

## Question 5: Where Can I Turn for Services?

**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.

### I. Introduction

The [2013 IACC Strategic Plan Update](#), included nine objectives related to *Question 5: Where Can I Turn for Services?* The objectives addressed access to services for individuals with ASD and their families, 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. Objectives also included support for research to 1) develop and evaluate the training of service providers who work with individuals with ASD, and 2) improve the effectiveness, cost-effectiveness, dissemination and implementation of evidence-based practices (IACC, 2016a). In 2013, 7% (\$20 million) of ASD-related research funding addressed issues related to services (*2013 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*, 2017). A lack of efficient funding raises considerable concerns regarding our ability 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).

With regard to services research and planning, there have been several notable positive changes over last few years, 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 a report in 2016, entitled [Youth with Autism: Roundtable Views of Services Needed during the Transition into Adulthood](#), that described the needs of youth with ASD transitioning to adulthood. New research on the cost of ASD across the lifespan has contributed to the knowledge base around ASD services. Researchers estimate that the lifetime costs of supporting an individual with ASD without intellectual disability is approximately \$1.4 million in the United States (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. Other studies show that caring for a child with ASD can cost more than \$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 have pointed to some of the areas in which individuals with ASD are not served well, they have not defined the solutions. Adequate, cost effective services are still lacking, as are strategies to decrease financial stress for families.

In what follows, 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.

## **II. Topic 1: Education and Healthcare System**

### **Education System**

Most school-aged children with ASD receive the majority of their care through the public education system (Boyd et al., 2014). The number of children served under the ASD category as well as the cost of their education is increasing. Educators working with students on the autism spectrum must address complex and growing set of challenges. There is relatively little research that provides specific guidance on addressing these challenges.

First, 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 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. Although educators have the capacity to learn to use innovative interventions well, implementation 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 in developing a strong culture and climate for quality implementation.

Second, 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 health or mental health challenges, 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. Models for recognizing and addressing these challenges in schools have not been developed and disseminated.

Third, 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, 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 the extant research or their of their capacity to learn.

Finally, our education system is not preparing children with autism for adulthood. Approximately half of students with ASD leave secondary school without employment or plans for further education. 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.

## **Health Care System**

Most children with ASD have needs that uneasily straddle multiple systems, especially the education and healthcare system.

There has been considerable progress in some areas of ASD services-related research. Mounting research shows that Medicaid Home and Community Based Services (HCBS) waivers can significantly meet the service needs of people with ASD and decrease the unmet health care needs, especially amongst those that 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). There has also been promising research on parent training programs for children with autism to help with reducing disruptive behaviors. Parent training can help to fill gaps in service availability and accessibility. One study found that a 24-week parent training program was superior to parent education for reducing disruptive behaviors (Bearss et al., 2015).

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. CMS also issued a report, [\*Autism Spectrum Disorders \(ASD\): State of the States of Services and Supports for People with ASD\*](#) in 2014. This study assessed existing state programs and supports for families living with ASD in 50 states and the District of Columbia, providing a comprehensive view of services that received support from various federal sources and were made available through state programs across the country (CMS, 2014).

### **III. Topic 2: Lifelong Supports**

#### **Appropriate services for those with co-occurring conditions**

Children and adults diagnosed with ASD will require substantial support to address both ASD symptoms and many co-occurring conditions like mental disorders, sleep problems, and feeding issues, among others (Zablotsky, Pringle, Colpe, Kogan, Rice, and Blumberg, 2015).

Unfortunately, there is a lack of understanding and awareness regarding the challenges faced by individuals with ASD and co-occurring conditions and their families (Battaglia, Detrick, and Fernandez, 2016). 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 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 research that these co-occurring conditions lead to premature death. 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). The committee recommends increasing implementation of services and evidence based approaches in addition to research to improve services for co-curing conditions.

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

The number of adults with autism receiving services through developmental disability agencies increased from 10% to 15% between 2008/9 and 2013/4 (Hiersteiner, 2017). A survey of adults with ASD who also 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. Fewer adults with autism were legally independent adults without guardianship (37%) than were adults without autism (53%).

### **Communication Supports**

People with ASD often have complex communication needs throughout their lifespan. Many people with ASD would benefit from the use of augmentative and alternative communication, but there is a lack of research examining the specific communication needs across the lifespan (Trembath et al., 2013). There is strong research support for augmentative and alternative communication for both adults with autism and those with whom they communicate, but there are significant barriers that impede people with ASD from acquiring relevant technology to assist with this communication. (Trembath et al., 2013.)

### **Caregiver Supports**

Caregivers can be under a lot of stress as they support their child's needs, manage medical and therapy appointments, and engage in work and other responsibilities (Autism Speaks, 2017). Families 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 of their child with ASD (Autism Speaks, 2017). Respite care has been shown to reduce hospitalizations among children with ASD (Mandell et al.). The high cost of services also creates increased financial stress for families, who often are the main caregivers across the lifespan.

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

An exploratory study adapted a 12-week parent training program aimed at facilitating transition to adulthood was successful in increasing knowledge of the adult service system and feelings of empowerment regarding advocating for adult services (Taylor, 2017).

## **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 children's' service needs, parents from lower income homes experience more barriers to accessing services. 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 had no services (Roux 2015). Overall, one fourth (26%) of young adults with autism received no services between high school and their early twenties (Roux 2015).

Taylor and Henninger's (2015) qualitative study of service receipt and unmet service needs during the last year of high school found that sampled youth were receiving fewer services than youth with autism captured in earlier NLTS2 data. Two-thirds of the current sample had unmet service needs during the last year of high school with 30% having three or more unmet needs. Specific needs included career counseling and job skills training, and life skills training. Youth with autism who did not have ID were far less likely to receive these services. Barriers included cost, geographic access to services, and lack of providers who accepted their insurance. Youth of minority racial/ethnic status, with more behavior problems, and whose parents were more anxious had more unmet service needs. Youth with co-occurring psychiatric diagnosis received more services on average than other youth with autism.

Results from the Pennsylvania Autism Needs Assessment survey, which represented people with autism ages 2-59 years) indicated that adults received fewer services with specific unmet needs 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 dx, sexuality, long-term planning), community engagement (individualized community activities geared to interests of individuals), socialization, and employment (Koffer and Miller, 2017).

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

Housing and residential care represent the highest cost category for adults with ASD (Buescher et al, 2014). Perhaps by virtue of the required infrastructure, housing options have been slow to respond to changing needs, values and research findings regarding adults with ASD. Lakin and colleagues (2008) describe the national agenda to increase the number of community-based housing options for individuals with intellectual disabilities as a way of increasing community participation and self-determined choice making. The recent final rule from the Centers for Medicaid Services gives clear preference to small, community-based homes over larger congregate care settings and intentional communities, and has profound implications for what

kinds of supporting housing will be available for adults with autism. Some advocates have hailed this ruling as a victory that will increase community participation; others, especially those who care for severely impaired and medically fragile individuals, have expressed grave concerns that appropriate care will not be available under this new financing arrangement. There are remarkably little data available to support which housing options work best for which individuals, with studies presenting contradictory findings regarding the level of community participation and choice making that individuals with ASD or ID have in different housing options (McConkey, 2007; Ticha, 2013). The largest challenge to conducting rigorous research on housing is disentangling the severity and needs of the individual from the housing option in which they are placed, given that on average, more severely impaired individuals end up in more restrictive housing arrangements. Thus, we do not know if observed findings regarding the association between housing arrangements and outcomes are due to the housing arrangement itself, or the selection of particular individuals into specific settings.

Research is desperately on the most appropriate housing arrangements and perhaps more importantly the best ways to increase the observability of what happens in these arrangements, strategies to increase community engagement, and strategies to maximize quality of life.

#### **IV. Topic 3: Workforce**

Underlying many of the challenges described in the above sections is the lack of a well-trained, supervised and motivated workforce. Several studies now have documented both 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 preparation, oversight in the field, or sense that the use of these practices are expected, supported and rewarded. The field of implementation science has begun to address how to change practitioner behavior through organizational change and direct-to-practitioner support, but 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 graduate.

#### **V. Topic 4: Coordination of Services**

Individuals with autism often require services provided through different agencies and paid for through different systems, and 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 builds systems of care for persons with ASD their families (Fueyo, Caldwell, Mattern, Zahid, & Foley, 2015). Use of these models is not widespread, however, nor

do they address a host of other coordination challenges. For example, analysis of the Department of Education's National Longitudinal Transition Study-2 (NLTLS2) found that only 58% of adults with ASD reported having received a transition plan by the federally required age. The transition plan is a critical document that offers a template for coordination between the school system and systems that serve adults. A 2012 GAO Report, GAO found that youth and their families faced challenges in identifying, navigating and establishing eligibility for adult services with disabilities, including autism (GAO-12-094). The same report found that adult service system did not routinely provide coordinated plan of services or objectives for youth making transition to autism and did less to ensure needed services would be provided.

#### **IV. Progress toward the Aspirational Goal**

The full funding of three objectives in Question 5 was achieved. There are some preliminary results from these studies but more information about their contributions to the field likely will unfold over the next few years. Funding for Question 5 objectives fell short in the areas of self-directed community services, as well as studies that evaluate the health and safety of people with ASD. Objectives surrounding health and safety were partially completed but it should be noted that this is an area requiring increased funding and attention. This this topic should be broadened to encompass many of the emerging subtopics to health and safety such as: mortality, wandering, and self-determination and self-autonomy.

#### **Cross Cutting Themes**

Several cross-cutting themes emerged that may influence further funding and research priorities for services for people with ASD and their families.

- **Support for effective educational services.** A growing body of research suggests the nationwide problem of ineffective educational programming and the needed for better educational workforce development, support, training and supervision.
- **Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in for youth and adults with ASD, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.** The committee recommends increasing implementation of services and evidence based approaches in addition to research to improve services for co-occurring conditions.
- **Support for integrated efforts to provide additional supports throughout the lifespan.** More funding is needed to study and implement the best mechanisms to coordinate services across agencies.
- **Increase support for caregivers (in addition to adult with ASD).** Caregivers needs services and supports to manage their child's medical and therapy appointments, as well as manage work and other responsibilities (Autism Speaks, 2017).

## New Objectives

The committee proposes three new objectives to replace the current nine that will hopefully increase the understanding of services research and further progress toward the aspirational goal:

- 1. Fully and successfully scale up evidence-based interventions in community settings.** Research is needed to identify best practices to scale up existing services and increase access to evidence based interventions in communities. 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). Funding for provider training should also be considered since limitations in qualified providers often results decreased access to evidence-based ASD interventions (Divan et al., 2015).
- 2. Reduce disparities in access and in outcomes for underserved populations.** Funding for research on health disparities and disparities in the utilization of ASD services is needed. Research will need to focus on health disparities, health inequity, and disparities in services access and utilization for underserved populations. The literature suggests disparities in utilization and access to healthcare, and educational services for those with ASD from underserved communities (Oswald and Haworth, 2016). 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). Underserved communities would include families with low socio-economic resources, youth and adults with severe intellectual impairment, those who are racial/ethnic minorities, and women.
- 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.** To ensure service model consistency and increased quality care across domains development of better metrics and measurement tools for health outcomes for people with ASD across the lifespan should be properly investigated and documented. Projects to support his objective would focus on metrics and measurements for ASD services, as well as federal, state and local programs. Researchers can greatly contribute to improving services by quantifying outcomes that can in turn inform effective service models (Payakachat, Tilford, and Kuhthau, 2012). 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).



## **Conclusion**

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 uptake 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 different populations. More innovative approaches and resulting research 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."

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