

Question 5: What Kinds of Services and Supports Are Needed to Maximize Quality of Life for People on the Autism Spectrum?

Aspirational Goal: Communities will develop, access, and implement high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD and their families.

Introduction

In previous editions of the *IACC Strategic Plan*, Question 5 (Services) addressed access and coordination of services for individuals with ASD and their families. Research on services and supports focuses on self-directed care, coordination of funding and services among state and local agencies, community-based supports, and the need to better measure the health, safety, and mortality of people with ASD. Previous Question 5 *Strategic Plan* objectives included support for research to develop and evaluate the training of service providers who work with individuals with ASD, and improve the efficacy, cost-effectiveness, dissemination, and implementation of evidence-based practices. In 2015, 6% (\$21 million) of ASD-related research funding from federal agencies and private organizations addressed issues related to services (*2014-2015 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*, 2017). A lack of sufficient funding raises considerable barriers for researchers to develop, test and implement service system delivery models that increase the supply of care and address the gaps between research and practice (Shattuck et al., 2012).

There have been several notable positive changes over last few years regarding services research and planning, particularly an increased focus on the needs of individuals with autism as they age out of childhood. For example, the U.S. Government Accountability Office (GAO) released two reports, the first entitled [Youth with Autism: Roundtable Views of Services Needed during the Transition into Adulthood in 2016](#) and the second entitled [Federal Agencies Should Take Additional Action to Support Transition-Age Youth](#), that described the needs of youth with ASD transitioning to adulthood and ways in which federal agencies might fill current service gaps. New research on the cost of ASD across the lifespan has contributed to the knowledge base around ASD services. Researchers estimate that the lifetime cost of supporting an individual with ASD without intellectual disability in the United States is approximately \$1.4 million (Buescher, Cidav, Knapp and Mandell, 2014). Contributors to total costs for children with ASD were direct nonmedical costs, such as special education (including early intervention services), and indirect nonmedical costs, such as parental productivity loss. For adults with ASD, contributors include accommodation (residential care or supportive living accommodation), direct medical costs, and individual productivity loss. Others studies show that caring for a child with ASD can cost over \$17,000 per year more than caring for a child without ASD, with 18% of these costs associated with increased use of health care services (Lavelle, Weinstein, Newhouse, Munir, Kuhlthau, and Prosser, 2014).

While these studies highlighted some of the areas in which the needs of individuals with ASD are not being met, they have not defined solutions. Adequate, cost-effective services are still lacking, as are strategies to decrease financial stress for families.

In this chapter, we describe gains and opportunities in specific service-related areas. For all the recent successes in ASD services research, gaps in services remain for children and adults with autism and their families.

Section II: Progress in the Field

Education System

Most school-aged children with autism receive the majority of their ASD-related services through the public education system (Boyd et al., 2014). The number of children receiving these services, as well as the cost of their education, is increasing. A growing body of research suggests a nationwide problem of ineffective educational programming and the need for stronger educational workforce development, support, training and supervision. With relatively little research on specific guidance to addressing challenges within the education system, it is necessary for educators working with students on the autism spectrum to address the complex and growing set of challenges.

While Federal and state legislation has placed a greater focus on accountability and performance standards, there is little agreement or standardization of how performance should be measured. The *No Child Left Behind Act* and the *Individuals with Disabilities Education Improvement Act* (IDEA) both state that students with ASD must have access to high-quality, research-based interventions that help keep them in the least restrictive instructional environment that can meet their learning needs. National programs such as the [SWIFT \(School-Wide Integrated Framework for Transformation\) Center](#) have documented change strategies and instructional approaches that can be used to meet these legal requirements. Federally-funded programs such as the [National Professional Development Center on ASD](#) have demonstrated improved outcomes when students are the recipients of evidence-based practices, and they have begun to develop practices to assist with scale-up of these interventions. Unfortunately, implementation of evidence-based practices remains the exception rather than the rule; implementation of innovative interventions is challenging due to limited fit with classroom needs and lack of professional support. New research in implementation science highlights the need for a systems approach that includes involving leadership in and across schools to develop a strong culture and climate for quality implementation.

Our definition of autism and our understanding of how autism co-occurs with other mental health challenges has expanded. Eighty percent of students with ASD have co-occurring physical or mental health challenges (Levy, 2010), requiring new education strategies and coordination across multiple service systems. Recent research has focused attention on co-occurring anxiety and depression, as well as suicide risk (Cassidy et al, 2014; Cassidy & Rodgers, 2017; Pelton &

Cassidy, 2017; Kraper et al 2017; Croen et al 2015; Mattila et al., 2010; Muris et al., 2008; (Leyfer et al., 2006; Gotham, Brunwasser, Lord, 2015[b]). Models for recognizing and addressing these challenges in schools have not yet been developed or disseminated.

Many schools have not fulfilled the promise of educating children with autism in the least restrictive and most integrated environment suited to their needs. While several models of inclusion have demonstrated efficacy (Nahmias, Kase, and Mandell, 2014), the type and quality of inclusion programming to which children with ASD have access is highly reflective of local policies, resources, and expertise rather than reflective of evidence-based practices grounded in research. There is also a need for quality interventions to help keep children with ASD in an instructional environment that maximizes their potential; because of the range of learning styles of children with ASD, students often need options such as distance learning and smaller group instruction.

Currently, the public education system is not adequately preparing all children with autism for adulthood. Although there have been improvements in recent years, approximately half of students with ASD leave secondary school without employment or plans for further education (Shattuck et al, 2012). While much of school programming is focused on those who will attend college, this is not an option for many students with ASD, who will leave school without the skills needed to enter the work force. During the transition to adulthood it is important to teach youth with autism the social and vocational skills necessary to have successful outcomes after leaving the education system.

Health Care System

There has been considerable progress in some areas of ASD services-related research within the healthcare system. One important funding stream for reimbursement of services provided to individuals with ASD is the Medicaid program. Jointly operated between the states and the federal government, Medicaid provides healthcare coverage for individuals below certain income thresholds and encompasses a wide array of benefits, such as case management, physical, occupational and speech therapies, and rehabilitative services that are often used by individuals with ASD. The [Early and Periodic Screening, Diagnostic and Treatment \(EPSDT\)](#), the child health portion of Medicaid, mandates the provision of medically necessary services found at section 1905(a) of the Social Security Act to Medicaid beneficiaries under the age of 21. EPSDT ensures that children and adolescents receive appropriate mental health, developmental, and specialty health services. In 2014, the Centers for Medicare and Medicaid Services (CMS) issued guidance affirming the applicability of EPSDT standards to the treatment of ASD. Outside of Medicaid, there are large disparities in insurance coverage and reimbursement rates based on differences in state health coverage mandates. The effects of the discrepancies in billing rates and reimbursement prevent implementation of evidence-based practices and interventions for individuals with ASD and their families.

There is a continued need for ASD insurance reform. Families of children with ASD who have a [medical home](#) – a partnership with their primary care doctor to provide personalized treatment plans - report fewer unmet needs and more shared decision making with healthcare providers (Golnik et al., 2012). The Affordable Care Act (ACA) of 2010, Section 2703, created an optional Medicaid State Plan benefit for states to establish Health Homes to coordinate care for people with Medicaid who have chronic conditions. While ASD is not a chronic condition listed in the statute, it is subject to state application, then review and approval. State ASD insurance mandates increase ASD diagnosis and treatment rates by 13%, after controlling for other variables (Mandell et al). This effect increases the longer the insurance mandates are in place. However, the number of children receiving ASD services is still less than would be expected given current prevalence estimates, though this does not control for public versus private service utilization.

Mounting research shows that [Medicaid Home and Community Based Services \(HCBS\) waivers](#) can significantly meet the service needs of people with ASD and decrease their unmet health care needs, especially among those who would not otherwise qualify for Medicaid (Leslie et al., 2017). Those with ASD who access services through waivers are also less likely to use inpatient and long-term services care (Cidav, Marcus, and Mandell, 2014). Since 2010, the Centers for Medicare & Medicaid Services (CMS) has undertaken several activities that have provided new information about ASD services available in the community. Among these is a report published in 2014, [Autism Spectrum Disorders \(ASD\): State of the States of Services and Supports for People with ASD](#), which assesses existing state programs and supports for families living with ASD in all 50 states and the District of Columbia (CMS, 2014).. This CMS study provides a comprehensive view of services that received support from various federal sources and were made available through state programs across the country.

Appropriate Services to Address Health and Safety Concerns

Recent studies have shown that people on the autism spectrum are at increased risk of many health challenges and premature mortality (Croen, 2015; Bilder et al, 2013). Research is needed to both understand what causes poor health and safety outcomes and to develop strategies to improve outcomes. Among the most pressing health concerns for children and adults diagnosed with ASD is ensuring adequate support to address co-occurring conditions, which may include mental disorders, sleep problems, gastrointestinal disturbances, or other issues (Zablotsky, Pringle, Colpe, Kogan, Rice, and Blumberg, 2015). Unfortunately, there is a lack of understanding and awareness among service providers regarding the challenges these conditions pose to individuals with ASD and their families (Battaglia, Detrick, and Fernandez, 2016). This often leads to a lack of appropriate services and multifaceted interventions. Parents of children with ASD and co-occurring psychiatric conditions are more likely than other parents of children with ASD to report that their child's needs are not being met (Zablotsky, Pringle, Colpe, Kogan, Rice, and Blumberg, 2015). A broad assessment of mental health, learning and

cognition problems associated with ASD is crucial to determine appropriate service and treatments for people with ASD throughout the lifespan (Posserud et al., 2016).

There is mounting evidence that these co-occurring conditions contribute to premature death among individuals with ASD. A Swedish study showed that the average death for an adult with autism is 54 years, and that loss of life years is mostly attributable to suicide, seizures and metabolic disease, among other conditions (Hirvikoski, Mittendorfer-Rutz, and Boman, 2016). To address these significant health disparities, it is necessary to increase implementation of services and evidence-based approaches in addition to research to improve services for co-occurring conditions.

Wandering behavior presents additional safety risks for some individuals with ASD. Recently, the National Autism Association (NAA) released a report stating a third of reported ASD wandering/elopement cases in the United States were either fatal or required some level of medical attention; while encounters with water, traffic, and other threats accounted for an additional 38% of cases (NAA, 2017). Among emergency care visits, adolescents with ASD accessed emergency department services four times as often as adolescents without ASD (Liu et al, 2017). There are also disparities in emergency department visits among children with ASD living in rural areas compared to urban places (Zhang et al, 2017). Ensuring broad access to services through more innovative strategies is necessary to close the gaps in health and safety for children and people with ASD. One strategy that has seen success is ECHO Autism, a University of Missouri telehealth program aimed at reducing wait times and improving primary care for children with autism living in remote areas (Sohl, Mazurek, Brown, 2017). The program has seen success in Missouri and plans to replicate and expand the model to isolated areas throughout the country and world.

The health care system needs to emphasize increasing access in underserved populations and increasing cultural competency among service providers. The literature suggests disparities in utilization and access to healthcare, and educational services for those with ASD from minority populations and families from lower socioeconomic status (SES) (Liptak et al, 2008; Oswald and Haworth, 2016; Frieden et al. 2014; Mandell et al. 2009; Zamora et al. 2015). Ethnic minority children with ASD tend to receive diagnoses almost one year later than White children and often received fewer specialty services (Magaña et al. 2013). Despite initiatives to increase the quality of healthcare provider interactions with families of children with ASD and developmental disabilities, the health service systems did not meet the needs of minority populations (Magaña et al. 2015). Disparities in access and utilization may be due to the lack of cultural competency of providers, perceived low quality of care, or the lack of the family centered care among other factors (Oswald and Haworth, 2016). While research has been funded to assess variations in and access to services in relation to health disparities, the research needs to be taken a step further to study how to address what we have learned. We need to better understand what portfolio of services will result in the best outcomes for diverse populations.

Overall, it is important to continue to support research to test quality services and supports as well as evidence-based interventions that can eventually be implemented in a community setting and be accessible through medical coverage. A systematic, evidence-based collaborative approach can facilitate the scaling up of evidence based practices in community settings. (Baker, Sanghvi, Hajeerhoy, Martin, and Lapping, 2013). Factors identified to aid in scaling up evidence based interventions in community settings are organizational support and readiness, program and implementer characteristics, and sustainability planning (Cooper, Bumbarger, and Moore, 2013).

Ensuring Individualization, Choice, Person-Centered Planning and Self-Direction

Often, service systems approach the needs of individuals with autism as a one-size fits all, yet the heterogeneity of autism requires different supports for different people. Individuals with ASD and their families want to be able to make choices about their lives and actively engage in the planning of their services and supports. According to a National Core Indicators survey, the number of adults with autism receiving services through developmental disability (DD) agencies increased from 10% to 15% between 2008/2009 and 2013/2014 (Hiersteiner, 2017). Further, of the adults with ASD who used DD services found that those with ASD had significantly less input into all measured life choices (e.g., choosing roommates, choosing day activities) compared with those without autism. Also, fewer adults with autism were legally independent adults without guardianship (37%) than were adults without autism (53%).

In recent years, there have been greater efforts to advocate for use of person-centered planning models, particularly in federal service systems. Medicaid-funded HCBS waivers are required to be furnished according to a person-centered plan of care, reflecting the services and supports that are important for the individual to meet needs identified through a functional assessment, as well as what is important to the individual in terms of preferences for the delivery of those services and supports. However, there are many individuals with ASD who are not using HCBS waivers but still need the right tools and services to achieve person-centered care throughout their lifespan. While research has identified some of the barriers to person-centered planning, the services community has yet to develop successful strategies to ensure individualization and choice for individuals with ASD to lead independent and meaningful lives.

Caregiver Supports

Caregivers may experience significant levels of stress as they support an individual's needs, manage medical and therapy appointments, while also engaging in work and other responsibilities (Schieve et al, 2007; Sim et al 2017; Autism Speaks, 2017). The high cost of services also creates increased financial strain for families, who often are the main caregivers across the lifespan. Families often need respite services to be able to take care of themselves,

have breaks from caregiving, and increase their own social and emotional wellbeing so they are in turn able to support and care for their family member with ASD (Autism Speaks, 2017). Also, respite care has been shown to reduce hospitalizations among children with ASD (Mandell et al., 2012). Mindfulness-Based Stress Reduction interventions have been shown to be helpful for families of individuals with disabilities, but those studies have primarily focused on families of children (Dykens et al., 2014).

Parent education about autism and parent training focused on teaching behavior management strategies are both effective in reducing disruptive behavior – with parent training having a slight advantage in one study (Bearss et al, 2015). More study is needed regarding the effectiveness of these services for different parent populations and across different types of parent educators.

Further, studies are needed to examine the transition of care from parents to other family members, once parents are no longer able to provide care. There is a rich history of caregiver transition research among adults with intellectual disability, but little is known about how this process plays out in ASD.

Outcomes, Quality of Services, and Service needs

One size does not fit all when addressing unmet service needs. Even though parents from both low- and high-income homes have awareness of their child's service needs, parents from lower-income homes report more barriers to accessing services. Specifically, they report needing more information about services and more in-home services, while higher-income parents report needing higher quality services (Pickard and Ingersoll, 2015).

Despite public investment in special education, studies show high rates of disconnection from jobs and continued education after high school. Of young adults who were not working or attending school, 28% also received no ASD-related services (Roux, 2015). Overall, one-fourth (26%) of young adults with autism received no services between high school and their early twenties (Roux, 2015).

A qualitative study of service receipt and unmet service needs during the last year of high school found that youth with ASD in this cohort were receiving fewer services than youth with ASD captured in earlier data from the Department of Education's National Longitudinal Transition Study-2 (NLTLS2) (Taylor & Henninger, 2015). Two-thirds of the sample from the 2015 study had unmet service needs during the last year of high school with 30% having three or more unmet needs. Specific needs included career counseling/job skills training and life skills training. Youth with autism without ID were far less likely to receive these services. Barriers included cost, geographic access to services, and lack of providers who accepted their insurance.

Results from the Pennsylvania Autism Needs Assessment survey, which represented people with autism ages 2-59 years indicated that adults received fewer services for their specific

unmet needs compared to other age groups in social skills training (43%), speech-language therapy (22%), individual supports (21%), and occupational therapy (21%) (Turcotte et al., 2016). Focus groups of Pennsylvania adults with ASD who use Medicaid-funded services and those who care for them found a specific set of needs: training (co-occurring diagnosis, sexuality, long-term planning), community engagement (individualized community activities geared to interests of individuals), socialization, and employment (Koffer and Miller, 2017).

The complex needs of the service system make it difficult to sustain implementation science. For example, organizations trying to implement evidence-based practices might not be able to maintain the cost to fund these services and supports long-term. Current and future research initiatives need to consider improving the service infrastructure.

Housing, Supports and Other Services across a Continuum of Severity and Need

Residential services, postsecondary education, employment supports, behavioral and communication supports, lifetime learning supports, and other services are discussed in more detail in Questions 4 and 6 of the Strategic Plan, but they are important to mention here in that these services must also be provided based on the continuum of severity and need and they must be integrated with other services as part of a coordinated system of services and care for individuals with ASD.

Workforce

Underlying many of the challenges described in the above sections is the lack of a well-trained, supervised and motivated workforce. Several studies have documented practitioners' lack of use of evidence-based practices in community settings, and the difficulties associated in implementing these practices because practitioners don't have the appropriate pre-service training and preparation, oversight in the field, or sense that the use of these practices are expected, supported and rewarded (Stahmer & Aarons, 2009; Stahmer et al, 2010). The field of implementation science has begun to address how to impact practitioner behavior through organizational change and direct-to-practitioner support. However, these strategies don't address more fundamental issues related to attracting highly qualified individuals to relevant professions, creating pre-service training programs that prepare individuals to deliver evidence-based care, and keep them in the field once they complete their education and/or training.

Coordination of Services

There is also a need for systematic analyses of the complexities of accessing the service systems. While there is a lack of research in this area, families face multifaceted challenges to access services that often delay the receipt of early intervention services for a child. Expansion of Section 2703 of the ACA to include ASD and other developmental disabilities may increase

the number of families who have a medical provider and a medical home and improve access to and coordination of care. Coordination of service sectors is urgently needed. Also, families must deal with different sources of funding for services, frequently with different rules for who, what and how many services can be provided, with no clear sources of information about what these sources are and how they interact. The different service sectors are not coordinated and often do not communicate with each other, particularly across health and social service agencies. In most instances, there is not funding to support coordination or an assigned liaison. There are other systematic barriers for families such as differences in the type and amount of services supported by insurance plans and the inequities and disparities in type and amount of services available among geographic location.

Individuals with autism often require services provided through different agencies and paid for through different systems. Care delivered across these systems often is inefficiently and ineffectively coordinated. Some of the challenges are endemic to systems that are providing care concurrently (e.g., the education and healthcare systems); other challenges are endemic to hand offs between systems as individuals age out of one set of programs into another.

Some service models have been shown to promote better integration of care. For example, health home models and medical home models provide conceptual frameworks to coordinate and integrate services, as well as build systems of care for persons with ASD and their families (Fueyo, Caldwell, Mattern, Zahid, & Foley, 2015). Use of these models is not widespread, however, nor do these models address a host of other coordination challenges. For example, analysis of the [National Longitudinal Transition Study-2](#) found that only 58% of youth with ASD reported having received a transition plan by the federally required age (Roux et al, 2015). The transition plan is a critical document that offers a template for coordination between the school system and systems that serve adults. In a 2012 report, the GAO found that youth and their families faced challenges in identifying, navigating and establishing eligibility for services for adults with disabilities, including autism (GAO-12-594). The same report found that adult service systems did not routinely provide coordinated plan of services or objectives for youth making transition to autism. There is a particular gap in implementing and evaluating the coordination between policy and practice for the services needs of individuals with ASD.

Summary

There are many opportunities for increased investment in ASD services research to fill important gaps in knowledge about what services are needed, how to best deliver them, which services work for which communities and strategies to increase implementation of best practices across settings. The Committee continues to highlight the need for the research portfolio to focus on developing practical, affordable and culturally-competent services and support approaches that can be used in a variety of settings, and for these approaches to be able to be adapted to the required scale to meet community needs. There also needs to be an understanding what portfolio of services will result in the best outcomes for diverse

populations. More innovative research approaches and the resulting data will be needed in the future to support progress toward the IACC Question 5 Aspirational Goal of creating an environment where "communities will develop, access, and implement high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD and their families."

Objectives

- 1. Scale up and implement evidence-based interventions in community settings.**
 - Identify best practices, including systematic evidence-based collaborative approaches, to scale up existing services and increase access to evidence-based interventions in communities.
 - Test and implement cost-effective healthcare services that increase the supply of care
 - Develop approaches that scale up the use of evidence-based practices in the educational setting that address the gaps between research and practice
 - Funding for provider training is a part of Question 7 Objective 2, but is cross-referenced here because successfully growing the service workforce is necessary to achieve this objective to successfully scale-up and delivery of evidence-based ASD interventions.

- 2. Reduce disparities in access and outcomes for underserved populations.**
 - Support research to understand and develop strategies to address health disparities, health inequity, and disparities in services access and utilization for underserved populations. Underserved communities include families with low socio-economic resources, youth and adults with severe intellectual impairment, those who are racial/ethnic minorities, and women.
 - Develop culturally competent service provision strategies, improve the quality of care and perception of quality of care to encourage utilization, and increase family centered care as well as other best practices to reduce disparities.

- 3. Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.**
 - Develop better metrics and measurement tools for health outcomes for people with ASD across the lifespan should be properly investigated and documented.
 - Develop, test, and implement metrics and measurements for ASD services, as well as federal, state and local programs.
 - Quantify outcomes in order to inform effective service models (Payakachat, Tilford, and Kuhthau, 2012- move ref to text).
 - Continued research into quality determinants of service is also recommended. Research supports that parents believe that the accessibility, continuity and flexibility of services were important determinants of quality (Rivard, Lépine, Mercier, et al., 2015 – move ref to text).

References (not in order)

- Autism Speaks. (2017). Respite Care and Autism. Retrieved from <https://www.autismspeaks.org/family-services/community-connections/respice-care-and-autism>
- Baker, J., Sanghvi, T., Hajeerhoy, N., Martin, L., & Lapping, K. (2013). Using an evidence-based approach to design large-scale programs to improve infant and young child feeding. *Food and nutrition bulletin*, 34(3 suppl2), S146-S155.
- Bears, K., Johnson, C., Smith, T., Lecavalier, L., Swiezy, N., Aman, M., ... & Sukhodolsky, D. G. (2015). Effect of parent training vs parent education on behavioral problems in children with autism spectrum disorder: a randomized clinical trial. *Jama*, 313(15), 1524-1533.
- Bilder D, Botts EL, Smith KR, Pimentel R, Farley M, Viskochil J, McMahon WM, Block H, Ritvo E, Ritvo RA, Coon H. (2013). Excess mortality and causes of death in autism spectrum disorders: a follow up of the 1980s Utah/UCLA autism epidemiologic study. *J. Autism Dev. Disord.* 43(5):1196–1204
- Boyd, B. A., Hume, K., McBee, M. T., Alessandri, M., Gutierrez, A., Johnson, L., ... & Odom, S. L. (2014). Comparative efficacy of LEAP, TEACCH and non-model-specific special education programs for preschoolers with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(2), 366-380.
- Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA pediatrics*, 168(8), 721-728.
- Centers for Medicare & Medicaid Services. Report on State Services to Individuals with Autism Spectrum Disorders (ASD). 2011 Apr. <http://www.cms.gov/apps/files/9-state-report.pdf>
- Cidav, Z., Marcus, S. C., & Mandell, D. S. (2014). Home- and Community-Based Waivers for Children with Autism: Effects on Service Use and Costs. *Intellectual and Developmental Disabilities*, 52(4), 239–248. <http://doi.org/10.1352/1934-9556-52.4.239>
- Cooper, B. R., Bumbarger, B. K., & Moore, J. E. (2015). Sustaining evidence-based prevention programs: Correlates in a large-scale dissemination initiative. *Prevention Science*, 16(1), 145-157.
- Divan, G., Hamdani, S. U., Vajartkar, V., Minhas, A., Taylor, C., Aldred, C., ... & Patel, V. (2015). Adapting an evidence-based intervention for autism spectrum disorder for scaling up in resource-constrained settings: the development of the PASS intervention in South Asia. *Global health action*, 8.
- Fueyo, M., Caldwell, T., Mattern, S. B., Zahid, J., & Foley, T. (2015). The health home: a service delivery model for autism and intellectual disability. *Psychiatric Services*, 66(11), 1135-1137.

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), 232-238.

Interagency Autism Coordinating Committee (IACC). (2014). IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research —2013 Update. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/strategic-plan/2013/index.shtml> .

Interagency Autism Coordinating Committee (IACC). (2016a). 2015 IACC Summary of Advances in Autism Spectrum Disorder Research. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <https://iacc.hhs.gov/publications/summary-of-advances/2015/>.

Jacobson, J.W. & Mulick, J.A. (2000). System and Cost Research Issues in Treatments for People with Autistic Disorders. *Journal of Autism and Developmental Disorders*, 30, 85.
doi:10.1023/A:1005691411255

Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, 133(3), e520-e529.

Leslie, D.L., et al. (2017). The Effects of Medicaid Home and Community-Based Services Waivers on Unmet Needs Among Children with Autism Spectrum Disorder. *Med Care* 55 (1), 57-63.

Nahmias, A. S., Kase, C., & Mandell, D. S. (2014). Comparing cognitive outcomes among children with autism spectrum disorders receiving community-based early intervention in one of three placements. *Autism*, 18(3), 311-320.

Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). (2016b). 2011-2012 IACC Autism Spectrum Disorder Research Portfolio Analysis Report. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: https://iacc.hhs.gov/publications/portfolio-analysis/2012/portfolio_analysis_2012.pdf

Oswald, D. P., & Haworth, S. M. (2016). Autism spectrum disorders. In *Handbook of Mental Health in African American Youth* (pp. 271-285). Springer International Publishing.

Payakachat, N., Tilford, J. M., Kovacs, E., & Kuhlthau, K. (2012). Autism spectrum disorders: a review of measures for clinical, health services and cost-effectiveness applications. *Expert Review of Pharmacoeconomics & Outcomes Research*, 12(4), 485–503.
<http://doi.org/10.1586/erp.12.29>

Rivard, M., Lépine, A., Mercier, C. et al. (2105). Quality Determinants of Services for Parents of Young Children with Autism Spectrum Disorders. *Journal of Child and Family Studies*, 24, 2388.
doi:10.1007/s10826-014-0041-2

Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Trani, J. F. (2012). Services for adults with an autism spectrum disorder. *The Canadian Journal of Psychiatry*, 57(5), 284-291.

United States Government Accountability Office (GAO). (2016). Youth with Autism: Round Table Views of Services Needed During the Transition into Adulthood. Retrieved from: <https://www.gao.gov/assets/690/680525.pdf>

United States Government Accountability Office (GAO). (2012). STUDENTS WITH DISABILITIES: Better Federal Coordination Could Lessen Challenges in the Transition from High School. Retrieved from: <http://www.gao.gov/assets/600/592329.pdf>

Zablotsky, B., Pringle, B. A., Colpe, L. J., Kogan, M. D., Rice, C., & Blumberg, S. J. (2015). Service and treatment use among children diagnosed with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics*, 36(2), 98.

Bearss K, Johnson C, Smith T, Lecavalier L, Swiezy N, Aman M, McAdam DB, Butter E, Stillitano C, Minshawi N, Sukhodolsky DG, Mruzek DW, Turner K, Neal T, Hallett V, Mulick JA, Green B, Handen B, Deng Y, Dziura J, Scahill L. JAMA. 2015 Apr 21;313(15):1524-33. [PMID: 25898050]

Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(12), 3063–3071. doi:[10.1007/s10803-014-2170-2](https://doi.org/10.1007/s10803-014-2170-2).

Buescher AV, Cidav Z, Knapp M, Mandell DS. JAMA Pediatr. 2014 Aug; 168(8): 721-8. Costs of autism spectrum disorders in the United Kingdom and the United States [PMID: 24911948]

Hiersteiner, Dorothy, et al. "Putting the Research in Context: The Life Experience and Outcomes of Adults on the Autism Spectrum Receiving Services in 29 States." *Inclusion* 5.1 (2017): 45-59.

Kaitlin H Koffer Miller, MaryMathew, Stacy L Nonnemacher, Lindsay L Shea. Program experiences of adults with autism, their families, and providers: Findings from a focus group study. *Autism* First published date: February-13-2017. [10.1177/1362361316679000](https://doi.org/10.1177/1362361316679000)

Lavelle TA, Weinstein MC, Newhouse JP, Munir K, Kuhlthau KA, Prosser LA. Economic burden of childhood autism spectrum disorders *Pediatrics*. 2014 Mar;133(3): e520-9. [PMID: 24515505]

Pickard, Katherine E., and Brooke R. Ingersoll. "Quality versus quantity: The role of socioeconomic status on parent-reported service knowledge, service use, unmet service needs, and barriers to service use." *Autism* (2015): 1362361315569745.

Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). National Autism Indicators Report: transition into young adulthood. *Philadelphia, PA: Life Course Outcomes Research Program, AJ Drexel Autism Institute, Drexel University*.

Taylor, J.L. & Henninger, N.A. J Autism Dev Disord (2015) Frequency and correlates of service access among youth with autism transitioning to adulthood. 45: 179. doi:10.1007/s10803-014-2203-x

Taylor, Julie Lounds, et al. "Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial." *Journal of Autism and Developmental Disorders* (2017): 1-12.

Turcotte, Paul, et al. "Service needs across the lifespan for individuals with autism." *Journal of autism and developmental disorders* 46.7 (2016): 2480-2489.

Zablotsky, Benjamin, et al. "Service and treatment use among children diagnosed with autism spectrum disorders." *Journal of developmental and behavioral pediatrics: JDBP* 36.2 (2015): 98.

Battaglia, M., Detrick, S., & Fernandez, A. (2016). Multidisciplinary Treatment for Adults with Autism Spectrum Disorder and Co-Occurring Mental Health Disorders: Adapting Clinical Research Tools to Everyday Clinical Practice. *Journal of Mental Health Research in Intellectual Disabilities*, 9(4), 232-249.

Posserud, M., Hysing, M., Helland, W., Gillberg, C., & Lundervold, A. J. (2016). Autism traits: The importance of "co-morbid" problems for impairment and contact with services. Data from the Bergen Child Study. *Research in developmental disabilities*.

Trembath, D., Iacono, T., Lyon, K., West, D., & Johnson, H. (2014). Augmentative and alternative communication supports for adults with autism spectrum disorders. *Autism*, 18(8), 891-902.

National Autism Association. (2017). Mortality & Risk in ASD Wandering/Elopement 2011-2016. <http://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf>

Seltzer, M.M., Greenberg, J.S., Hong, J., Smith, L.E., Almeida, D.M., Coe, C., & Stawski, R.S. (2010). Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, 40(4), 457-69.

Kristin Sohl, Micah O. Mazurek, Rachel Brown. **ECHO Autism: Using Technology and Mentorship to Bridge Gaps, Increase Access to Care, and Bring Best Practice Autism Care to Primary Care.** *Clinical Pediatrics*, 2017; 56 (6): 509 DOI: [10.1177/0009922817691825](https://doi.org/10.1177/0009922817691825)

Zhang, W., Mason, A.E., Boyd, B. et al. J Autism Dev Disord (2017) 47: 590. doi:10.1007/s10803-016-2982-3

Liu, G., Pearl, A.M., Kong, L. et al. J Autism Dev Disord (2017) 47: 347. doi:10.1007/s10803-016-2953-8

Mandell, D. S., Xie, M., Morales, K. H., Lawer, L., McCarthy, M., & Marcus, S. C. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Archives of pediatrics & adolescent medicine*, 166(1), 68-73.

Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, 1(2), 142-147.

Cassidy, S., & Rodgers, J. (2017). Understanding and prevention of suicide in autism. *The Lancet Psychiatry*.

Pelton, M. K., & Cassidy, S. A. (2017). Are autistic traits associated with suicidality? A test of the interpersonal-psychological theory of suicide in a non-clinical young adult sample. *Autism Research*.

Kraper, C. K., Kenworthy, L., Popal, H., Martin, A., & Wallace, G. L. (2017). The Gap Between Adaptive Behavior and Intelligence in Autism Persists into Young Adulthood and is Linked to Psychiatric Co-morbidities. *Journal of Autism and Developmental Disorders*, 1-11.

Croen LA1, Zerbo O2, Qian Y2, Massolo ML2, Rich S3, Sidney S2, Kripke C4. *Autism*. 2015 Oct;19(7):814-23. doi: 10.1177/1362361315577517. Epub 2015 Apr 24. The health status of adults on the autism spectrum.

Mattila ML, Hurtig T, Haapsamo H, et al. (2010) Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: a community-and clinic-based study. *Journal of Autism and Developmental Disorders* 40(9): 1080–1093.

Muris P, Steerneman P, Merckelbach H, et al. (2008) Comorbid anxiety symptoms in children with pervasive developmental disorders. *Journal of Anxiety Disorders* 12: 387–393.

Leyfer OT, Folstein SE, Bacalman S, et al. (2006) Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. *Journal of Autism and Developmental Disorders* 36: 849–861.

Bilder, D., Botts, E. L., Smith, K. R., Pimentel, R., Farley, M., Viskochil, J., ... & Coon, H. (2013). Excess mortality and causes of death in autism spectrum disorders: a follow up of the 1980s Utah/UCLA autism epidemiologic study. *Journal of autism and developmental disorders*, 43(5), 1196-1204.

Sim A1, Vaz S1, Cordier R1, Joosten A1, Parsons D1, Smith C1, Falkmer T1,2,3,4. *Dev Neurorehabil*. 2017 Jun 9:1-11. doi: 10.1080/17518423.2017.1326185. [Epub ahead of print] Factors associated with stress in families of children with autism spectrum disorder.

Schieve, Laura A., et al. "The relationship between autism and parenting stress." *Pediatrics* 119.Supplement 1 (2007): S114-S121.

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, peds-2011.

Stahmer, A., Reed, S., Shin, S., & Mandell, D. (2010). Fidelity of implementation of evidence-based practice in community classrooms. In *Presentation at the 9th international meeting for autism research (IMFAR)*.

Stahmer, A. C., & Aarons, G. A. (2009). Attitudes toward adoption of evidence-based practices: A comparison of autism early intervention providers and children's mental health providers. *Psychological Services*, 6(3), 223.

Levy, S. E., Giarelli, E., Lee, L. C., Schieve, L. A., Kirby, R. S., Cunniff, C., ... & Rice, C. E. (2010). Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. *Journal of Developmental & Behavioral Pediatrics*, 31(4), 267-275.

Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: Data from the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics: JDBP*, 29(3), 152–160. doi:[10.1097/DBP.0b013e318165c7a0](https://doi.org/10.1097/DBP.0b013e318165c7a0).

Frieden, T. R., Jaffe, H. W., Cono, J., Richards, C. L., & Iademarco, M. F. (2014). Prevalence of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report. Surveillance Summaries*, 63(2), 1–21.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGiuseppi, C., Durkin, M. S., ... & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493–498. doi:[10.2105/AJPH.2007.131243](https://doi.org/10.2105/AJPH.2007.131243).

Zamora, I., Williams, M. E., Higareda, M., Wheeler, B. Y., & Levitt, P. (2015). Brief report: Recruitment and retention of minority children for autism research. *Journal of Autism and Developmental Disorders*. doi:[10.1007/s10803-015-2603-6](https://doi.org/10.1007/s10803-015-2603-6).

Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, 51(3), 141–153. doi:[10.1352/1934-9556-51.3.141](https://doi.org/10.1352/1934-9556-51.3.141).

Magaña, S., Parish, S. L., & Son, E. (2015). Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? *American Journal on Intellectual and Developmental Disabilities*, 120(6), 504–513. doi:[10.1352/1944-7558-120.6.504](https://doi.org/10.1352/1944-7558-120.6.504).