and educational materials to blind, visually impaired, and print-disabled students with disabilities through the **Bookshare** project; and
- Significantly increasing the provision of evidence-based professional development modules for professionals and parents to better deliver remote and hybrid education and structure learning environments.

Rehabilitation Services Administration (RSA)

The **Rehabilitation Services Administration (RSA)** is a component of the OSERS and provides leadership and resources to assist state and other agencies in providing rehabilitation and other services to individuals with disabilities, including those with ASD, to maximize their employment, independence, and integration into the community and the competitive labor market. While not specifically focused on health and well-being, RSA activities support employment and integration, part of the social determinants of health, and has a positive impact on the physical and mental health and overall well-being of individuals with disabilities, including individuals with ASD.

ENVIRONMENTAL PROTECTION AGENCY (EPA)

The **U.S. Environmental Protection Agency (EPA)** aims to protect human health and the environment through such activities as the development and enforcement of environmental regulations, the support of grants and laboratories for scientific research, and the publication of materials for public access. EPA works to ensure that all parts of society have access to accurate information sufficient to effectively participate in managing human health and environmental risks. EPA-funded research and activities broadly impact the health and well-being of individuals with disabilities, including those with ASD, and their families.

The goal of the **Children’s Environmental Health and Disease Prevention Research Centers (Children’s Centers)**, an extramural grant program jointly funded by the EPA and NIEHS, is to understand how environmental factors affect children’s health and promote translation of basic research findings into intervention and prevention methods to prevent adverse health outcomes.

The 2013 EPA Children’s Centers award to **University of California (UC), Davis** was funded under EPA’s Science to Achieve Results (STAR) grant program and focuses on environmental risk factors for ASD and developmental delays. Specifically, the UC Davis center studies the epigenetic mechanisms of toxicant exposure on immune function, develops and applies new biomarkers of autism risk, characterizes the potential health effects of environmental exposures and various life stages, and predicts long-term clinical and behavioral consequences. The environmental chemicals that this center examines with regard to ASD include polybrominated diphenyl ethers (PBDEs), perfluorooctanoic acid (PFOA), perfluorooctanesulfonic acid (PFOS), and pesticides. Several notable research findings have resulted from this project. Children’s Centers researchers have identified potential links between air pollution, pesticides, occupational exposures, phthalates, and risks of ASD. This project was funded through FY 2019.

The EPA also provides funding to the **Agency for Toxic Substances and Disease Registry (ATSDR)**, under an interagency agreement, to support 10 **Pediatric Environmental Health Specialty Units (PEHSUs)**. PEHSUs provide medical information and advice on environmental conditions, including working with health care professionals, parents, schools and community groups, and others to provide information on protecting children and reproductive-age adults from environmental hazards. PEHSUs offer advice on prevention, diagnosis, management, and treatment of environmentally related health effects in children, which may include ASD.

Extramural grants funded by the EPA that impact the health and well-being of individuals on the autism spectrum include grants on the Multiplexed human BrainSphere Developmental Neurotoxicity Test for Six Key Events of Neural Development (**R839505**) and the Integrated blood brain barrier – computational model development to predict doses of concern for compound linked neurotoxicity (**RD840027**).

DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT (HUD)

The **Department of Housing and Urban Development (HUD)** works to strengthen the housing market in order to bolster the economy and protect consumers, meet the need for quality affordable rental homes, utilize housing as a platform for improving quality of life, and build inclusive and sustainable communities free from discrimination. HUD-funded activities broadly impact the well-being of individuals with disabilities, including those with ASD, and their families.

HUD administratively enforces several civil rights laws prohibiting housing discrimination, including the Fair Housing Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act (ADA). With few exceptions, the Fair Housing Act covers housing throughout the country.

Section 504 of the Rehabilitation Act

Section 504 provisions apply to recipients of HUD financial assistance, including the Community Development Block Grant, Public Housing, Multifamily, Housing Choice Voucher, and other programs. HUD’s Section 504 regulations (at 24 CFR § 8.4c) permit exclusion of persons without disabilities from the benefits of a program if the program is limited by federal statute or executive order to individuals with disabilities and also permits exclusion of a specific class of individuals with disabilities from a program if the program is limited by federal statute or executive order to a different class of individuals. However, HUD does not have disability-specific programs, such as housing specifically for persons with ASD.

Section 811 Supportive Housing for Persons with Disabilities

The HUD Section 811 program provides funding to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities. The program supports two major types of assistance: (1) capital grants and project-based rental assistance for nonprofit developers to build, rehabilitate, or acquire small group homes or scatter site housing units with the availability of supportive services for very low-income persons with disabilities and (2) project-based rental assistance for state housing agencies in partnership with state Health and Human Services/Medicaid agencies to provide housing for extremely low-income persons with disabilities with access to appropriate supportive services.

In August 2020, HUD **awarded over \$74 million in grants** to 12 state housing agencies to support affordable rental housing for extremely low-income persons with disabilities. The awards will support up to five years of rental assistance for approximately 2,400 units of housing in buildings participating in project rental assistance through the Section 811 program. HUD also **awarded \$54.7 million in capital advance and project rental assistance grants** to 15 community organizations through the Section 811 program. The grants were awarded to organizations who will create permanent supportive housing models that will be at the forefront of design, service delivery, and efficient use of federal resources. Awardees must promote long-term housing security and facilitate community integration of persons with disabilities. In 2020, HUD issued an **eviction moratorium** and offered **additional funds to properties receiving project-based rental assistance under the Section 811 program**, as part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act.

Housing Choice Voucher Program

The **Housing Choice Voucher (HCV)** program is the federal government's major program for assisting very low-income families, older adults, and people with disabilities to afford decent, safe, and sanitary

housing in the private rental market. HCVs are administered locally by public housing agencies (PHAs).

Mainstream Voucher Program

Mainstream vouchers assist very low-income adults with disabilities with tenant-based rental assistance. Participants receive a voucher and are free to choose any housing in the private rental market that meets the requirements of the program. Similar to the regular housing choice voucher, Mainstream vouchers are administered locally by PHAs. The 2017, 2018, and 2019 Appropriations Acts funded new Mainstream vouchers. Since 2018, HUD has awarded over \$500 million in funding to PHAs to support 50,000 new Mainstream vouchers. Under the authority of the CARES Act, **HUD allocated nearly \$77 million for Mainstream vouchers in May 2020 and another \$87 million in November 2020.**

Emergency Housing Voucher Program

The **Emergency Housing Voucher (EHV)** is a special program available through the American Rescue Plan Act (ARPA) that will provide 70,000 housing choice vouchers to local PHAs. The program will assist individuals and families who are experiencing homelessness, at risk of homelessness, recently homeless, or victims of domestic violence, dating violence, stalking, sexual assault, or human trafficking. In 2021, **HUD announced the award of the first tranche of ARPA funds for EHV's.** Specifically, HUD awarded \$1.1 billion - 70,000 vouchers - for 626 PHAs administering the HCV Program.

HUD has additional special purpose voucher programs that serve people with disabilities:

- **Vouchers for Non-Elderly Persons with Disabilities.** Since 1997, HCVs have been awarded under different special purpose voucher program types to serve very low-income non-elderly adults with disabilities (NED).
- **HUD-VASH.** The **HUD-Veterans Affairs Supportive Housing (HUD-VASH)** Program combines HUD's HCV rental assistance for homeless veterans with case management and clinical services provided by the VA.

- **Family Unification Program and Foster Youth to Independence.** The **Family Unification Program (FUP)** is a program under which HCVs are provided to eligible families and youths involved in the child welfare system. The **Foster Youth to Independence (FYI)** initiative makes HCV assistance available to youth at least 18 years and not more than 24 years of age who left foster care or will leave foster care.

Public Housing

Public housing was established to provide decent and safe rental housing for eligible low-income families, older adults, and persons with disabilities. Public housing comes in all sizes and types, from scattered single-family houses to high rise apartments for older adults. There are approximately 1.2 million households living in public housing units, managed by some 3,300 PHAs.

Homeless Assistance Programs

Homelessness assistance programs provide funding to states and local governments and nonprofit providers to serve individuals and families across the U.S. who are affected by homelessness.

DEPARTMENT OF JUSTICE (DOJ)

The **U.S. Department of Justice (DOJ)** ensures fair and impartial administration of justice for all Americans. DOJ-funded research and activities broadly impact the well-being of individuals with disabilities, including those with ASD, and their families.

Within DOJ, the **Civil Rights Division** works to uphold the civil and constitutional rights of people with disabilities, including people with ASD and other DD. The Division coordinates the implementation and enforcement of Section 504 of the Rehabilitation Act and Title II of the ADA across the federal government. Section 504 of the Rehabilitation Act states that “no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under” any program or activity that either receives federal financial assistance or is conducted by any Executive agency or the United States Postal Service. Title II of the

ADA requires that state and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings). Title II covers all activities of state and local governments regardless of the government entity’s size or receipt of federal funding.

In response to the COVID-19 pandemic, the Civil Rights Division issued statements recognizing the impact of the pandemic on people with disabilities and reiterating its commitment to enforcing civil rights laws.

- The **Statement by Assistant Attorney General for Civil Rights Eric S. Dreiband, Protecting Civil Rights While Responding to the Coronavirus Disease 2019 (COVID-19)**, which was issued in 2020, provided that “[a]s the global response to the COVID-19 pandemic continues, the Department will remain vigilant in enforcing civil rights laws. We must ensure that fear and prejudice do not limit access to housing, schools, benefits, services, jobs, and information, among other things, on account of race, sex, religion, national origin, disability, or other protected classes. Further, access to accurate emergency and health information is critical to providing all people with the ability to make informed decisions and protect themselves, their families, and the community at large.”
- Furthermore, the **Statement by the Principal Deputy Assistant Attorney General for Civil Rights, Leading a Coordinated Civil Rights Response to Coronavirus (COVID-19)**, which was issued in 2021, recognized that people with disabilities suffer disproportionately high rates of death and greater risk of infection and hospitalization. Among the guiding principles for meeting nondiscrimination obligations were ensuring equal access for people with disabilities and avoiding disability discrimination under both the ADA and Section 504 “when making decisions about who will receive medical care, including vaccines and hospital beds. It also includes crafting and implementing policies such as crisis standards of care, visitation rules, and vaccine distribution plans.”

- The Civil Rights Division coordinated with other federal agencies to ensure that policies and programs created in response to the COVID-19 pandemic did not exclude or discriminate against people with disabilities, including people with ASD.

The **Educational Opportunities Section (EOS)** of DOJ enforces anti-discrimination statutes and court decisions that impact students with autism in elementary and secondary schools and institutions of higher education, including, variously, the ADA, Section 504 of the Rehabilitation Act, the Equal Educational Opportunities Act (EEOA) (not post-secondary), Title VI of the Civil Rights Act, and Title IX of the Education Amendments of 1972, and upholds the rights of students under the 14th Amendment to the U.S. Constitution in educational settings.

- EOS continues to enforce Title II of the ADA in public schools to prevent placement of students with disabilities in segregated settings. For example, the Commonwealth of Pennsylvania entered a settlement with EOS agreeing not to allow placement of students with disabilities in Alternative Education for Disruptive Youth (AEDY) programs when that referral is based upon behavior related to the student’s disabilities. The Section has sued the State of Georgia for the creation and operation of the statewide Georgia Network for Educational and Therapeutic Support (GNETS) program that encourages local schools to remove students with disabilities from general education settings to place them in segregated GNETS programs.
- EOS has launched multiple investigations into the use of “abbreviated days” (aka “shortened days”) as a means of discipline or behavior control. The Section has entered settlement agreements with Lewiston, Maine; Toledo, Ohio; and North Gibson, Indiana, and has launched an initiative to investigate seclusion and restraint practices, in addition to shortened day policies and practices, in five districts across the U.S. Students with autism are frequently isolated in seclusion rooms or sent home before the end of the school day rather than requiring staff to try alternate interventions or to determine the trigger for behavior and modify the student’s environment. Shortened days and the use of seclusion segregate students with autism and other disabilities from their peers and deny equal opportunities for education and enrichment in the learning process.
- EOS also has addressed discriminatory discipline of students with disabilities in multiple investigations, settlement agreements, and other resolutions. Statistics demonstrate that students with disabilities experience discipline at a far higher rate than students without disabilities in general education schools. According to a **2018 Government Accountability Office (GAO) Report**, students with disabilities make up about 12% of the overall K-12 student population but 25% of students suspended out of school and 20% of students given in-school suspension. Students with disabilities received 27.5% of referrals to law enforcement and 27.5% of school-based arrests.
- The Section has entered into agreements with districts to adopt better programs for behavior management that improve outcomes and enhance the student climate, better report behavior and discipline incidents, and train teachers to improve classroom management skills. For example, on January 18, 2017, the Section entered into an agreement with the Covington Independent Public Schools that required the District to provide reasonable modifications of school policy for students with disabilities to avoid the use of exclusionary discipline and contact with law enforcement. Under the agreement, the District developed a protocol to identify students who are disproportionately subject to disciplinary referrals; provided those students with interventions and supports intended to reduce disciplinary actions; took prompt and effective steps to help students who were in crisis; implemented a code of conduct that focused on positive interventions, rather than punitive discipline; trained administrators and teachers on how to provide all students with effective interventions and supports; and ceased requesting school resource officers (SROs) to enforce disciplinary rules. The agreement ended when the District achieved compliance in October 2020.

The **Disability Rights Section (DRS)** of DOJ administers and enforces the ADA to achieve equal opportunity for people with disabilities in the U.S. DRS has addressed the unnecessary segregation of people with IDD and expanded opportunities for people with IDD to work in competitive integrated employment. DRS has also addressed alleged discrimination by private schools and childcare centers against students with ASD on the basis of their disability. The Section also coordinates the implementation and enforcement of Section 504 of the Rehabilitation Act and Title II of the ADA across the federal government. Key concepts that are common to the Department's Section 504 and ADA regulations include reasonable modifications, program accessibility, and effective communication.

- **Examples and Resources to Support Criminal Justice Entities in Compliance with Title II of the Americans with Disabilities Act** is a guidance document that was released in 2017 to facilitate criminal justice entities' compliance with the ADA in their interactions with individuals with mental health disabilities or IDD.
- **ADA Requirements: Testing Accommodations** is a guidance document that was released in 2015 to ensure that people with disabilities who are taking standardized examinations for the purpose of gaining entry to high school, college, or graduate programs, or for those attempting to obtain professional licensure or certification for a trade, have the opportunity to fairly compete for and pursue such opportunities. The guidance addresses a testing entity's obligation to offer exams in a manner that is accessible to people with disabilities and does not measure a person's disability but instead measures the individual's aptitude or achievement level.
- **ADA Requirements: Effective Communication** is a guidance document that was released in 2014 to ensure that state and local governments and businesses and nonprofit organizations that serve the public communicate with people with vision, hearing, or speech disabilities in a manner that is equally as effective as their communication with people without disabilities.

- In collaboration with ED's Office for Civil Rights and OSERS, DOJ's Civil Rights Division released **Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools** in 2014 to address the obligation of public schools to meet the communication needs of students with disabilities.

The **Special Litigation Section (SPL)** of DOJ enforces Title II of the ADA, the Civil Rights of Institutionalized Persons Act, and 34 U.S.C. § 12601 of the Violent Crime Control and Law Enforcement Act of 1994. The Section's work has addressed conditions at health care facilities for individuals with disabilities, the rights of individuals with disabilities to live in their communities and not facilities, and the appropriate diversion of individuals with disabilities from the criminal justice system.

The **Office of Justice Programs (OJP)** is a principle funding, research, and statistical component of the DOJ. It is a leading source of federal funding for state, tribal, and local criminal and juvenile justice agencies through six Bureaus and Program Offices. The DOJ OJP focuses on equipping and strengthening communities, justice systems, and other sectors through the dissemination of innovative and best practices, research, and statistics; grant funding and training and technical assistance; and fostering relationships.

The **Bureau of Justice Assistance (BJA)** is a component of the OJP and helps make American communities safer by strengthening the nation's criminal justice system. Its grants, training and technical assistance, and policy development services provide state, local, and tribal governments with the cutting-edge tools and best practices they need to reduce violent and drug-related crime, support law enforcement, and combat victimization. Programs supported by the BJA are described below.

History of National Partnerships and Today

In 2013, BJA funded The Arc of the United States to create the **National Center on Criminal Justice and Disability (NCCJD)** to address challenges the justice

system faces when it encounters people with disabilities in the areas of law enforcement, courts, and corrections. NCCJD's Pathways to Justice Initiative works to increase criminal justice professionals' capacities to respond to individuals with disabilities by providing training, technical assistance, and education. It brings together professionals from the disability and criminal justice fields to share their expertise and provides training, using a team approach, with the goal of becoming the go-to resource in their community or state on issues related to criminal justice and disability.

In FY 2019, NCCJD, as a subrecipient of BJA's **National Training and Technical Assistance (TTA) Initiative**, increased its capacity to serve local jurisdictions by updating Pathways to Justice's curriculum and increasing the number of trainings available under the National TTA Initiative. NCCJD also initiated the creation of an Advanced IDD Module that incorporates IDD into crisis response for first responders. This new module was piloted with the District of Columbia Metropolitan Police Department and Baltimore County Police Department in recent months and continues to be developed. Additionally, NCCJD developed new content, namely several new fact sheets intended to raise awareness regarding the number of people with IDD encountering the justice system. These fact sheets are available through BJA's **Police-Mental Health Collaboration (PMHC) Toolkit**. Pathways to Justice is available to law enforcement agencies and district attorneys' offices through the **Pathways to Justice** website.

Other training and technical assistance on disability response is currently available through BJA's portfolio of programming. The **Law Enforcement-Mental Health Collaboration Support Center** offers free training and resources to communities exploring ways to improve their law enforcement and service provider responses to people with behavioral health conditions or IDD. Through this center, community partners may request assistance through NCCJD in the areas of training and technical assistance, information and referral, resource collection and creation, and education. At present, NCCJD has provided five jurisdictions with individualized consultation.

Webinars and Products Supported by BJA and Available through the Council of State Governments (CSG) Justice Center

- **Working with People with Developmental Disabilities Webinar** (2019)
- **How to Respond Effectively to People with IDD Webinar** (2020)
- **Diverting People with IDD Webinar** (2020)
- **Collaborate, Train, & Engage Webinar** (2021)
- Case Scenarios/TA Write-Up

Upholding Kevin and Avonte's Law

Kevin and Avonte's Law was enacted in 2018 to help protect individuals with autism or other DD who may wander away from safety. The law promotes initiatives that reduce the risk of injury or death related to the wandering characteristics of some children with autism. It amended the Violent Crime Control and Law Enforcement Act of 1994 and reauthorized the Missing Alzheimer's Disease Patient Alert Program. It allows DOJ grants to be used by law enforcement agencies and nonprofits for programs to:

- Facilitate training and emergency protocols for school personnel,
- Provide first responders with additional information and resources, and
- Make locating technology programs available for individuals who may wander from caregivers.

Kevin and Avonte's Law authorized BJA to support local efforts through the Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities Program. Following a competitive solicitation for proposals, BJA made funding available to selected local jurisdictions to reduce the numbers of deaths and injuries of individuals with forms of dementia, such as Alzheimer's disease, or DD, such as ASD, who, due to their condition, wander from safe environments. The program is intended to support and address public safety challenges by providing direct grants to health care agencies, law enforcement, public safety agencies, and nonprofit organizations

in two categories. For Category 1, award recipients will implement locative technologies to track missing individuals. Category 2 award recipients will develop or operate programs to prevent wandering, increase individuals' safety, and facilitate rescue. Since February of 2020, BJA has made 29 awards throughout the U.S. to support local communities in responding to people in need of assistance.

In FY 2019, **An Academic-based Training Initiative to Improve Police Responses for People with Mental Illness and Intellectual and Developmental Disabilities** was awarded to the University of Cincinnati. This program was awarded in February of 2020 (active through 2025) to enhance, pilot, train, support, distribute, and implement BJA's national crisis response curriculum, a 40-hour training program developed to prepare police officers in their response to people experiencing crises related to behavioral health disorders and cognitive/physical disabilities. This training, titled "Crisis Response and Intervention Training", was designed to complement the development and delivery of collaborative crisis response programs planned by law enforcement agencies and mental health/disability service providers in the community. This current cooperative agreement recipient will assist a new, competitively awarded cohort of site-based grantees, awarded through BJA's current funding opportunity, **Collaborative Crisis Response Training Program**, which closed July 20, 2021. Program applicants will plan a best practice program, including the newly revised 40-hour curriculum, and deploy a comprehensive strategy with the goal of a sustainable crisis response and intervention program for people with mental health issues and disabilities.

Webinars and Products Developed with University of Cincinnati (FY19-21 Academic Training Project)

The **Academic Training to Enhance Police Engagement with People with Behavioral Health Issues and Developmental Disabilities** is designed to enhance, implement, and evaluate crisis intervention team and disability response training for law enforcement and first responders that is academically based and transdisciplinary.

For webinar recordings and products, visit The **Academic Training to Inform Police Responses: A National Curriculum to Enhance Police Engagement with People with Behavioral Health Issues and Developmental Disabilities**.

BJA's Law Enforcement Mental Health Peer-to-Peer Learning Sites as a Resource in Response

Through the CSG Justice Center and the International Association of Chiefs of Police (IACP), BJA makes 14 law enforcement learning sites available, free of cost, to local communities, to serve as training and technical assistance experts to increase and enhance collaborative responses for people with mental illness and IDD. BJA's national sites are the Arlington Police Department (Massachusetts), Houston Police Department (Texas), Los Angeles Police Department (California), Madison Police Department (Wisconsin), Madison County Sheriff's Office (Tennessee), Portland Police Department (Maine), Salt Lake City Police Department (Utah), Tucson Police Department (Arizona), and the University of Florida Police Department. BJA recently completed a national application process for additional host-agencies with mental health, behavioral health, and disability expertise. Five additional sites were added in May of 2021: Bexar County Sheriff's Department (Texas), Harris County Sheriff's Department (Texas), Miami-Dade County Police Department (Florida), Yavapai County Sheriff's Office (Arizona), and Wichita Police Department (Kansas).

Although many law enforcement agencies train their officers to understand the needs of people with ASD, some states have moved towards passing legislation that makes training mandatory in local jurisdictions. States that currently have laws making training mandatory include California, New York, Maryland, and Pennsylvania. Resources to track these laws include the National Conference of State Legislatures (NCSL) **State Trends in Law Enforcement Legislation: 2014-2017** and the National Down Syndrome Society (NDSS) **Law Enforcement Training Toolkit**.

DEPARTMENT OF LABOR (DOL)

The **U.S. Department of Labor (DOL)** works to foster full access to gainful employment opportunities for all Americans, including youth and adults with disabilities. DOL also seeks to advance career pathways for youth and adults through its support for workforce development and job training programs, including apprenticeships. Employment is a key social determinant of health. Thus, DOL-funded activities carry key implications for the health and well-being of individuals with disabilities, including people on the autism spectrum, and their families.

Federal Laws that Support Employment as a Social Determinant of Health

The Rehabilitation Act and the ADA outline four core goals that shape the work at DOL to support full access to employment for youth and adults with disabilities. The four goals include ensuring economic self-sufficiency, independent living, full participation, and equality of opportunity. These four priorities relate directly to efforts to promote access to competitive, integrated employment and the attainment of health, wellness, and a high quality of life. The Rehabilitation Act especially has major implications for youth and adults on the autism spectrum because this law defines autism as a significant disability. Thus, improving opportunities to secure and maintain employment has received a key focus in federal policy and activities to support the health and wellness of people with disabilities, including youth and adults on the autism spectrum.

The Family and Medical Leave Act (FMLA) enables employees to use up to 12 weeks of unpaid leave for circumstances that include supporting their physical and mental health and wellness. Employees can exercise their FMLA time to access health care services and supports that maintain their quality of life and ensure they can continue working in their jobs. Likewise, federal policy has emphasized the importance of independent living and related health focuses to attain, maintain, and advance in gainful employment opportunities and career pathways. The **Workforce Innovation and Opportunity Act of 2014 (WIOA)**

includes provisions that re-authorize the federally funded Centers for Independent Living (CILs). The CILs provide five core services: independent living skill development, information and referral, individual and systems advocacy, peer support and mentoring, and postsecondary transition for youth with disabilities.

Initiatives at the Office of Disability Employment Policy (ODEP)

The **Guideposts for Success: Framework for the Future** to support all youth, including youth with disabilities, emphasize efforts to foster access to health care services. Developed for DOL's **Office of Disability Employment Policy (ODEP)**, the Guideposts prioritize skills to navigate the health care system to access services for medical, mental health, and reproductive health needs. The Guideposts also stress that youth with disabilities attain the skills and knowledge needed to access self-care, make health care decisions, and engage in self-advocacy.

ODEP is running a three-year, \$2.1 million research project on Supporting Employment for Young Adults on the Autism Spectrum that recognizes employment as a key social determinant of health. Launched in FY 2021, this project seeks to learn practices, approaches, strategies, and policies to enhance and increase access to work-based learning and gainful employment for young adults on the autism spectrum. It also aims to identify ways to help propel career paths for young adult job seekers on the autism spectrum and support mental and physical health and wellness. This project emphasizes the inclusion of people on the autism spectrum who have diverse backgrounds, communication styles, and support needs for services. It informs ODEP's work to enhance policies and practices that drive access to gainful employment and career pathways for people with disabilities.

Federal initiatives that interconnect health care and employment include **the Retaining Employment and Talent after Injury/Illness Network (RETAIN)**, which was launched in 2018. The RETAIN demonstration projects facilitate the development of approaches and strategies for people to stay at work and return

to work after an injury or illness. Funded by ODEP and the SSA, RETAIN has supported demonstration grants to eight state teams. The goals of the RETAIN initiative include ensuring retention of employment and participation in the labor force for people who acquire or may likely develop disabilities that inhibit their ability to work.

RETAIN also focuses on decreasing long-term work absence; this emphasis includes reducing the need for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). The RETAIN initiative is highly relevant for people on the autism spectrum: Research shows that many people on the autism spectrum have secondary conditions that can affect their physical and mental health and wellness. Additionally, people on the autism spectrum may meet the eligibility criteria for SSDI and SSI. In 2021, the RETAIN initiative awarded four-year, Phase 2 grants to five of the state teams from Phase 1 to build upon their success in supporting stay-at-work and return-to-work for people with disabilities.

ODEP launched the **Advancing State Policy Integration for Recovery and Employment (ASPIRE)** initiative in 2020. ASPIRE seeks to support and expand access to competitive, integrated employment for people with mental health conditions. It assists seven states that are working to integrate their policies, programs, and funding systems to expand evidence-based mental health services for people with mental health conditions. ASPIRE emphasizes the use of best and promising practices, such as the Individual Placement and Support Model of Supported Employment.

In addition to policy development work with states and federal agencies, ODEP disseminates a broad range of disability employment information and resources for employers through its website. ODEP's **Topic Resource Webpage on Autism** shares resources and information for employers, job seekers on the autism spectrum, service providers, policymakers, and transition-aged youth on the autism spectrum. Likewise, ODEP's website offers a **Topic Resource Webpage on Mental Health** and a **Topic Resource Webpage on Health Care**.

DOL's Response to the COVID-19 Pandemic

Since 2020, DOL has supported workers and job seekers as they navigated the COVID-19 pandemic and economic adversity. DOL has hosted a **resource website on COVID-19** with information on workplace safety, employee rights, unemployment insurance, and paid leave under federal COVID-19 laws. ODEP has also provided resources and information to assist workers and job seekers with disabilities during the COVID-19 pandemic.

For instance, the **Job Accommodation Network (JAN)**, a technical assistance (TA) center funded by ODEP, has helped support workers, job seekers, service providers, and others during the COVID-19 pandemic. JAN has continued to offer free, expert, and confidential assistance on accommodations for both work and the job search; this assistance has included guidance on accommodations and supports for changes to work activities during the pandemic and shifts to teleworking or remote-based job training for some workers and trainees. It has also released tailored COVID-19 resources on:

- **ADA and Accommodation Lessons Learned: COVID-19 Edition;**
- **FAQ: COVID-19 Vaccination and the Americans with Disabilities Act;**
- **Supporting Employees with Mental Health and Cognitive Conditions While Teleworking;**
- **Coronavirus (COVID-19), Stress, and Mental Health Conditions;**
- **Requesting and Negotiating Accommodations During the Pandemic;**
- **Engaging in the Interactive Process during the COVID-19 Pandemic;**
- **Masks for COVID-19 Management and ADA Accommodations;**
- **Accommodating Employees with COVID-19-Related Symptoms;**
- **COVID-19 Long Haulers and the Americans with Disabilities Act;**
- **Make Telework Work: Transitioning to Telework;**

- **The ADA and Managing Reasonable Accommodation Requests from Employees with Disabilities in Response to COVID-19;** and
- **Accommodation Strategies for Returning to Work during the COVID-19 Pandemic.**

Likewise, the **Employer Assistance and Resource Network on Disability Inclusion (EARN)**, ODEP's TA center for employers, has also issued COVID-19 resources on how to support workers with disabilities during the pandemic. EARN's COVID-19 resources have included:

- **Disability-Inclusive COVID-19 Workplace Health and Safety Plans;**
- **COVID-19 and Job Applicants and Employees with Disabilities: Emerging Practices to Employ and Protect Workers;** and
- **Adopting an Integrated Teleworking Policy for Employees with and without Disabilities.**

EARN also maintains a **mental health toolkit** to empower employers in supporting mental health in the workplace.

Additionally, ODEP has released key resources for the COVID-19 pandemic that focused on inclusive apprenticeships, state and youth policies, and remote-based work. These resources released by projects at ODEP have included:

- **Apprenticeship Inclusion Models (AIM): Emerging Lessons for Inclusive Apprenticeship Programs: Managing through the COVID-19 Crisis and Beyond;**
- **State Exchange on Employment & Disability (SEED):**
 - **Apprenticeships: A Pipeline for Inclusive Recovery** and
 - **COVID-19: Federal Disability-Specific and Other Related Guidance;**
- **Partnership on Employment & Accessible Technology (PEAT): The Virtual Workplace: PEAT Priorities and Next Steps;** and
- **Center for Advancing Policy on Employment for Youth (CAPE-Youth): State COVID-19 Response: Youth with Disabilities.**

NATIONAL SCIENCE FOUNDATION (NSF)

The mission of the **National Science Foundation (NSF)** is to promote the progress of science; to advance the national health, prosperity, and welfare; and to secure the national defense. NSF is the only federal agency whose mission includes support for all fields of fundamental science and engineering, except for medical sciences. While NSF does not have an ASD research program, the agency has awarded numerous research grants through the years that include basic science research with implications for the health and well-being of individuals with ASD and other DD. These research awards, including current active awards, fall under a portfolio that emphasizes neuroscience, cognitive sciences, education and learning research, and workforce development. The NSF's **award search website** offers the public the opportunity to learn about specific NSF awards.

SOCIAL SECURITY ADMINISTRATION (SSA)

The mission of the **Social Security Administration (SSA)** is to deliver quality Social Security services to the public. SSA administers two disability programs authorized under the Social Security Act – the Social Security Disability Insurance program (SSDI; Title II) and the Supplemental Security Income program (SSI; Title XVI). The SSDI program pays benefits to disabled individuals and certain family members if they are “insured,” meaning that they worked long enough—and recently enough—and paid Social Security taxes on their earnings. SSI is a federal income supplement program funded by general tax revenues (not Social Security taxes) that is designed to help aged, blind, and disabled people who have little or no income by providing cash to meet basic needs for food, clothing, and shelter. These programs provide economic support toward the health and well-being of people with disabilities by helping to meet their basic needs. Under these programs, the SSA evaluates claims relating to ASD for both adults (aged 18-64 years) and children (aged <18 years). Primary diagnosis is not relevant with respect to the population aged 65+ years.

As of December 2019, 383,941 individuals with a primary impairment of ASD (210,021 children and 173,920 adults) received SSI payments. Children received an average monthly payment of \$658, and adults received an average monthly payment of \$627. In addition, there were 91,537 SSDI beneficiaries with a primary impairment of ASD, of whom 28% were workers and 72% adult children. Workers received an average monthly payment of \$749, and adult children received an average monthly payment of \$869. Approximately one third of SSDI beneficiaries received both SSDI and SSI.

SSA follows a five-step sequential evaluation process for evaluating adult disability claims:

1. Consider whether the adult is engaging in substantial gainful activity.
2. Consider whether he or she has a severe medically determinable impairment. At this step, SSA considers the diagnosis of ASD in conjunction with the medical and other evidence to establish the medically determinable impairment and its severity.
3. Consider whether the severe medically determinable impairment(s) meets or medically equals one of the listings. At this step, ASD is considered under mental disorders listing 12.10 in 20 CFR Part 404, Subpart P, Appendix 1. If the adult does not have an impairment that meets or medically equals a listing, SSA determines the residual functional capacity (RFC) resulting from the ASD and any coexisting medically determinable impairments.
4. Determine whether the person's RFC would permit him or her to perform any past relevant work he or she may have.
5. Determine whether the person's RFC would permit him or her to perform any other work that exists in the national economy.

SSA follows a three-step sequential evaluation process for evaluating child disability claims:

1. Consider whether the child is engaging in substantial gainful activity.

2. Determine whether the child has a severe medically determinable impairment that meets or medically equals a listing. At this step, ASD is considered under mental disorders listing 112.10 in 20 CFR Part 404, Subpart P, Appendix 1.
3. Determine whether the child's ASD and coexisting medically determinable impairment(s) functionally equal the listings, using the whole-child approach.

In calendar year 2019, SSA processed over 24,439 first-time adult and 32,607 first-time child claims for ASD. Of those claims, 73% of adult claims and 76% of child claims met requirements following initial determination/reconsideration and were allowed benefits, compared to 41% and 48%, respectively, for all impairments.

SSA staff worked with researchers at the A.J. Drexel Autism Institute at Drexel University to analyze participation trend for adults with ASD in the SSI program. In the resulting publication,⁴⁶ the authors found that a large and growing number of adults with autism receive SSI benefits. This finding underscores the importance of future research related to the economic security of adults on the autism spectrum.

An additional study, which was produced by SSA staff in collaboration with Mathematica, a policy research and evaluation organization, was released in May 2021: **Changing Stays? Duration of Supplemental Security Income Participation by First-Time Child Awardees and the Role of Continuing Disability Reviews**. This article provides new evidence of the changing role of the SSI program for low-income children, including children with ASD, since 1997. The authors use administrative records from the SSA to identify new SSI awardees and track their histories in the SSI and SSDI programs.

SSA has also undertaken several COVID-19-related activities that broadly target individuals with disabilities but would also benefit individuals with ASD.

The COVID-19 pandemic has forced SSA to limit in-person appointments to critical need situations. Following this shift in operating posture, a substantial drop in the number of SSI applicants was observed. Many individuals—especially older adults and those with limited English proficiency—rely on in-person meetings to get the help they need. SSA stands ready to assist these groups with online and telephone services. Older adults wanting to apply for SSI payments must call the national hotline (800-772-1213). Those who are deaf or hard of hearing can call TTY 800-325-0778. SSA also provides free interpreter services in more than 150 languages.

At the end of 2020, SSA began an outreach program for people currently receiving Disability Insurance benefits who could potentially be eligible for additional payments through SSI. These individuals received letters from SSA to notify them of their potential eligibility. The letter provided a phone number people could call for additional information and SSI eligibility screening.

In addition, SSA joined with external partners to launch a new national outreach campaign. The goal of the campaign was to connect eligible individuals to SSI and SSDI benefits. The SSI and SSDI programs provide critical financial assistance, including life-saving access to health care and the Supplemental Nutrition Assistance Program in many cases.

Key components of SSA's ongoing outreach campaign are:

- Working with community-based groups that can assist with taking applications for SSI and SSDI;
- Launching a national advertising campaign on TV, radio, and social media, with emphasis on children with disabilities; and
- Adding a number of new online tools and informational pages, including:
 - Online resources for **People Helping Others** access SSA services,
 - Online **Outreach Materials for Vulnerable Populations** for partner groups to use, and
 - Updated information for **Faith-Based and**

Community Groups, including a new toolkit and fact sheets about SSI and SSDI.

SSA also added an **online informational page** that specifically address COVID-19.

DEPARTMENT OF TRANSPORTATION (DOT)

The **U.S. Department of Transportation (DOT)** works to ensure transportation that is fast, safe, efficient, accessible, and convenient to improve the quality of life of people in the U.S. DOT-funded research and activities broadly impact the well-being of individuals with disabilities, including those with ASD, and their families.

The DOT's **Accessible Transportation Technologies Research Initiative (ATTRI)** is a joint multi-modal, multi-agency initiative, co-led by the Federal Highway Administration, Federal Transit Administration (FTA), and Intelligent Transportation Systems Joint Program Office, with support from NIDILRR within HHS/ACL, and other federal partners. The ATTRI Program developed and implemented transformative applications to improve mobility options for all travelers, particularly those with disabilities. ATTRI research focuses on removing barriers to transportation for people with visual, hearing, cognitive, and mobility disabilities. Technologies and creative service models funded by ATTRI offer all Americans enhanced travel choices and accessibility at levels once only imagined. DOT has awarded application development funding for **Wayfinding and Navigation, Pre-trip Concierge & Virtualization, and Safe Intersection Crossing**, with NIDILRR awarding a grant in the **Robotics and Automation** technology area.

Working together, the four technology areas provide the basis for an accessible transportation network that is far more economical, expansive, and welcoming than previously available, which is of increasing importance not only to travelers with disabilities but to all travelers in the U.S. A number of ATTRI technology sites explore different solutions, and applications are available to assist travelers with cognitive disabilities, including those with ASD.

The **National Rural Transit Assistance Program (RTAP)** operates under a cooperative agreement between the FTA and the Neponset Valley Transportation Management Association, and its mission is to address the training and technical assistance needs of rural and tribal transit operators across the nation and to support state RTAP programs. The National RTAP provides technical assistance related to ASD and travel, including an Easterseals Project Action Consulting presentation during a session of the 2017 National RTAP Technical Assistance Conference and response to a recent technical assistance request for autism training for school bus drivers.

On February 11, 2020, NIMH sponsored a **free webinar** which featured presentations by the National Center for Mobility Management and the FTA on transportation and mobility services for youth with autism transitioning out of high school. The webinar helped users leverage mobility resources and develop connections with transportation providers and services.

DEPARTMENT OF VETERANS AFFAIRS (VA)

The **Department of Veterans Affairs (VA)** is committed to fulfilling President Abraham Lincoln’s promise “to care for him who shall have borne the battle, and for his widow, and his orphan” by serving and honoring the men and women who are America’s veterans. As part of this commitment, the VA’s **Veterans Health Administration** is currently serving 9 million enrolled veterans each year, including veterans with autism or other disabilities, through the largest integrated health care network in the U.S., with 1,255 health care facilities. In addition, the **Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA)**, a health benefits program which provides coverage to the spouse or widow(er) and children of veterans not eligible for TRICARE, allows ABA as a covered health benefit.

INTERAGENCY COORDINATION

There are currently two mechanisms for coordination of autism activities across the federal government:

the Interagency Autism Coordinating Committee (IACC) and the National Autism Coordinator (NAC). This section describes recent activities of the IACC and the NAC that are related to improving the health and well-being of individuals with ASD.

Interagency Autism Coordinating Committee (IACC)

The **Interagency Autism Coordinating Committee (IACC)** was established in its current form by Congress under the CAA of 2006 (**Public Law 109-416**), and was most recently reauthorized under the Autism CARES Act of 2019 (**Public Law 116-60**), to provide advice to the HHS Secretary concerning issues related to ASD and to coordinate federal ASD-related efforts. Among other functions, the IACC develops and regularly updates a *Strategic Plan for ASD*, monitors federal and community ASD activities, and serves as a forum for public input on issues related to ASD. The Autism CARES Act of 2019 outlines requirements for the membership of the IACC, which includes representatives of federal agencies and public members from a variety of stakeholder groups within the autism community. Public membership includes autistic individuals, parents and legal guardians of children and adults on the autism spectrum, autism researchers, and leaders of national research, service, and advocacy organizations.

Federal members of the IACC represent the following departments and agencies that address ASD research or services:

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)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)

- National Institutes of Health (NIH)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

Department of Defense (DoD)

Department of Education (ED)

Department of Justice (DOJ)

Department of Labor (DOL)

Department of Veterans Affairs (VA)

Department of Housing and Urban Development (HUD)

Environmental Protection Agency (EPA)

Social Security Administration (SSA)

DOL, DOJ, HUD, and VA are new additions to the membership of the IACC under the Autism CARES Act of 2019.

The IACC reconvened in July 2021 following a hiatus from March 2020 to July 2021 to allow for the appointment of new members to the Committee under the Autism CARES Act of 2019. The activities of federal agencies and private organizations to respond to the needs of the autism community in the wake of the COVID-19 pandemic was a top priority item, along with racial equity and health disparities in autism, which were both topics of discussion at the meeting that took place on **July 21-22, 2021**. The Committee will continue to discuss these and other issues related to the health and well-being of people on the autism spectrum in the future.

The following are highlights of the activities of the IACC in 2018 and 2019 and of NIMH's Office of Autism Research Coordination (OARC), which coordinates and manages the IACC, in 2020 and 2021:

IACC Full Committee Meeting Presentations

At its full Committee meetings, the IACC regularly invites presenters to speak about topics of interest to the Committee and the broader autism community, including health and well-being. The goal of these presentations is to inform the IACC and the autism community about recent scientific advances, new re-

search funding announcements and service programs, policy updates, and other important issues. Invited speakers include researchers, advocates, federal agency officials, and others. These presentations and their associated discussions highlighted areas of concern or progress relevant to the seven research priority areas of the *IACC Strategic Plan* and helped to inform the future strategic planning activities of the Committee. The topics highlighted at IACC meetings in 2018 and 2019 that are relevant to health and well-being of people on the autism spectrum include research on health disparities, early detection, employment, aggression and self-injury, wandering, disability financial planning, housing, health care, prevalence, communications technologies, and systems of care. Summaries of these presentations are included in the *IACC Strategic Plan for ASD 2018-2019 Update*. Archived videos of each presentation and the full slide sets are available on the **IACC website**.

IACC Health Outcomes Working Group

During the Autism CARES Act of 2014 authorization period, the IACC convened a Working Group on health and wellness issues for autistic individuals. In response, the IACC established the Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum. The Working Group, composed of IACC members and invited external stakeholders with expertise in a variety of areas, was formed to gather information, discuss issues, and develop activities and recommendations for consideration by the full IACC. The Working Group focused their efforts on identifying the challenges people on the autism spectrum face pertaining to health and wellness, as well as co-occurring physical and mental health challenges.

To begin to address these particular needs of the autism community, the Working Group met by conference call in 2018 and convened public workshops in September 2018 and May 2019. The **September 2018 workshop** addressed several of the most common physical health issues that are reported by the autism community as areas of concern and featured speakers who addressed the topics of epilepsy, sleep, gastrointestinal disorders, and

patient-provider and health care services issues. The workshop also addressed the issue of health care transitions from pediatric to adult care and the needs for training for adult health care providers in autism, as well as approaches to increasing health literacy and advocacy within the autism community. A **second workshop in May 2019** focused on the mental health issues experienced by individuals on the autism spectrum, including anxiety, depression, suicide, self-injurious behaviors, aggression, and mental health services. Highlights from these two workshops are summarized in the ***IACC Strategic Plan for ASD 2018-2019 Update***. Additional working group materials, including archived workshop videos and meeting documents, are available on the IACC website. The IACC Working Group began work to draft a report on physical and mental health conditions affecting individuals on the autism spectrum and their families that will be continued and completed under the new Committee that convened in July 2021.

IACC Housing Working Group

During the Autism CARES Act of 2014 authorization period, the IACC voted to convene a working group to address housing concerns among individuals on the autism spectrum and their families. The goal of the Working Group was to research best practices on housing, review implementation of current federal regulations, and address housing issues faced by autistic individuals, including those with more severe disabilities.

The Working Group convened in 2019, beginning with a conference call in June to discuss potential activities to improve housing issues. The Working Group decided to organize **a workshop in July 2019** that would address the housing needs of people on the autism spectrum. The workshop included advocates in the community that have established different successful housing models for individuals with autism across the spectrum. A summary of presentations and discussions of this workshop is included in the ***IACC Strategic Plan for ASD 2018-2019 Update***. Members of the IACC discussed the outcome of the workshop at the July 2019 full Committee meeting and decided that the issues

highlighted will serve as an excellent base for the new IACC to consider further activities and action related to housing for people on the autism spectrum.

OARC/NIMH-Sponsored Special Event: *The Federal Response to COVID-19: Addressing the Needs of the Autism and Disability Communities*

The OARC sponsored a **virtual event** in April 2021 to discuss the impact of the COVID-19 pandemic on people on the autism spectrum and their families and the response of federal agencies. The event featured presentations from NIMH, CDC, ED, and DOL. Six autism community stakeholders from across the community engaged in a dialogue with the agency speakers. Discussion focused on the adverse impacts of the pandemic on mental and physical health as well as strategies for resilience and the emergence of innovations in areas such as telehealth and telework during the pandemic. Other topics discussed included efforts to ensure that people with disabilities are prioritized for vaccination, efforts to address the impact of the pandemic on students with disabilities, and programs to assist people with disabilities with employment challenges and access to employment opportunities during the pandemic. Efforts to address racial disparities across these areas was also a cross-cutting theme in this virtual event. The recorded event and slides are available on the **IACC website**.

HHS National Autism Coordinator (NAC)

The Autism CARES Act of 2014 required the designation of a National Autism Coordinator (NAC), “an existing official within the Department of Health and Human Services to oversee, in consultation with the Secretaries of Defense and Education, national ASD research, services, and support activities.” The duties of the NAC include coordination and implementation of federal ASD activities, taking into account the ***IACC Strategic Plan***, as well as ensuring that federal ASD efforts are not unnecessarily duplicative. The NAC accomplishes cross-agency and cross-departmental coordination in part through the activity of the Federal Interagency Workgroup on ASD (FIWA), an all-federal working group of representatives from the following federal departments and agencies:

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)
- HHS 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)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

Department of Education (ED)

Department of Defense (DoD)

Department of Justice (DOJ)

Department of Housing and Urban Development (HUD)

Department of Labor (DOL)

Department of Transportation (DOT)

Environmental Protection Agency (EPA)

Social Security Administration (SSA)

The NAC serves as the FIWA Chair. The goal of the FIWA is to work with the NAC to enhance internal coordination of federal ASD activities. This includes exchange of information across agencies regarding autism-related activities, ensuring progress toward

implementation of *IACC Strategic Plan* recommendations, and coordination of federal reporting activities related to the Autism CARES Act. The FIWA has assisted with tracking the implementation of recommendations of the *HHS Report to Congress on Young Adults and Transitioning Youth with Autism Spectrum Disorder*, which was completed as required under the Autism CARES Act of 2014, and to determine what progress has been made in specific areas of transition-related work. The FIWA has also taken an active role in providing agency information for the development of this *2021 Report to Congress on the Health and Well-Being of Individuals with ASD*.

Transition-Aged Youth Webinar Series

The OARC and the HHS NAC co-sponsored a series of webinars in FY 2020 in an effort to disseminate information and resources that address the needs of transition-aged youth and young adults on the autism spectrum. The **first webinar** explored the topic of transition from pediatric to adult health care and featured speakers from HRSA and **Got Transition/ The National Alliance to Advance Adolescent Health**, as well as an autistic young adult and her mother discussing their experience. The **second webinar** addressed transportation and mobility options to support postschool transition. Featured speakers included an autistic self-advocate and representatives from the **National Center for Mobility Management, Partners for Youth with Disabilities**, and the DOT's **Federal Transit Administration**. The **final webinar** explored expanding career pathways for youth and young adults on the autism spectrum and the importance of employment to health, featuring a presentation from DOL's ODEP.

Agency Recommendations

This chapter of the report covers Section 399DD(b)(2) (C) and (E) of the Public Health Service Act, as amended by the Autism CARES Act of 2019, which require: (C) “recommendations on establishing best practices guidelines to ensure interdisciplinary coordination between all relevant service providers receiving Federal funding”; and (E) “recommendations that seek to improve health outcomes for such individuals, including across their lifespan, by addressing (i) screening and diagnosis of children and adults; (ii) behavioral and other therapeutic approaches; (iii) primary and preventative care; (iv) communication challenges; (v) aggression, self-injury, elopement, and other behavioral issues; (vi) emergency room visits and acute care hospitalization; (vii) treatment for co-occurring physical and mental health conditions; (viii) premature mortality; (ix) medical practitioner training; and (x) caregiver mental health”.

The recommendations that follow were developed by the FIWA, an interagency working group convened by the HHS NAC to internally coordinate and consider strategies to implement federal ASD activities, taking into account the recommendations of the IACC (described in the previous section). FIWA members considered broad issues related to the health and well-being of individuals on the autism spectrum in the context of their agency missions and programs and identified areas where increased or focused activity could close gaps in research, services, and policy. In order to fully realize these recommendations, it will be necessary to combine the efforts of the federal government with those of other partners, including state and local agencies, community and advocacy organizations, private research funders, professional associations, and others.

List of Recommendations

The following recommendations are organized according to the list of topics outlined in the requirements in the Autism CARES Act of 2019 (above).

Interdisciplinary coordination of federal resources

Interdisciplinary coordination of federal resources will enable existing systems and resources to be accessed and utilized more effectively by individuals on the autism spectrum and their families.

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.
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.
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.

Screening and diagnosis of ASD in children and adults

Better screening and diagnostic methods and guidelines will result in more timely linkages to treatments and interventions for individuals on the autism spectrum.

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.

Behavioral and other therapeutic interventions

Improved interventions for individuals on the autism spectrum, as well as enhanced systems to deliver these interventions, will likely have a positive effect on overall health and well-being.

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.
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.
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.

Primary, preventative, and emergency/acute care

Improvements in the delivery of primary, preventative, and emergency care will improve overall health and well-being of individuals on the autism spectrum while potentially also reducing existing strains on the health care system.

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 ASD.
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 health care 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.

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.

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

Increased understanding and more effective treatment of co-occurring conditions will improve the quality of life for individuals on the autism spectrum.

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.

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.

Caregiver mental health and supports

Recognizing and attending to the mental health and support needs of caregivers will positively impact their lives as well as those for whom they provide care.

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.

Quality of life factors

Identifying and improving critical quality of life factors will directly and indirectly impact the health and well-being of individuals on the autism spectrum.

21. Support activities, research, and resources that contribute to improving the overall well-being of individuals with ASD, 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.

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.



SUMMARY AND CONCLUSIONS



Summary and Conclusions

Approximately 1 in 54 children in the U.S. has been identified with ASD,¹ and the prevalence of ASD in adults has been estimated at approximately 2%.² Defined by social and communicative difficulties, autism often co-occurs with a variety of physical and mental health conditions. Both the core characteristics of autism and these co-occurring conditions can lead to poor health outcomes in autistic individuals.¹¹⁻¹⁶ Since the enactment of the Combating Autism Act in 2006, and its most recent reauthorization under the Autism CARES Act of 2019, federal departments and agencies, in partnership with the community, have made significant strides in addressing many of the pressing health and well-being needs of individuals and families affected by ASD. This Report highlights many of these federal efforts and provides recommendations to expand upon them.

Several federal departments and agencies are funding research to better understand the impact of ASD on physical and mental health and well-being:

- ACL-funded research focuses on the development of interventions to improve outcomes for individuals with disabilities such as ASD, including community living and participation among individuals with autism across the lifespan.
- Research funded by AHRQ includes a project focused on using computational approaches to mine electronic health records for ASD-related health data to enable the creation of large autism-related data sets for research.
- Through the SEED Teen initiative, CDC is collecting detailed data on topics including adolescent health, use of health care and education services, experiences with health care providers, current level of functioning (including strengths and difficulties), and parental expectations and family impacts.
- NIH funds a large portfolio of research projects seeking to understand the biology of ASD, develop improved screening and diagnostic tools, develop enhanced interventions, and improve long-term outcomes for people with ASD.
- Projects funded by the Army's ARP include those focused on investigating and improving health outcomes and promoting community inclusion (employment, education, and social inclusion) for those living with ASD.
- The ATTRI Program, led by DOT with support from ACL, seeks to develop and implement transformative applications to improve mobility options for all travelers, particularly those with disabilities.

There are also many examples of federal activities focused on improving health- and well-being-related services and supports for individuals on the autism spectrum and their families:

- HHS's Healthy People 2030 initiative objectives focus on increasing developmental screening and increasing the proportion of children with ASD who receive special services.
- ACF's efforts to increase broad developmental and behavioral screening have helped inform the early childhood field and ultimately benefit children with all disabilities, including those on the autism spectrum.
- CMS recently initiated the HCBS Special Projects contract to advance the delivery of HCBS for specific Medicaid-eligible populations, including youth with disabilities who are transitioning out of the foster care system and adults with IDD living with and cared for by aging parents and guardians.

- The HRSA-funded interdisciplinary clinics associated with the LEND and DBP training grants are making evidence-based services available to health professionals across the nation, particularly in underserved communities, to increase their understanding of ASD/DD and make them aware of emerging evidence regarding ASD evaluation and interventions.
 - IHS's BH2I funds projects seeking to plan, develop, implement, and evaluate behavioral health integration with primary care, community-based settings, and/or integrating primary care, nutrition, diabetes care, and chronic disease management.
 - SAMHSA's CMHI program provides funds to create systems of care: a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, organized into a coordinated network, that builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school and the community, and throughout life.
 - NIH supports services research projects on transition-aged youth and adults with ASD, including topics such as improving competitive employment outcomes. NIH is also addressing the need for more services research aimed at adults and transition-aged youth by enriching the pool of autism researchers focused on this specific population through career development and enhancement awards.
 - A DoD-funded study aims to further understand the impact of ABA services delivered to participants in the TRICARE ACD and provide important data regarding the most beneficial amount of ABA services.
 - ED has recently funded 15 new personnel development grants that prepare master's level personnel (e.g., early interventionists, special educators, and related services providers) to serve children with disabilities, including children with ASD.
 - DOJ recently made two awards to national providers in support of their National Training and Technical Assistance Initiative to Improve Law Enforcement-based Responses to People with Mental Health Disorders and Intellectual and Developmental Disabilities.
 - The RETAIN initiative, co-funded by DOL and SSA, interconnects health care and employment by facilitating the development of approaches and strategies for people to stay at work and return to work after an injury or illness.
 - The EPA provides funding to support 10 PEHSUs, which offer advice to health professionals and families on prevention, diagnosis, management, and treatment of environmentally related health effects in children, which may include ASD.
 - The Community Integration Working Group, a collaborative effort between ACL, CMS, ASPE, and HUD, is working on initiatives to improve community integration for people with disabilities.
- Federal agencies have also developed new programs or adapted existing programs to help mitigate the impact of the COVID-19 pandemic on the health and well-being of individuals with disabilities, including individuals on the autism spectrum, and their families:
- CDC funded 43 State and Territorial Act Early COVID-19 Response Teams, tasked with carrying out a state/territory-wide needs assessment, identifying and addressing barriers to early identification of children with ASD and other DD and identifying strategies to improve resiliency among children and families.
 - HRSA's LEND training program transitioned to virtual delivery, and telehealth and teleconsultation increased during the pandemic to meet the needs of individuals with ASD/DD and their families.
 - NIH created the RADx-UP initiative to reduce COVID-19 associated morbidity and mortality for vulnerable and underserved populations, including individuals with ASD and other DD, that are disproportionately affected by the SARS-CoV-2 virus.

- ED undertook a variety of activities to support families and address the needs of children with disabilities during the COVID-19 pandemic and recently announced new grant opportunities for Research to Accelerate Pandemic Recovery in Special Education.
- DOL created numerous webpages and documents to support workers with disabilities during the pandemic, including a COVID-19 resource page and information disseminated through JAN and EARN.
- OARC/NIMH sponsored a **special event** in April 2021 to discuss the impact of the pandemic on individuals on the autism spectrum and their families and the response of federal agencies, including the perspectives of key federal agencies and community stakeholders.
- The IACC discussed the impact of the pandemic and strategies for recovery at their July 21-22, 2021, meeting.

The members of the FIWA developed 23 recommendations to improve the health and well-being of individuals on the autism spectrum. The recommendations propose potential solutions to several critical needs, including:

- Increased federal coordination in providing services and supports;
- Improved screening and diagnostic tools;
- Optimized behavioral and other therapeutic interventions;
- Enhanced primary, preventative, and emergency care systems;
- Better treatment of co-occurring conditions;
- Recognition of caregiver mental health and support needs; and
- Improving other quality of life factors.

Adopting these recommendations and fully maximizing their potential to fill critical needs in the autism community will require the action of federal agencies, as well as state and local agencies, community and advocacy organizations, private research funders, professional associations, and others.

Moving forward, more research, services, and supports are critically needed to address the needs of individuals on the autism spectrum and their caregivers across the lifespan. In addition to focusing on physical and mental health, it is crucial to understand and appreciate the role that social determinants of health and other quality of life factors contribute to overall well-being of people on the autism spectrum. In addition, continued efforts will be needed to address racial disparities in diagnosis and access to health care and other services for individuals on the autism spectrum. Coordination of federal activities and engagement with the autism community through avenues such as the IACC will continue to play critical roles in ensuring that federal departments and agencies are able to be responsive to the evolving needs of the community and emerging opportunities to improve the health and well-being of people on the autism spectrum and their families.



APPENDICES



Appendix I: References

1. Maenner MJ, Shaw KA, Baio J; EdS1, Washington A, Patrick M, DiRienzo M, Christensen DL, Wiggins LD, Pettygrove S, Andrews JG, Lopez M, Hudson A, Baroud T, Schwenk Y, White T, Rosenberg CR, Lee LC, Harrington RA, Huston M, Hewitt A; PhD-7, Esler A, Hall-Lande J, Poynter JN, Hallas-Muchow L, Constantino JN, Fitzgerald RT, Zahorodny W, Shenouda J, Daniels JL, Warren Z, Vehorn A, Salinas A, Durkin MS, Dietz PM. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveill Summ.* 2020 Mar 27;69(4):1-12. [PMID: 32214087]
2. Dietz PM, Rose CE, McArthur D, Maenner M. National and State Estimates of Adults with Autism Spectrum Disorder. *J Autism Dev Disord.* 2020 Dec;50(12):4258-4266. [PMID: 32390121]
3. Shaw KA, Maenner MJ, Baio J; EdS1, Washington A, Christensen DL, Wiggins LD, Pettygrove S, Andrews JG, White T, Rosenberg CR, Constantino JN, Fitzgerald RT, Zahorodny W, Shenouda J, Daniels JL, Salinas A, Durkin MS, Dietz PM. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016. *MMWR Surveill Summ.* 2020 Mar 27;69(3):1-11. [PMID: 32214075]
4. Hiremath CS, Sagar KJV, Yamini BK, Girimaji AS, Kumar R, Sravanti SL, Padmanabha H, Vykunta Raju KN, Kishore MT, Jacob P, Saini J, Bharath RD, Seshadri SP, Kumar M. Emerging behavioral and neuroimaging biomarkers for early and accurate characterization of autism spectrum disorders: a systematic review. *Transl Psychiatry.* 2021 Jan 13;11(1):42. [PMID: 33441539]
5. Loubersac J, Michelon C, Ferrando L, Picot MC, Baghdadli A. Predictors of an earlier diagnosis of Autism Spectrum Disorder in children and adolescents: a systematic review (1987-2017). *Eur Child Adolesc Psychiatry.* 2021 Apr 28. [PMID: 33909143]
6. Shattuck PT, Durkin M, Maenner M, Newschaffer C, Mandell DS, Wiggins L, Lee LC, Rice C, Giarelli E, Kirby R, Baio J, Pinto-Martin J, Cuniff C. Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *J Am Acad Child Adolesc Psychiatry.* 2009 May;48(5):474-483. [PMID: 19318992]
7. McDonnell CG, DeLucia EA, Hayden EP, Penner M, Curcin K, Anagnostou E, Nicolson R, Kelley E, Georgiades S, Liu X, Stevenson RA. Sex Differences in Age of Diagnosis and First Concern among Children with Autism Spectrum Disorder. *J Clin Child Adolesc Psychol.* 2021 Sep-Oct; 50(5): 645-655. [PMID: 33136459]
8. Begeer S, Mandell D, Wijnker-Holmes B, Venderbosch S, Rem D, Stekelenburg F, Koot HM. Sex differences in the timing of identification among children and adults with autism spectrum disorders. *J Autism Dev Disord.* 2013 May;43(5): 1151-6. [PMID: 23001766]
9. Constantino JN, Abbacchi AM, Saulnier C, Klaiman C, Mandell DS, Zhang Y, Hawks Z, Bates J, Klin A, Shattuck P, Molholm S, Fitzgerald R, Roux A, Lowe JK, Geschwind DH. Timing of the Diagnosis of Autism in African American Children. *Pediatrics.* 2020 Sep;146(3):e20193629. [PMID: 32839243]

10. Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGuseppi C, Durkin MS, Giarelli E, Morrier MJ, Nicholas JS, Pinto-Martin JA, Shattuck PT, Thomas KC, Yeargin-Allsopp M, Kirby RS. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health*. 2009 Mar;99(3):493-8. [PMID: 19106426]
11. Soke GN, Maenner MJ, Christensen D, Kurzius-Spencer M, Schieve LA. Prevalence of Co-occurring Medical and Behavioral Conditions/Symptoms Among 4- and 8-Year-Old Children with Autism Spectrum Disorder in Selected Areas of the United States in 2010. *J Autism Dev Disord*. 2018 Aug;48(8):2663-2676. [PMID: 29524016]
12. Davignon MN, Qian Y, Massolo M, Croen LA. Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD. *Pediatrics*. 2018 Apr;141(Suppl 4):S335-S345. [PMID: 29610415]
13. Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, Kripke C. The health status of adults on the autism spectrum. *Autism*. 2015 Oct;19(7):814-23. [PMID: 25911091]
14. Mason D, McConachie H, Garland D, Petrou A, Rodgers J, Parr JR. Predictors of quality of life for autistic adults. *Autism Res*. 2018 Aug;11(8):1138-1147. [PMID: 29734506]
15. Dovgan K, Mazurek MO. Impact of multiple co-occurring emotional and behavioural conditions on children with autism and their families. *J Appl Res Intellect Disabil*. 2019 Jul;32(4):967-980. [PMID: 30941865]
16. Graham Holmes L, Zampella CJ, Clements C, McCleery JP, Maddox BB, Parish-Morris J, Udhmani MD, Schultz RT, Miller JS. A Lifespan Approach to Patient-Reported Outcomes and Quality of Life for People on the Autism Spectrum. *Autism Res*. 2020 Jun;13(6):970-987. [PMID: 32154664]
17. Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. *Br J Psychiatry*. 2016 Mar;208(3):232-8. [PMID: 26541693]
18. Malik-Soni N, Shaker A, Luck H, Mullin AE, Wiley RE, Lewis MES, Fuentes J, Frazier TW. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatr Res*. 2021 Mar 25:1-8. [PMID: 33767375]
19. Maddox BB, Crabbe S, Beidas RS, Brookman-Frazee L, Cannuscio CC, Miller JS, Nicolaidis C, Mandell DS. "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*. 2020 May;24(4):919-930. [PMID: 31674198]
20. Bilaver LA, Sobotka SA, Mandell DS. Understanding Racial and Ethnic Disparities in Autism-Related Service Use Among Medicaid-Enrolled Children. *J Autism Dev Disord*. 2021 Sep;51(9):3341-3355. [PMID: 33219917]
21. Bishop-Fitzpatrick L, Mazefsky CA, Eack SM. The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism*. 2018 Aug;22(6):703-711. [PMID: 28666391]
22. Shea LL, Verstrete K, Nonnemacher S, Song W, Salzer MS. Self-reported community participation experiences and preferences of autistic adults. *Autism*. 2021 Jan 25:1362361320987682. [PMID: 33491462]
23. Lynch SL, Irvine AN. Inclusive education and best practice for children with autism spectrum disorder: An integrated approach. *International Journal of Inclusive Education*. 2009 Dec 1;13(8):845-59. doi: 10.1080/13603110802475518

24. Carter EW, Harvey MN, Taylor JL, Gotham K. Connecting Youth and Young Adults with Autism Spectrum Disorders to Community Life. *Psychol Sch.* 2013 Nov;50(9):888-898. [PMID: 26236045]
25. Ohl A, Grice Sheff M, Small S, Nguyen J, Paskor K, Zanjirian A. Predictors of employment status among adults with Autism Spectrum Disorder. *Work.* 2017;56(2):345-355. [PMID: 28211841]
26. Scott M, Milbourn B, Falkmer M, Black M, Bölte S, Halladay A, Lerner M, Taylor JL, Girdler S. Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism.* 2019 May;23(4):869-901. [PMID: 30073870]
27. Schall C, Wehman P, Avellone L, Taylor JP. Competitive Integrated Employment for Youth and Adults with Autism: Findings from a Scoping Review. *Psychiatr Clin North Am.* 2020 Dec;43(4):701-722. [PMID: 33127003]
28. Haas K, Gibbs V. Does a Person's Autism Play a Role in Their Interactions with Police: The Perceptions of Autistic Adults and Parent/Carers. *J Autism Dev Disord.* 2021 May;51(5):1628-1640. [PMID: 32809172]
29. Salerno-Ferraro AC, Schuller RA. Perspectives from the ASD community on police interactions: Challenges & recommendations. *Res Dev Disabil.* 2020 Oct;105:103732. [PMID: 32663737]
30. Khanna R, Jariwala-Parikh K, West-Strum D, Mahabaleshwarkar R. Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders.* 2014 Mar 1;8(3):157-67. doi:10.1016/j.rasd.2013.11.003
31. Karpur A, Vasudevan V, Lello A, Frazier TW, Shih A. Food insecurity in the households of children with autism spectrum disorders and intellectual disabilities in the United States: Analysis of the National Survey of Children's Health Data 2016-2018. *Autism.* 2021 Jun 2:13623613211019159. [PMID: 34075809]
32. Feeley C, Deka D, Lubin A, McGackin M. Detour to the Right Place: A Study with Recommendations for Addressing the Transportation Needs and Barriers of Adults on the Autism Spectrum in New Jersey. Rutgers. 2015 Sept. Available at: <http://vtc.rutgers.edu/detour-to-the-right-place/>
33. **Data Source:** Medicare administrative claims data for calendar year 2016, specifically Medicare fee-for-service (FFS) beneficiaries with both Medicare Parts A and B full year coverage. Beneficiaries who received Medicare Advantage (Medicare Part C) at any time during 2016 were excluded because the services they received are collected by private companies and are not included in Medicare administrative claims data. The resulting final sample size was 30,987,261 beneficiaries. The ASD-specific statistics have not yet been published; however, the results of the IDD beneficiaries were published in 2019, available at: Reichard A, Haile E, Morris A. Characteristics of Medicare Beneficiaries with Intellectual or Developmental Disabilities. *Intellect Dev Disabil.* 2019 Oct;57(5):405-420. [PMID: 31568735]
34. **CHF:** American Heart Association Council on Epidemiology and Prevention Statistics Committee and Stroke Statistics Subcommittee. Heart Disease and Stroke Statistics-2019 Update: A Report From the American Heart Association. *Circulation.* 2019 Mar 5;139(10):e56-e528. [PMID: 30700139]
COPD: Croft JB, Wheaton AG, Liu Y, Xu F, Lu H, Matthews KA, Cunningham TJ, Wang Y, Holt JB. Urban-Rural County and State Differences in Chronic Obstructive Pulmonary Disease - United States, 2015. *MMWR Morb Mortal Wkly Rep.* 2018 Feb 23;67(7):205-211. [PMID: 29470455]
Diabetes: Bullard KM, Cowie CC, Lessem SE, Saydah SH, Menke A, Geiss LS, Orchard TJ, Rolka DB, Imperatore G. Prevalence of Diagnosed Diabetes in Adults by Diabetes Type - United States, 2016. *MMWR Morb Mortal Wkly Rep.* 2018 Mar 30;67(12):359-361. [PMID: 29596402]
Hypertension: Fryar CD, Ostchega Y, Hales CM, Zhang G, Kruszon-Moran D. Hypertension

Prevalence and Control Among Adults: United States, 2015-2016. NCHS Data Brief. 2017 Oct;(289):1-8. [PMID: 29155682]

Obesity: Hales CM, Carroll MD, Fryar CD, Ogden CL. Prevalence of Obesity Among Adults and Youth: United States, 2015-2016. NCHS Data Brief. 2017 Oct;(288):1-8. [PMID: 29155689]

- 35. ADHD:** Faraone SV, Biederman J. What is the prevalence of adult ADHD? Results of a population screen of 966 adults. *J Atten Disord*. 2005 Nov;9(2):384-91. [PMID: 16371661]
- Conduct Disorders:** Moore AA, Silberg JL, Roberson-Nay R, Mezuk B. Life course persistent and adolescence limited conduct disorder in a nationally representative US sample: prevalence, predictors, and outcomes. *Soc Psychiatry Psychiatr Epidemiol*. 2017 Apr;52(4):435-443. [PMID: 28180930]
- Anxiety:** Anxiety and Depression Association of America. (2019). Facts and Statistics. Available at: <https://adaa.org/about-adaa/press-room/facts-statistics>. (Retrieved 2/20/2020).
- Bipolar Disorder:** National Institute of Mental Health. Statistics: Bipolar Disorder. Available at: <https://www.bipolar-lives.com/bipolar-disorder-statistics.html> (Retrieved 2/20/2020).
- Major Depressive Disorders:** National Institute of Mental Health. Statistics: Major Depression. Available at: <https://www.nimh.nih.gov/health/statistics/major-depression.shtml> (Retrieved 2/20/2020).
- Personality Disorders:** Sansone RA, Sansone LA. Personality disorders: a nation-based perspective on prevalence. *Innov Clin Neurosci*. 2011 Apr;8(4):13-8. [PMID: 21637629]
- PTSD:** U.S. Department of Veterans Affairs. Epidemiology of PTSD. Available at: <https://www.ptsd.va.gov/professional/treat/essentials/epidemiology.asp#two>. (Retrieved 2/20/2020).
- Schizophrenia and Other Psychotic Disorders:** National Institute of Mental Health. Statistics: Schizophrenia. Available at: <https://www.nimh.nih.gov/health/statistics/schizophrenia.shtml> (Retrieved 2/20/2020).
- 36.** Musumeci MB, Chidambaram P. Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending. KFF Issue Brief. June 2019 Available at: <https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending/>
- 37.** Kogan MD, Vladutiu CJ, Schieve LA, Ghandour RM, Blumberg SJ, Zablotsky B, Perrin JM, Shattuck P, Kuhlthau KA, Harwood RL, Lu MC. The Prevalence of Parent-Reported Autism Spectrum Disorder Among US Children. *Pediatrics*. 2018 Dec;142(6):e20174161. [PMID: 30478241]
- 38.** Satterstrom FK, Kosmicki JA, Wang J, Breen MS, De Rubeis S, An JY, Peng M, Collins R, Grove J, Klei L, Stevens C, Reichert J, Mulhern MS, Artomov M, Gerges S, Sheppard B, Xu X, Bhaduri A, Norman U, Brand H, Schwartz G, Nguyen R, Guerrero EE, Dias C; Autism Sequencing Consortium; iP-SYCH-Broad Consortium, Betancur C, Cook EH, Gallagher L, Gill M, Sutcliffe JS, Thurm A, Zwick ME, Børglum AD, State MW, Cicek AE, Talkowski ME, Cutler DJ, Devlin B, Sanders SJ, Roeder K, Daly MJ, Buxbaum JD. Large-Scale Exome Sequencing Study Implicates Both Developmental and Functional Changes in the Neurobiology of Autism. *Cell*. 2020 Feb 6;180(3):568-584.e23. [PMID: 31981491]
- 39.** Alexander Arguello P, Addington A, Borja S, Brady L, Dutka T, Gitik M, Koester S, Meinecke D, Merikangas K, McMahon FJ, Panchision D, Senthil G, Lehner T. From genetics to biology: advancing mental health research in the Genomics ERA. *Mol Psychiatry*. 2019 Nov;24(11):1576-1582. [PMID: 31164699]
- 40.** Parker KJ, Oztan O, Libove RA, Mohsin N, Karhson DS, Sumiyoshi RD, Summers JE, Hinman KE, Motonaga KS, Phillips JM, Carson DS, Fung LK, Garner JP, Hardan AY. A randomized placebo-controlled pilot trial shows that intranasal vasopressin improves social deficits in children with autism. *Sci Transl Med*. 2019 May 8;11(491):eaau7356. [PMID: 31043522]

41. Voss C, Schwartz J, Daniels J, Kline A, Haber N, Washington P, Tariq Q, Robinson TN, Desai M, Phillips JM, Feinstein C, Winograd T, Wall DP. Effect of Wearable Digital Intervention for Improving Socialization in Children With Autism Spectrum Disorder: A Randomized Clinical Trial. *JAMA Pediatr.* 2019 May 1;173(5):446-454. [PMID: 30907929]
42. Laxman DJ, Taylor JL, DaWalt LS, Greenberg JS, Mailick MR. Loss in services precedes high school exit for teens with autism spectrum disorder: A longitudinal study. *Autism Res.* 2019 Jun;12(6):911-921. [PMID: 31033222]
43. Broder Fingert S, Carter A, Pierce K, Stone WL, Wetherby A, Scheldrick C, Smith C, Bacon E, James SN, Ibañez L, Feinberg E. Implementing systems-based innovations to improve access to early screening, diagnosis, and treatment services for children with autism spectrum disorder: An Autism Spectrum Disorder Pediatric, Early Detection, Engagement, and Services network study. *Autism.* 2019 Apr;23(3):653-664. [PMID: 29633852]
44. Pierce K, Gazestani VH, Bacon E, Barnes CC, Cha D, Nalabolu S, Lopez L, Moore A, Pence-Stophaeros S, Courchesne E. Evaluation of the Diagnostic Stability of the Early Autism Spectrum Disorder Phenotype in the General Population Starting at 12 Months. *JAMA Pediatr.* 2019 Jun 1;173(6):578-587. [PMID: 31034004]
45. Feinberg E, Augustyn M, Broder-Fingert S, Bennett A, Weitzman C, Kuhn J, Hickey E, Chu A, Levinson J, Sandler Eilenberg J, Silverstein M, Cabral HJ, Patts G, Diaz-Linhart Y, Fernandez-Pastrana I, Rosenberg J, Miller JS, Guevara JP, Fenick AM, Blum NJ. Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial From DBPNet. *JAMA Pediatr.* 2021 Mar 1;175(3):243-250. [PMID: 33427861]
46. Anderson KA, Hemmeter J, Rast JE, Roux AM, Shattuck PT. Trends in Supplemental Security Income Payments to Adults With Autism. *Psychiatr Serv.* 2020 Jun 1;71(6):602-607. [PMID: 32264799]

Appendix II: CDC-Supported ASD Publications: Study to Explore Early Development (SEED)

Manuscripts published in the past three years specifically addressing the health and developmental characteristics of children with ASD and use of services among families and children with ASD are listed below:

1. Wiggins LD, Rubenstein E, Windham G, Barger B, Croen L, Dowling N, Giarelli E, Levy S, Moody E, Soke G, Fields V, Schieve L. Evaluation of sex differences in preschool children with and without autism spectrum disorder enrolled in the study to explore early development. *Res Dev Disabil*. 2021 May;112:103897. [PMID: 33610079]
2. Wiggins LD, Nadler C, Rosenberg S, Moody E, Reyes N, Reynolds A, Alexander A, Daniels J, Thomas K, Giarelli E, Levy SE. Many Young Children with Autism Who Use Psychotropic Medication Do Not Receive Behavior Therapy: A Multisite Case-Control Study. *J Pediatr*. 2021 May;232:264-271. [PMID: 33493493]
3. Reynolds AM, Soke GN, Sabourin KR, Croen LA, Daniels JL, Fallin MD, Kral TVE, Lee LC, Newschaffer CJ, Pinto-Martin JA, Schieve LA, Sims A, Wiggins L, Levy SE. Gastrointestinal Symptoms in 2- to 5-Year-Old Children in the Study to Explore Early Development. *J Autism Dev Disord*. 2021 Jan 4. [PMID: 33394243]
4. Hiruma L, Pretzel RE, Tapia AL, Bodfish JW, Bradley C, Wiggins L, Hsu M, Lee LC, Levy SE, Daniels J. A Distinct Three-Factor Structure of Restricted and Repetitive Behaviors in an Epidemiologically Sound Sample of Preschool-Age Children with Autism Spectrum Disorder. *J Autism Dev Disord*. 2021 Jan 2. [PMID: 33387232]
5. Fields VL, Soke GN, Reynolds A, Tian LH, Wiggins L, Maenner M, DiGuseppi C, Kral TVE, Hightshoe K, Schieve LA. Pica, Autism, and Other Disabilities. *Pediatrics*. 2021 Feb;147(2):e20200462. [PMID: 33408069]
6. Wiggins LD, DiGuseppi C, Schieve L, Moody E, Soke G, Giarelli E, Levy S. Wandering Among Preschool Children with and Without Autism Spectrum Disorder. *J Dev Behav Pediatr*. 2020 May;41(4):251-257. [PMID: 31977588]
7. Tian LH, Wiggins LD, Schieve LA, Yeargin-Allsopp M, Dietz P, Aylsworth AS, Elias ER, Hoover-Fong JE, Meeks NJL, Souders MC, Tsai AC, Zackai EH, Alexander AA, Dowling NF, Shapira SK. Mapping the Relationship between Dysmorphology and Cognitive, Behavioral, and Developmental Outcomes in Children with Autism Spectrum Disorder. *Autism Res*. 2020 Jul;13(7):1227-1238. [PMID: 32567802]
8. Fields VL, Soke GN, Reynolds A, Tian LH, Wiggins L, Maenner M, DiGuseppi C, Kral TVE, Hightshoe K, Ladd-Acosta C, Schieve LA. Association between pica and gastrointestinal symptoms in preschoolers with and without autism spectrum disorder, Study to Explore Early Development. *Disabil Health J*. 2020 Dec 13:101052. [PMID: 33358227]
9. Ellis Weismer S, Rubenstein E, Wiggins L, Durkin MS. A Preliminary Epidemiologic Study of Social (Pragmatic) Communication Disorder Relative to Autism Spectrum Disorder and Developmental Disability Without Social Communication Deficits. *J Autism Dev Disord*. 2020 Oct 9:10.1007/s10803-020-04737-4. [PMID: 33037562]
10. Cordero C, Schieve LA, Croen LA, Engel SM, Maria Siega-Riz A, Herring AH, Vladutiu CJ, Seashore CJ, Daniels JL. Neonatal jaundice in association with autism spectrum disorder and developmental disorder. *J Perinatol*. 2020 Feb;40(2):219-225. [PMID: 31388117]
11. Wiggins LD, Rice CE, Barger B, Soke GN, Lee LC, Moody E, Edmondson-Pretzel R, Levy SE. DSM-5

criteria for autism spectrum disorder maximizes diagnostic sensitivity and specificity in preschool children. *Soc Psychiatry Psychiatr Epidemiol*. 2019 Jun;54(6):693-701. [PMID: 30850887]

12. Wiggins LD, Barger B, Moody E, Soke G, Pandey J, Levy S. Brief Report: The ADOS Calibrated Severity Score Best Measures Autism Diagnostic Symptom Severity in Pre-School Children. *J Autism Dev Disord*. 2019 Jul;49(7):2999-3006. [PMID: 28265795]
13. Shapira SK, Tian LH, Aylsworth AS, Elias ER, Hoover-Fong JE, Meeks NJL, Souders MC, Tsai AC, Zackai EH, Alexander AA, Yeargin-Allsopp M, Schieve LA. A Novel Approach to Dymorphology to Enhance the Phenotypic Classification of Autism Spectrum Disorder in the Study to Explore Early Development. *J Autism Dev Disord*. 2019 May;49(5):2184-2202. [PMID: 30783897]
14. Rubenstein E, Croen L, Lee LC, Moody E, Schieve LA, Soke GN, Thomas K, Wiggins L, Daniels J. Community-based service use in preschool children with autism spectrum disorder and associations with insurance status. *Res Autism Spectr Disord*. 2019 Oct;66:101410. [PMID: 32831903]
15. Reynolds AM, Soke GN, Sabourin KR, Hepburn S, Katz T, Wiggins LD, Schieve LA, Levy SE. Sleep Problems in 2- to 5-Year-Olds With Autism Spectrum Disorder and Other Developmental Delays. *Pediatrics*. 2019 Mar;143(3):e20180492. [PMID: 30745433]
16. Reinhartsen DB, Tapia AL, Watson L, Crais E, Bradley C, Fairchild J, Herring AH, Daniels J. Expressive Dominant Versus Receptive Dominant Language Patterns in Young Children: Findings from the Study to Explore Early Development. *J Autism Dev Disord*. 2019 Jun;49(6):2447-2460. [PMID: 30937735]
17. Levy SE, Rescorla LA, Chittams JL, Kral TJ, Moody EJ, Pandey J, Pinto-Martin JA, Pomykacz AT, Ramirez A, Reyes N, Rosenberg CR, Schieve L, Thompson A, Young L, Zhang J, Wiggins L. ASD Screening with the Child Behavior Checklist/1.5-5 in the Study to Explore Early Development. *J Autism Dev Disord*. 2019 Jun;49(6):2348-2357. [PMID: 30739222]
18. Kral TV, Chittams J, Bradley CB, Daniels JL, DiGuseppi CG, Johnson SL, Pandey J, Pinto-Martin JA, Rahai N, Ramirez A, Schieve LA, Thompson A, Windham G, York W, Young L, Levy SE. Early life influences on child weight outcomes in the Study to Explore Early Development. *Autism*. 2019 May;23(4):954-962. [PMID: 30102071]
19. DiGuseppi C, Sabourin KR, Levy SE, Soke GN, Lee LC, Wiggins L, Schieve LA. Injury-related treatments and outcomes in preschool children with autism spectrum disorder: Study to Explore Early Development (SEED). *Research in Autism Spectrum Disorders*. 2019;66:101413. doi: 10.1016/j.rasd.2019.101413.
20. Barger B, Moody EJ, Ledbetter C, D'Abreu L, Hepburn S, Rosenberg SA. Temperament Similarities and Differences: A Comparison of Factor Structures from the Behavioral Style Questionnaire in Children with and Without Autism Spectrum Disorder. *J Autism Dev Disord*. 2019 May;49(5):1749-1762. [PMID: 30604350]
21. DiGuseppi C, Levy SE, Sabourin KR, Soke GN, Rosenberg S, Lee LC, Moody E, Schieve LA. Injuries in Children with Autism Spectrum Disorder: Study to Explore Early Development (SEED). *J Autism Dev Disord*. 2018 Feb;48(2):461-472. [PMID: 29022199]
22. Soke GN, Rosenberg SA, Rosenberg CR, Vasa RA, Lee LC, DiGuseppi C. Self-injurious behaviors in children with autism spectrum disorder enrolled in the Study to Explore Early Development. *Autism*. 2018 Jul;22(5):625-635. [PMID: 28635306]
23. Soke GN, Rosenberg SA, Rosenberg CR, Vasa RA, Lee LC, DiGuseppi C. Brief Report: Self-Injurious Behaviors in Preschool Children with Autism Spectrum Disorder Compared to Other Developmental Delays and Disorders. *J Autism Dev Disord*. 2018 Jul;48(7):2558-2566. [PMID: 29429009]

Manuscripts that address the etiology of ASD include those listed below:

1. Ames JL, Ladd-Acosta C, Fallin MD, Qian Y, Schieve LA, DiGuseppi C, Lee L, Kasten EP, Zhou G, Pinto-Partin J, Howerton EM, Eaton CL, Croen LA. Maternal Psychiatric Conditions, Treatment With Selective Serotonin Reuptake Inhibitors, and Neurodevelopmental Disorders. 2021 Aug;90(4):253-262. [PMID: 34116791]
2. Matias S, Pearl M, Lyall K, Croen LA, Kral TVE, Fallin D, Lee L, Bradley CB, Schieve LA, Windham GC. Maternal Prepregnancy Weight and Gestational Weight Gain in Association with Autism and Developmental Disorders in Offspring. 2021 Sep;29(9):1554-1564. [PMID: 34347372]
3. McGuinn LA, Windham GC, Kalkbrenner AE, Bradley C, Di Q, Croen LA, Fallin MD, Hoffman K, Ladd-Acosta C, Schwartz J, Rappold AG, Richardson DB, Neas LM, Gammon MD, Schieve LA, Daniels JL. Early Life Exposure to Air Pollution and Autism Spectrum Disorder: Findings from a Multisite Case-Control Study. *Epidemiology*. 2020 Jan;31(1):103-114. [PMID: 31592868]
4. Windham GC, Anderson M, Lyall K, Daniels JL, Kral TVE, Croen LA, Levy SE, Bradley CB, Cordero C, Young L, Schieve LA. Maternal Pre-pregnancy Body Mass Index and Gestational Weight Gain in Relation to Autism Spectrum Disorder and other Developmental Disorders in Offspring. *Autism Res*. 2019 Feb;12(2):316-327. [PMID: 30575327]
5. Soke GN, Maenner M, Windham G, Moody E, Kaczaniuk J, DiGuseppi C, Schieve LA. Association Between Breastfeeding Initiation and Duration and Autism Spectrum Disorder in Preschool Children Enrolled in the Study to Explore Early Development. *Autism Res*. 2019 May;12(5):816-829. [PMID: 30852853]
6. Sabourin KR, Reynolds A, Schendel D, Rosenberg S, Croen LA, Pinto-Martin JA, Schieve LA, Newschaffer C, Lee LC, DiGuseppi C. Infections in children with autism spectrum disorder: Study to Explore Early Development (SEED). *Autism Res*. 2019 Jan;12(1):136-146. [PMID: 30475448]
7. Rubenstein E, Young JC, Croen LA, DiGuseppi C, Dowling NF, Lee LC, Schieve L, Wiggins LD, Daniels J. Brief Report: Maternal Opioid Prescription from Preconception Through Pregnancy and the Odds of Autism Spectrum Disorder and Autism Features in Children. *J Autism Dev Disord*. 2019 Jan;49(1):376-382. [PMID: 30132098]
8. Rubenstein E, Wiggins LD, Schieve LA, Bradley C, DiGuseppi C, Moody E, Pandey J, Pretzel RE, Howard AG, Olshan AF, Pence BW, Daniels J. Associations between parental broader autism phenotype and child autism spectrum disorder phenotype in the Study to Explore Early Development. *Autism*. 2019 Feb;23(2):436-448. [PMID: 29376397]
9. McGuinn LA, Windham GC, Messer LC, Di Q, Schwartz J, Croen LA, Moody EJ, Rappold AG, Richardson DB, Neas LM, Gammon MD, Schieve LA, Daniels JL. Air pollution, neighborhood deprivation, and autism spectrum disorder in the Study to Explore Early Development. *Environ Epidemiol*. 2019 Oct;3(5):e067. [PMID: 32478281]

10. Levy SE, Pinto-Martin JA, Bradley CB, Chittams J, Johnson SL, Pandey J, Pomykacz A, Ramirez A, Reynolds A, Rubenstein E, Schieve LA, Shapira SK, Thompson A, Young L, Kral TVE. Relationship of Weight Outcomes, Co-Occurring Conditions, and Severity of Autism Spectrum Disorder in the Study to Explore Early Development. *J Pediatr.* 2019 Feb;205:202-209. [PMID: 30314662]
11. Croen LA, Qian Y, Ashwood P, Zerbo O, Schendel D, Pinto-Martin J, Daniele Fallin M, Levy S, Schieve LA, Yeargin-Allsopp M, Sabourin KR, Ames JL. Infection and Fever in Pregnancy and Autism Spectrum Disorders: Findings from the Study to Explore Early Development. *Autism Res.* 2019 Oct;12(10):1551-1561. [PMID: 31317667]
12. Croen LA, Qian Y, Ashwood P, Daniels JL, Fallin D, Schendel D, Schieve LA, Singer AB, Zerbo O. Family history of immune conditions and autism spectrum and developmental disorders: Findings from the study to explore early development. *Autism Res.* 2019 Jan;12(1):123-135. [PMID: 30095240]
13. Cordero C, Windham GC, Schieve LA, Fallin MD, Croen LA, Siega-Riz AM, Engel SM, Herring AH, Stuebe AM, Vladutiu CJ, Daniels JL. Maternal diabetes and hypertensive disorders in association with autism spectrum disorder. *Autism Res.* 2019 Jun;12(6):967-975. [PMID: 30969030]

Appendix III: HRSA-Supported ASD Research Studies and Tools

TABLE 1: AUTISM INTERVENTION RESEARCH NETWORK ON PHYSICAL HEALTH (AIR-P) STUDIES

Year Initiated*	Study Title	Description	Status
2008	Autism Treatment Network (ATN) Registry	The AIR-P, through the ATN data registry, has made comprehensive data about children with ASD available to a broader research community.	Ongoing
2015	Physical Exercise to Reduce Anxiety in Underserved Children with ASD	Study to examine the feasibility and efficacy of a physical exercise intervention to reduce anxiety in children from underserved families.	Ongoing
2015	Improving Participation in Dental Care and Oral Health Outcomes for Underserved Children with ASD	Study to improve home dental hygiene, oral health, and compliance with dental procedures in underserved populations with ASD by comparing the efficacy of the AIR-P Dental Toolkit with a combined regimen involving the toolkit and a parent-mediated behavioral intervention.	Completed 8/31/2018
2018	Resiliency Program for Siblings of Children with Autism Spectrum Disorder	Pilot study to improve resiliency in teenage siblings of children with ASD.	Ongoing
2018	Registry Call-Back Assessment: Secondary Analyses	These secondary analyses arise from various young investigator interests in mining existing ASD Registry data. Topics include parental stress, exercise, oral health, and core autism symptoms.	Completed 8/31/2018
2019	Ameliorate Childhood Obesity Risk from Newer Antipsychotics for Individuals with Autism Spectrum Disorder	Pilot study adapted an empirically validated pediatric weight management program for youth with ASD who gain weight on second-generation antipsychotics (SGAs).	Completed 8/31/2020
2019	Evaluation of a Multimedia Sleep Education Package in Children with ASD	Pilot study to explore whether a multimedia sleep education package can be successfully provided to families and show efficacy in improving sleep habits and sleep problems along with parenting sense of competence.	Completed 8/31/2020

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Year Initiated*	Study Title	Description	Status
2019	The Emotion Awareness and Skills Enhancement Program for Youth with ASD and Intellectual Disability (EASE-ID): A Mind-Body Intervention to Improve Sleep, Health, and Emotion Regulation	Pilot study to extend the benefits of a previously developed mindfulness-based intervention, the EASE Program, to youth with ASD and ID and evaluate its impact on sleep and overall physical health.	Completed 8/31/2018
2020	Health Services and Systems Node: Health Research, Practice, and Policy Needs Assessments and Research Studies	The goal is to develop clear metrics and foster connections among researchers and policy makers to improve care coordination and service delivery on population-level life course outcomes for autistic individuals. Specific research priorities include supporting health care navigation and models of transition practices, training primary care providers in the adult health system, and educating individuals and families about transition care.	New
2020	State Implementation of Health Risk Screening Tools	The overarching aim is to examine health outcomes and patterns of access to subsequent recommended care among children with autism in states that have implemented a health risk screening tool compared to a) states that do not have a health risk screening tool and b) states that utilize other approaches to screening for health risks.	New
2020	Social Network Linkages to Grow Autism Physical Health Research	Aims to improve life outcomes for individuals with ASD through social network research. This study investigates how to strengthen employment outcomes for young adults on the autism spectrum in extended high school.	New

* From 2008-2020, the AIR-P awardee was Massachusetts General Hospital (MGH). In September 2020, the AIR-P awardee changed to University of California, Los Angeles (UCLA). All activities initiated prior to 2020 are attributed to AIR-P MGH; all activities initiated in 2020 and beyond are attributed to AIR-P UCLA.

TABLE 2: AIR-P TOOLS AND GUIDELINES

Tool/Guideline Name	Description
EEG Guide for Parents	Parents and providers may have concerns or questions about how to help children with ASD successfully complete an EEG. Two toolkits (one for parents and one for providers) were developed to provide information about the EEG procedure, how a child's ASD diagnosis might affect his or her experience, and how to help children with ASD successfully prepare for and complete an EEG.
EEG Guide for Providers	Parents and providers may have concerns or questions about how to help children with ASD successfully complete an EEG. Two toolkits (one for parents and one for providers) were developed to provide information about the EEG procedure, how a child's ASD diagnosis might impact his or her experience, and how to help children with ASD successfully prepare for and complete an EEG.
Puberty and Adolescence	All parents eventually face the challenge of teaching their children about the natural changes of puberty. However, parents of preteens with ASD may need the help of additional strategies to ease the transition. This tool provides guidance on the subject of puberty that can be directly applied to preteens with ASD. The tool aims to increase families' understanding of puberty and their ability to adapt to these changes with confidence.
Melatonin and Sleep Problems: A Guide for Parents	Melatonin is a common medicine a doctor or health care provider may suggest to help improve sleep. This toolkit provides parents with information about melatonin and helps parents decide if melatonin is right for their child.
Guideline on Treatment of Anxiety	The combined AIR-P/ATN network developed systematic ways to assess and treat coexisting conditions such as ASD and anxiety. This guideline provides methods for managing this and other coexisting conditions for which management was previously highly variable or sporadic. This guidance is intended for parent and professional communities.
Guideline on the Treatment of Irritability and Problem Behaviors	The combined AIR-P/ATN network developed systematic ways to assess and treat irritability and problem behaviors when they coexist with ASD. This guideline provides methods for managing this and other coexisting conditions for which management was previously highly variable or sporadic. This guidance is intended for parent and professional communities.
Bedtime Routines	The combined AIR-P/ATN network produced a short accessible video on bedtime routines. Network parents, clinicians, and researchers used materials developed by combined network, including the toolkit "Strategies to Improve Sleep", and up-to-date research to inform this video.
Daytime Habits	The combined AIR-P/ATN network produced a short accessible video on daytime habits that may impact a child's sleep. Network parents, clinicians, and researchers used materials developed by combined network, including the toolkit "Strategies to Improve Sleep", and up-to-date research to inform this video.

Tool/Guideline Name	Description
First-Then Boards for Children with Autism Spectrum Disorder	The combined AIR-P/ATN network produced a short accessible video on first-then boards, a visual aid that helps identify the direct consequences of an action, such as a reward for good behavior. Network parents, clinicians, and researchers used materials developed by combined network, including the toolkit “Visual Supports”, and up-to-date research to inform this video.
Visual Schedule for Children with Autism Spectrum Disorder	The combined AIR-P/ATN network produced a short accessible video on visual schedules, which are often used to help children with autism better transition to a new activity. Network parents, clinicians, and researchers used materials developed by combined network, including the toolkit “Visual Supports”, and up-to-date research to inform this video.
“Adulting” Modules and Data Collection Instruments	Pilot-tested a range of “adulting” modules and data collection instruments on physical and mental health, health care, relationships, financial well-being, civic engagement, and other important developmental topics for young adults with >100 UCLA students.
UCLA Needle Anxiety Protocol	The UCLA needle anxiety protocol uses QI principles to recognize and implement strategies that health care providers can use to treat autistic patients and their families and improve overall performance.
Self-Determined Learning Model of Instruction (SDLMI)-Autism with Facilitator’s Guide Tip Sheet	This includes an interactive design to develop the materials supporting future research using the SDLMI-Autism in community-based settings to promote self-determination and other valued outcomes in autistic adolescents.

TABLE 3: AUTISM INTERVENTION RESEARCH NETWORK ON BEHAVIORAL HEALTH (AIR-B) STUDIES

Year Initiated*	Study Title	Description	Status
2015	Mind the Gap	This multi-phase study aims to address the critical need to increase access to care for under-resourced children with ASD/DD and their families by conducting several focus groups and interviews with parents of low-income, minority children with ASD/DD across different sites (UCLA, UC Davis, University of Pennsylvania, and University of Rochester) to better understand challenges, barriers, and needs in the community.	Ongoing
2015	Building Better Bridges	This multi-phase study aims to identify the barriers to successful transitions between educational systems for children with ASD/DD by conducting focus groups and interviews with parents of children with ASD/DD across different sites (UCLA, UC Davis, University of Pennsylvania, and University of Rochester) to identify transition barriers. The findings informed an intervention to improve transition outcomes for children with ASD/DD and their families.	Ongoing
2017	PARTNER	The PARTNER study aims to measure and monitor change among AIR-B community partners. Findings have informed AIR-B on how to improve collaborations and maximize resource sharing among AIR-B community partners to strengthen community care systems for underserved children with ASD/DD and their families.	Ongoing

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Year Initiated*	Study Title	Description	Status
2020*	Implementation Strategy Intervention for Remaking Recess	Remaking Recess is a school-based social/peer engagement intervention for children ages 5 to 12. RR combines both peer-mediated (employing typically developing peers to support children with ASD/DD) and adult-facilitated (employing school personnel to facilitate social engagement for children with ASD/DD) approaches to increase children’s social skills.	New
2020*	Implementation Strategy Intervention for Self-Determination Learning Model of Instruction	The Self-Determination Learning Model of Instruction (SDLMI) is a self-advocacy intervention for adolescents with IDD (13 to 22 years old; 22 is the upper age limit of high school for individuals with disabilities). The SDLMI intervention enables the facilitator to teach students to self-direct the goal setting and attainment process to achieve educationally relevant goals and enhance self-determination.	New
2020*	Implementation Strategy Intervention for Mind the Gap	Mind the Gap is a family navigation intervention for children newly diagnosed under age 8 to engage under-resourced families in accessing intervention services after an ASD/DD diagnosis.	New

*Note: For all AIR-B studies that initiated in 2020, the implementation strategy, UNITED (“Using Novel Implementation Tools for Evidence-based intervention Delivery”) will be incorporated and will involve team building and sustainment via social networking. UNITED will be used to test how best to implement Remaking Recess, SDLMI, and Mind the Gap in the community. This implementation strategy intervention will help identify and train the best members of each organization or school to implement Remaking Recess, SDLMI, and Mind the Gap at that site. Intervention sites include: UCLA, UC Davis, University of Pennsylvania, University of Rochester, University of Kansas, University of Washington, and Drexel University.

TABLE 4: AIR-B TOOLS

Tool/Guideline Name	Description
Mind the Gap Parent Resource Binder (available in English and Spanish)	This toolkit provides parents with resources that will guide them throughout the process of acquiring services for their newly diagnosed children. This binder includes topics such as: what is ASD, navigating the system, parent rights and child advocacy, understanding challenging behavior, communication development, dealing with stigma, from anxiety to acceptance, your social network, healthy lifestyle, and basic needs.
Building Better Bridges Transition Passport	This tool supports parents with children undergoing a school transition, which contains a transition checklist, parent and student guide, a brief overview of the student, and resources tailored to meet the needs of the parent/caregiver and educational team members.
Social Dynamics of Intervention	This tool measures change for the Building Better Bridges school transition intervention through social network mapping of the levels of communication and cooperation between all members of the child’s transition team.
PARTNER	This tool consists of surveys to measure the impact of engagement on the interagency collaboration of community partners.
Transition Back to School Resource Handbooks (available in English, Spanish, and Korean)	To help guide students transitioning back to school during the COVID-19 pandemic, AIR-B developed a handbook for parents and teachers in English, Spanish, and Korean. Webinars on how to use the handbook are available in all three languages.
Community Conference (recordings available in English, Spanish, and Korean)	In collaboration with community partners, AIR-B organizes an annual community conference in English, Spanish, and Korean. The theme of the March 2021 community conference focused on self-determination and the intersection of race/ethnicity and disability as well as helpful strategies parents/teachers/ self-advocates used in distance learning throughout the COVID-19 pandemic.

TABLE 5: DEVELOPMENTAL BEHAVIORAL PEDIATRICS RESEARCH NETWORK (DBPNET) STUDIES

Year Initiated*	Study Title	Description	Status
2013	Maternal Immune Status and Autism Severity	This study proposes to replicate the presence of maternal autoantibodies in mothers of children with ASD in a geographically diverse population (Pennsylvania and Arkansas) utilizing the DBPNet and determine the association of these antibodies with autism severity and behavioral impairments.	Ongoing
2014	Project EARLY: Engagement, Assessment, Referral, and Linkage for Young Children	The goal of the project is to provide real-world primary care practices with a replicable model of care that increases early identification and access to timely diagnostic and early intervention services for a vulnerable population of urban families.	Ongoing
2014	Preliminary Validation of Selected Pediatric PROMIS Measures in Children with Autism Spectrum Disorder: A DBPNet Study	The purpose of this project is to determine the validity of the NIH Patient Reported Outcome Measurement Information System (PROMIS) pediatric parent-proxy reported Peer Relationships, Family Involvement, and Psychological Distress measures in 5- to 12-year-old children with ASD and elucidate how appropriately parents believe the PROMIS measures assess the constructs of peer relationships, family involvement, and psychological distress in their 5- to 12-year-old child with ASD.	Ongoing
2017	Online Parenting Training in Pivotal Response Treatment: Increasing Access to Care.	The purpose of this pilot project is to assess the initial acceptability/feasibility of the online training program and collect the necessary pilot data in order to submit a multi-site R01 grant across DBPNet sites.	Ongoing
2018	Diagnosis of Psychological Distress and Anxiety among Children with Intellectual Disability and Autism by Clinicians in Developmental-Behavioral Pediatrics, Child Psychiatry and Psychology: A Qualitative study	The purpose of this study is to understand how clinicians in the fields of Developmental-Behavioral Pediatrics, Child Psychiatry, and Psychology diagnose and manage psychological distress and anxiety among children with ASD and ID through qualitative analyses including focus groups and individual interviews.	Ongoing

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Year Initiated*	Study Title	Description	Status
2018	The Role of the Autism Diagnostic Observation Schedule in the Diagnosis of Autism by a Developmental-Behavioral Pediatrician: A DBPNet Study	The goals of this study are to determine the frequency with which the results of an Autism Diagnostic Observation Schedule (ADOS-2) alter the diagnostic conclusions of developmental behavioral pediatricians evaluating a child age 18 months to 5 years 11 months for possible ASD and to evaluate factors that are associated with the likelihood that the results of an ADOS-2 will alter developmental behavioral pediatricians' clinical diagnosis of ASD.	Ongoing
2018	A Retrospective Description of the Effectiveness and Adverse Effects of Stimulants and Alpha-2 Agonists (A2A) Used by Developmental-Behavioral Pediatricians for the Treatment of ADHD in Preschool Aged Children	The primary objective of this study is to determine the percentage of preschool-aged children with ADHD who responded positively to stimulants and A2A based on a review of data in the EHR and to determine if there is a difference in the positive response rate to these two classes of medication. The secondary objectives are to describe type and frequency of adverse effects to stimulants and A2A when prescribed for the treatment of preschool-aged children for ADHD.	Ongoing
2019	Understanding the Management of ADHD by Members of the Society for Developmental and Behavioral Pediatrics	The objective of this study is to describe the current practices of professionals in the Society of Developmental Behavioral Pediatrics regarding the assessment and management of ADHD in general and complex ADHD in particular. A secondary objective is to identify if there are demographic factors (e.g., practice location, clinician years in practice, clinician frequency of ADHD care, etc.) that impact practice patterns.	Ongoing
2019	Improving Rates of Behavioral Treatment in Preschoolers through MEHealth for ADHD Software	The primary aims of this study is to collect pilot data for an online behavioral parent training intervention for preschool-aged children with ADHD.	Ongoing
2020	Improving Access and Outcomes for Children with ADHD	The primary aim of this study is to collect pilot data for an online behavioral parent training intervention delivered by community-based paraprofessionals for children with ADHD.	New
2020	Medication Treatment of ADHD in Children with ASD and Intellectual Disability	This is a secondary data analysis of data for the EHR study evaluating medication treatment of ADHD in children with ASD.	New

TABLE 6: DBPNET TOOLS AND GUIDELINES

Tool/Guideline Name	Description
ADHD Guideline	The DBPNet research director led the development of the complex ADHD guidelines published by the Society for Developmental and Behavioral Pediatrics.

TABLE 7: HEALTHY WEIGHT RESEARCH NETWORK (HWRN) STUDIES

Year Initiated*	Study Title	Description	Status
2017	Trajectory of BMI in Children with ASD – a Follow-up to a Feeding Intervention	The goal of this project is to follow up with participants from a randomized controlled (wait-list) trial on parent training for feeding, in which 42 parents of children with ASD aged 2 to 7 learned behavioral strategies to increase their child’s acceptance of new foods, improve their child’s behavior during meals, and teach self-help skills related to meals. BMI, behavioral difficulties associated with meals, family practices around meals, parent stress, and three-day food records were assessed at three time points. The goal is to use these data to elucidate risk factors for obesity that are specific for children with ASD.	Completed 6/30/2019
2017	Supporting Preschool Teachers to Promote Physically Active Plan Among Children with ASD and DD	The goal of this study is to develop and provide preliminary evidence that supports an online professional development program for preschool teachers who work with children with ASD/DD that is free of charge and can be accessed at any time, in any location, thus building the capacity of child care settings to appropriately promote sufficient daily physical activity, and ultimately healthy weight, among this population.	Completed 6/30/2019
2017	Does Food Addiction Mediate the Relationship between BMI and ASD?	This study seeks to identify possible psychological mechanisms underpinning overeating and its links to increased BMI in children with ASD. The rationale for the proposed research is that identifying psychological mechanisms underlying overeating in ASD will allow examination of neural underpinnings of these behaviors and provide treatment targets, both of which can be explored in subsequent applications for grant funding.	Completed 6/30/2019
2018	The Validity of Image-Assisted Food Records in Adolescents with IDD	The goal of this project is to assess the feasibility of conducting an energy intake validation study in adolescents with IDD and to evaluate the agreement and compare mean daily energy intake obtained from image-assisted three-day food records with mean daily energy expenditure in 20 adolescents with IDD.	Completed 6/30/2019
2018	Engaging Children With Behavioral Health And Neurodevelopmental Disorders And Their Parents To Prevent Summer Weight Gain: Piloting The Game Squad Home Exergaming and Virtual Health Coaching Intervention	This project was funded through supplemental funding awarded to the HWRN by the Maternal and Child Health Bureau (MCHB). It piloted a physical activity and healthy lifestyle intervention for youth with neurobehavioral and behavioral health disorders through the use of exergaming (X-Box technology) and virtual coaching.	Completed 6/30/2019

TABLE 8: HWRN TOOLS AND GUIDELINES

Tool/Guideline Name	Description
“Let’s Go” Toolkits by Maine Medical Center and HWRN	These toolkits support professionals who work with children with ID and DD. The objective of these toolkits is to provide resources for creating opportunities for all children to lead healthy lives. The toolkits aim to increase healthy eating and physical activity and decrease the risk of obesity among children with these disabilities.
Video Sports Illustrated for Children with Disabilities	This interactive tool shows a video of children with disabilities playing baseball, soccer, swimming, track and field, basketball, and Wii-sports. Children who watch the video have the opportunity to describe their level of enthusiasm for each sport. At the end, they list their two favorite sports. Because the tool is visual rather than verbal, it is most appropriate for children with disabilities who have communication difficulties.
Assessing Community Satisfaction with Community Based Participatory Research	This survey assesses the satisfaction of HWRN Advisory Board members and conference participants with their level of engagement in projects about children and families with disabilities.
Measure of Adaptive Behaviors Surrounding Eating	This tool is used by clinicians and researchers to assess adolescents’ abilities to engage in behaviors such as assisting with meal preparation and feeding themselves. The questions in this tool respond to a lack of appropriate existing measures to assess engagement in adaptive behaviors surrounding eating. When fully developed, this new adaptive eating behaviors measure will provide a useful tool for researchers and clinicians interested in assessing adaptive behaviors surrounding eating.
Strategies to Optimize Healthy Eating on a Low Budget	This tool was developed for people on a limited food budget to assist in buying and preparing healthy food. Because many people with disabilities have modest incomes, the tool provided information on how they and their families can navigate this difficult subject.
Expert Panel Recommendations on Obesity Management by Primary Care Providers for Children with ASD	The expert panel prepared the first set of recommendations on obesity management in children with ASD for dissemination to the public. This will be published in the journal <i>Pediatrics</i> .
Nutrition Education Workshops for Adults with Disabilities	This manualized series of 11 workshops is a six-month interactive curriculum for people with DD and their care providers. Its development was supported in part by a 2014 grant from the NIH.
Positive Health Practices Curriculum for Adults with Developmental Disabilities	This manualized intervention—available in paper and web-based formats—promotes healthy eating and physical activity for adults with disabilities. Its development was sponsored in part in 2015 by the Pennsylvania Office of Developmental Programs’ Department of Public Welfare.
A Novel Weight Loss Tool for Adolescents with Intellectual Disabilities	This tool was developed from an R01 randomized controlled weight loss trial for overweight/obese adolescents with ID. It was published in the <i>Journal of the Academy of Nutrition and Dietetics</i> .

TABLE 9: AUTISM LONGITUDINAL DATA PROJECT (ALDP) STUDIES

Year Initiated*	Study Title	Description	Status
2017	Early Life Origins of ASD: Role of Maternal and Cord Blood Metabolome, Placental Histology and Fetal Growth Trajectory	ALDP leverages the Boston Birth Cohort to accomplish the following aims: Aim 1. Examine the role of maternal and cord blood metabolomes in ASD; Aim 2. Examine placental histological findings in relation to the risk of ASD; Aim 3. Examine in utero fetal growth patterns in relation to the risk of ASD; Aim 4. Integrate multi-dimensional data to develop early prediction models and test interventions; and Aim 5. Provide leadership in education, training, and dissemination.	Ongoing
2017	Opioid Crisis	These studies aim to examine the long-term impact of maternal opioids use during pregnancy on child health outcomes during critical developmental stages (fetal, early childhood, and school-aged).	Ongoing
2017	US Maternal and Childhood Obesity Epidemics	These studies aim to examine the inter-generational impact of environmental obesogen exposure by examining maternal blood lead levels during pregnancy and maternal folate levels on her child's long-term risk of overweight or obesity (from birth up to 15 years of age).	Ongoing
2017	Rising Rate of Attention Deficit Hyperactivity Disorder (ADHD) in US Children	These studies aim to examine the association of maternal and fetal blood biomarkers of acetaminophen (Tylenol) and its metabolites with child risk of ADHD.	Ongoing
2019	ALDP Ancillary Study 1	Response to U.S. opioid crisis: A prospective birth cohort study to examine the long-term impact of maternal opioid use during pregnancy on child health outcomes.	Completed 8/31/2020
2019	ALDP Ancillary Study 2	Response to U.S. maternal and childhood obesity epidemics: A prospective birth cohort study to examine the inter-generational impact of maternal prenatal environmental obesogen exposure (lead, mercury) on her child's long-term risk of overweight or obesity from birth up to 15 years of age.	Completed 8/31/2020

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Year Initiated*	Study Title	Description	Status
2019	ALDP Ancillary Study 3	Response to rising rate of ADHD in U.S. children: A prospective birth cohort study to examine the association of maternal and fetal blood biomarkers of acetaminophen (Tylenol) and its metabolites with child risk of ADHD.	Completed 8/31/2020
2020	A Prospective Birth Cohort Study on Cord Blood Folate Sub-Types and Risk of Autism Spectrum Disorder	This is the first study to show that folate sub-types have differential effects on ASD risk. This work is published in a leading nutrition journal.	New
2020	The Association between Atopic Diseases and Neurodevelopmental Disabilities in a Longitudinal Cohort	In recognition of many comorbidities associated with ASD, this study focuses on a less studied comorbidity: allergic diseases in ASD. This work is currently under review by a pediatric journal.	New
2020	The Impact of the COVID-19 Pandemic on Clinical Visits among High-Risk Minority Children: Findings from the Boston Birth Cohort	This is the first prospective study to examine the impact of the COVID-19 pandemic on clinical encounters among high-risk minority children, including children with ASD. This paper is being prepared for publication.	New
2020	The Impact of the COVID-19 Pandemic on Clinical Visits among High-Risk Minority Mothers: Findings from the Boston Birth Cohort	This is the first longitudinal study to evaluate the impact of COVID-19 pandemic on maternal clinical encounters in understudied U.S. minority mothers, including those with children of ASD.	New
2020	Interaction Between Maternal Immune Activation and Antibiotic Use during Pregnancy and Child Risk of Autism Spectrum Disorder	This prospective study lent further support for the role of immune activation in the development of ASD.	New

TABLE 10: ALDP TOOLS

Tool/Guideline Name	Description
ASD Early Prediction Algorithm	<p>Although ASD is typically diagnosed after age 2, the root causes of ASD and the underlying biomarkers may be traced back long before clinical manifestations of ASD. The ASD early prediction algorithm raises the prospect that if high-risk children can be identified at an earlier stage, then intensive intervention can be considered to prevent or at least improve their health outcomes associated with a future ASD diagnosis.</p>

TABLE 11: AUTISM TRANSITIONS RESEARCH PROJECT (ATRP) RESEARCH STUDIES

Year Initiated*	Study Title	Description	Status
2017	Factors Associated with Healthy Life Outcomes and Access to Needed Services among Transition Age Youth	Secondary data analysis is used to examine the factors associated with healthy life outcomes and access to needed services among transition-aged youth with ASD. Data sources include the SSA and Vocational Rehabilitation administrative data; national surveys; and various state-level data sources. Aims are to describe changes over time in the size, demographics, health, and disability characteristics (i.e. needs); access to services and related life outcomes; and to describe the distribution and correlates of access to services and related life outcomes.	Ongoing
2017	Service Network Coordination and Social Capital	This project applies a mixed methods approach to adapt a method to measure transition-aged youth and adolescents' (TAYA) social capital and the coordination of intervention team members. The aims are to adapt a measure of social capital for the postsecondary transition and to pilot test the adapted social capital measure with TAYA with ASD, their parents, and transition coordinators before and after leaving high school.	Ongoing
2017	Transition Odyssey	The project will develop and pilot test a scalable interview protocol to understand TAYA, family, and provider insights about the transition process, the genesis of disparities, and factors that influence outcomes. The aims are to understand the unique transition-related service access experiences of TAYA, and to understand participant perspectives about what constitutes healthy life outcomes.	Ongoing

TABLE 12: ATRP TOOLS

Tool/Guideline Name	Description
National Autism Indicators Reports	<p>The National Autism Indicators Report (NAIR) series presents research findings and raises awareness about the unique service needs of TAYA with ASD to inform policies and programs with the best available evidence. NAIR topics have included: transition into young adulthood; vocational rehabilitation; DD services and outcomes in adulthood; high school students on the autism spectrum; children on the autism spectrum and family financial hardship; health and health care; and family perspectives on services and supports.</p>
Measurement Protocols for TAYA with ASD	<p>The two qualitative pilot studies, “Service Network Coordination and Social Capital” and “Transition Odyssey” are developing measurement protocols including youth, parent, and provider interviews and network protocols that can be used in future public health and services research on autism and transition. The first adapts an existing approach to measuring the social context of service provision and care coordination using innovative methods from social network analysis. The second adapts and integrates methods from two existing studies to develop a feasible, reliable, and valid approach to obtaining the perspectives of diverse TAYA and their caregivers.</p>

TABLE 13: AUTISM FIELD-INITIATED RESEARCH STUDIES (AUTISM FIRST)

Year Initiated*	Study Title	Description	Status
2017	Facing Your Fears in School Settings: Implementing a Cognitive Behavioral Therapy Program for Students with ASD or Other Special Learning Needs	This study aims to test a cognitive behavior therapy program for youth with ASD in school settings. Children with ASD are at high risk for developing clinically significant anxiety, which markedly interferes with peer relationships, family functioning, and participation in academic programming.	Ongoing
2017	Expanding pathways to early screening and intervention for underserved toddlers with ASD (ASD-PATH)	This study aims to increase pathways of access to early detection and intervention for toddlers from Hispanic and low-income families in King County, Washington, by building community capacity for providing specialized screening, intervention, and family-centered care within the context of existing, accessible federally supported programs.	Ongoing

TABLE 14: SECONDARY DATA ANALYSIS RESEARCH (SDAR) STUDIES

Year Initiated*	Study Title	Description	Status
2019	Understanding the impact of disparity in special education services for underrepresented groups with ASD	This study aims to characterize youth-level sociodemographic disparities in special education for under-resourced youth with ASD and sequentially to understand the impact of these disparities into young adulthood.	Ongoing
2019	Characterizing the Health and Healthcare Utilization of Girls with Autism Spectrum Disorder in Florida	This study aims to address the gap in understanding the health care experiences of girls with ASD by using the OneFlorida Data Trust, a repository of Florida statewide electronic health record data and Medicaid administrative records, which includes health data for 74% of all Floridians.	Completed 8/31/2020
2019	Race and Ethnic Discrepancies in Developmental Surveillance and Early Intervention	This study aims to determine whether racial/ethnic discrepancies in the conjoint receipt of developmental screening and monitoring exist and if differences in developmental surveillance receipt predict racial/ethnic discrepancies of identified ASD in children under the age of 3.	Completed 6/30/2019
2018	The Validity of Image-Assisted Food Records in Adolescents with IDD	The goal of this project is to assess the feasibility of conducting an energy intake validation study in adolescents with IDD and to evaluate the agreement and compare mean daily energy intake obtained from image-assisted three-day food records with mean daily energy expenditure in 20 adolescents with IDD.	Ongoing
2019	Effects of Augmentative and Alternative Communication (AAC) Interventions on Speech Production for Individuals with Autism Spectrum Disorders and Other Developmental Disabilities: a Systematic Review and Meta-analysis	This study aims to synthesize the intervention literature on the effects of AAC intervention on natural speech production in individuals with ASD and other developmental disabilities.	Ongoing

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Year Initiated*	Study Title	Description	Status
2020	The Intersection of Public Health Insurance and Community Connectedness for Kids with ASD/IDD and Their Family Caregivers: A Nationally Representative Study	This study aims to understand the experiences of children and family caregivers that use public health insurance programs and how these experiences differ for those with different levels of connectedness to their communities. Specific outcomes of interest include behavioral health and school participation of children, overall health of children and family caregivers, and economic engagement of family caregivers. The study will use 2014-2017 pooled National Health Interview Survey and link child, parent, and family data.	New
2020	Assessing and Improving Health Care Transition (HCT) Services for Youth with Autism Spectrum Disorder	This study aims to develop and validate a measure of HCT services within a nationally representative survey and utilize this measure to examine access to HCT services among youth with ASD, youth with special health care needs, and youth without special health care needs.	New
2020	Disparities in Health Care Access and Utilization of Children during Autism Insurance Reform	Research on factors contributing to access and utilization disparities in the U.S. pediatric population during autism insurance reform has been sparse. This study intends to fill this gap through two specific aims: 1) identify the determinants that contribute to disparities in health care access and utilization among children with ASD by early and late policy adopting states and 2) investigate potential changes in hospitalization patterns for children with ASD, prior to and following comprehensive ASD insurance reform.	New
2020	An Ecological Approach to Understanding Obesity Risk among Children with ASD	The study uses the social-ecological framework to understand obesity risk in children with ASD. The prevalence of ASD and childhood obesity are increasing, and children with ASD are at an increased risk of obesity compared to typically developing children. As obesity in children with ASD may increase with age, there is a need to explore factors in adolescents with ASD as they transition to adult health care.	New

Appendix IV: List of Acronyms

A2A: alpha-2 agonists	AoD: Administration on Disabilities
AAC: augmentative and alternative communication	APRIL: Association of Programs for Rural Independent Living
ABA: Applied Behavior Analysis	ARP: Autism Research Program
ACD: Comprehensive Autism Care Demonstration	ARPA: American Rescue Plan Act
ACE: Autism Centers of Excellence (NIH)	ASD: autism spectrum disorder
ACE Report: <i>America's Children and the Environment</i> Report (EPA)	ASD PEDS Network: ASD Pediatric Early Detection, Engagement, and Services Network
ACF: Administration for Children and Families	ASPE: Assistant Secretary for Planning and Evaluation
ACL: Administration for Community Living	ASPEN Intervention Program: ASD Screening and Parent Engagement Intervention Program
ADA: Americans with Disabilities Act	ASPIRE: Advancing State Policy Integration for Recovery and Employment
ADDM Network: Autism and Developmental Disabilities Monitoring Network	ATN: Autism Speaks Autism Treatment Network
ADFM: Active Duty Family Member	ATRP: Autism Transitions Research Project
ADHD: attention deficit/hyperactivity disorder	ATSDR: Agency for Toxic Substances and Disease Registry
ADOS: Autism Diagnostic Observation Schedule	ATTRI: Accessible Transportation Technologies Research Initiative
AEDY: Alternative Education for Disruptive Youth	AUCD: Association of University Centers on Disability
AFIRM: Autism Focused Intervention Resources and Modules	Autism CARES Act: Autism Collaboration, Accountability, Research, Education, and Support Act
AHRQ: Agency for Healthcare Research and Quality	Autism FIRST Program: Autism Field-Initiated Research Studies Program
AI/AN: American Indian/Alaska Natives	Autism SDAR Program: Autism Secondary Data Analysis Research Program
AIM: Apprenticeship Inclusion Models	Autism SIIP: Autism Single Investigator Innovation Program
AIR-P: Autism Intervention Research Network on Physical Health	
AIR-B: Autism Intervention Research Network on Behavioral Health	
ALDP: Autism Longitudinal Data Project	

- AVP:** arginine vasopressin
- BCBA:** Board Certified Behavior Analyst
- BH2I:** Behavioral Health Integration Initiative
- BHDAP:** Office of Behavioral Health, Disability, and Aging Policy
- BHC:** Behavioral Health Clinician
- BJA:** Bureau of Justice Assistance
- BMI:** body mass index
- C-SSRS:** Columbia Suicide Severity Rating Scale
- CAA:** Combating Autism Act of 2006
- CAA:** Consolidated Appropriations Act of 2021 (CMS)
- CANDO:** Center for Autism and Neurodevelopmental Disorders
- CAPE-Youth:** Center for Advancing Policy on Employment for Youth
- CARA:** Combating Autism Reauthorization Act of 2011
- CARES Act:** Coronavirus Aid, Relief, and Economic Security Act (HUD)
- CDC:** Centers for Disease Control and Prevention
- CDER:** Center for Drug Evaluation and Research
- CDMRP:** Congressionally Directed Medical Research Program
- CHAMPVA:** Civilian Health and Medical Program of the Department of Veterans Affairs
- CHF:** congestive heart failure
- CHIP:** Children's Health Insurance Program
- CIL:** Center for Independent Living
- CMCS:** Center for Medicaid & CHIP Services
- CMHI:** Children's Mental Health Initiative
- CMS:** Centers for Medicare & Medicaid Services
- COPD:** chronic obstructive pulmonary disorder
- COVID-19:** coronavirus disease 2019
- CP:** cerebral palsy
- CPIR:** Center for Parent Information and Resources
- CPRC:** Community Parent Resources Center
- CRAFFT:** Car, Relax, Alone, Forget, Friends, Trouble
- CSESA:** Center on Secondary Education for Students with Autism Spectrum Disorders
- CSG:** Council of State Governments
- CYW:** Center for Youth Wellness
- DBP:** developmental-behavioral pediatric
- DBPNet:** Developmental-Behavioral Pediatrics Research Network
- DD:** developmental disabilities
- DD Act:** Developmental Disabilities Assistance and Bill of Rights Act
- DHA:** Defense Health Agency
- DIAL:** Disability Information and Access Line
- DoD:** Department of Defense
- DOJ:** Department of Justice
- DOL:** Department of Labor
- DOT:** Department of Transportation
- DRS:** Disability Rights Section
- DSM:** Diagnostic and Statistical Manual of Mental Disorders

EARN: Employer Assistance and Resource Network on Disability Inclusion

EASE: Emotion Awareness and Skills Enhancement

ECHO: Extended Care Health Option

ECLS-K:2011: Early Childhood Longitudinal Study, Kindergarten Class of 2010-11

ED: Department of Education

EEOA: Equal Educational Opportunities Act

EEG: electroencephalogram

EHR: electronic health record

EHS: Early Head Start

EHV: Emergency Housing Voucher

EOS: Educational Opportunities Section

EPA: Environmental Protection Agency

EPSDT requirements: Early and Periodic Screening, Diagnostic, and Treatment requirements

FACES: Family and Childhood Experiences

FAPE: free and appropriate public education

FBCH: Fort Belvoir Community Hospital

FDA: Food and Drug Administration

FFS: fee-for-service

FIWA: Federal Interagency Workgroup on ASD

FMLA: Family and Medical Leave Act

FTA: Federal Transit Administration

FUP: Family Unification Program

FXS: Fragile X Syndrome

FY: fiscal year

FYI: Foster Youth to Independence

GAD-7: General Anxiety Disorder-7

GAO: Government Accountability Office

GIS: Geographic Information System

GNETS: Georgia Network for Educational and Therapeutic Support

GNO: Girls Night Out

GPS: Global Positioning System

HCBS: Home and Community-Based Services

HCT: health care transition

HCV: Housing Choice Voucher

HHS: Department of Health and Human Services

HRI: health-related independence

HRSA: Health Resources and Services Administration

HS: Head Start

HUD: Department of Housing and Urban Development

HUD-VASH: Department of Housing and Urban Development-Veterans Affairs Supportive Housing

HWRN: Healthy Weight Research Network

IACC: Interagency Autism Coordinating Committee

IACP: International Association of Chiefs of Police

ICP: Indian Children's Program

ID: intellectual disabilities

IDD: intellectual and/or developmental disabilities

IDEA: Individuals with Disabilities Education Act

IEP: Individualized Education Plan

IES: Institute of Education Sciences

IFSP: Individualized Family Service Plan

IHS: Indian Health Service

ILRU: Independent Living Research Utilization

JAN: Job Accommodation Network

JBLM CARES: Joint Base Lewis McChord Center for Autism Resources, Education and Services

K-12: kindergarten to 12th grade

LAUNCH: Linking Actions for Unmet Needs in Children’s Health

LEND: Leadership Education in Neurodevelopmental and Other Related Disabilities

LGBTQIA+: Lesbian, Gay, Bisexual, Transgender, Queer and/or Questioning, Intersex, and Asexual and/or Ally

M-CHAT: Modified Checklist for Autism in Toddlers

MCH: maternal and child health

MCHB: Maternal and Child Health Bureau

MCN: Muscogee (Creek) Nation

MFP: Money Follows the Person

MGLS:2017: Middle Grades Longitudinal Study

MHS: Military Health System

n4a: National Association of Area Agencies on Aging

NAC: National Autism Coordinator

NACDD: National Association of Councils on Developmental Disabilities

NAIR: National Autism Indicators Report

NCATS: National Center for Advancing Translational Sciences

NCBDDD: National Center on Birth Defects and Developmental Disabilities

NCCJD: National Center on Criminal Justice and Disability

NCEE: National Center for Education Evaluation and Regional Assistance

NCER: National Center for Education Research

NCES: National Center for Education Statistics

NCHS: National Center for Health Statistics

NCIL: National Council on Independent Living

NCSER: National Center for Special Education Research

NCSL: National Conference of State Legislatures

NDRN: National Disabilities Rights Network

NDSS: National Down Syndrome Society

NED: non-elderly adults with disabilities

NICHD: Eunice Kennedy Shriver National Institute of Child Health and Human Development

NIDCD: National Institute on Deafness and Other Communication Disorders

NIDILRR: National Institute on Disability, Independent Living, and Rehabilitation Research

NIEHS: National Institute of Environmental Health Sciences

NIH: National Institutes of Health

NIMH: National Institute of Mental Health

NINDS: National Institute of Neurological Disorders and Stroke

NLP: natural language processing

NLTS 2012: National Longitudinal Transition Study 2012

NSCH: National Survey of Children's Health

NSF: National Science Foundation

OARC: Office of Autism Research Coordination

OASIS: Online and Applied System for Intervention Skills

ODEP: Office of Disability Employment Policy

ODPHP: Office of Disease Prevention and Health Promotion

OESE: Office of Elementary and Secondary Education

OHS: Office of Head Start

OJP: Office of Justice Programs

OMH: Office of Minority Health

OPE: Office of Postsecondary Education

OPRE: Office of Planning, Research, and Evaluation

ORR: Office of Refugee Resettlement

OS-PCORTF: Office of the Secretary Patient-Centered Outcomes Research Trust Fund

OSEP: Office of Special Education Programs

OSERS: Office of Special Education and Rehabilitative Services

P&A: Protection and Advocacy System

PARSEC: Participation in Rural Settings to Engage in Communities

PBDEs: polybrominated diphenyl ethers

PDCM Model: Professional Development and Case Management Model

PEAT: Partnership on Employment & Accessible Technology

PEHSU: Pediatric Environmental Health Specialty Unit

PFOA: perfluorooctanoic acid

PFOS: perfluorooctanesulfonic acid

PHA: public housing agency

PHAP: Public Health Associate Program

PHQ-9: Patient Health Questionnaire

PHQ-A: Patient Health Questionnaire Modified for Adolescents

PIR: Program Information Report

PLAY: Play & Language for Autistic Youngsters

PMHC Toolkit: Police-Mental Health Collaboration Toolkit

PPACA: Patient Protection and Affordable Care Act

PROMIS: NIH Patient Reported Outcome Measurement Information System

PSC: Pediatric Symptom Checklist

PTI: Parent Training and Information Center

R&D: Research and Development

RADx-UP Initiative: Rapid Acceleration of Diagnostics-Underserved Populations Initiative

RCDC: Research, Condition, and Disease Categorization

RePORT: Research Portfolio Online Reporting Tools

RETAIN: Retaining Employment and Talent After Injury/Illness Network

RFC: residual functional capacity

RRTC: Rehabilitation Research and Training Center

RSA: Rehabilitation Services Administration

RTAP: Rural Transit Assistance Program

SAMHSA: Substance Abuse and Mental Health Services Administration

SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

SBIR: Small Business Innovation Research

SDLMI: Self-Determined Learning Model of Instruction

SEED: Study to Explore Early Development (CDC)

SEED: State Exchange on Employment & Disability (DOL)

SPA: state plan amendment

SPL: Special Litigation Section

SRO: school resource officer

SSA: Social Security Administration

SSDI: Social Security Disability Insurance

SSI: Supplemental Security Income

STAR: Science to Achieve Results

SWYC: Survey of Well-Being of Young Children

SY: school year

T-STEP: TEACCH School Transition to Employment and Postsecondary Education

TA: technical assistance

TAYA: transition-age youth and adolescents

TBHCE: Telebehavioral Health Center of Excellence

TEACCH: Treatment and Education of Autistic and Related Communication Handicapped Children

TRACK: Tools for Reading to Acquire Content Knowledge

TSC: Tuberous Sclerosis Complex

TTA: Training and Technical Assistance

UC: University of California

UCLA: University of California, Los Angeles

UCEDD: University Centers for Excellence in Developmental Disabilities Education, Research, and Service

UNITED: Using Novel Implementation Tools for Evidence-based Intervention Delivery

USPSTF: U.S. Preventive Services Task Force

U.S.: United States

VA: Department of Veterans Affairs

WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

WIOA: Workforce Innovation and Opportunity Act of 2014

WPAFB: Wright Patterson Air Force Base

YPSC: Youth Pediatric Symptom Checklist



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